PALGRAVE *Studies in Oral History*

SECOND WIND

ORAL HISTORIES OF LUNG TRANSPLANT SURVIVORS

MARY JO FESTLE

PALGRAVE *Studies in Oral History*

Series Editors: Linda Shopes and Bruce M. Stave

The Order Has Been Carried Out: History, Memory, and Meaning of a Nazi Massacre in Rome, by Alessandro Portelli (2003)

Sticking to the Union: An Oral History of the Life and Times of Julia Ruuttila, by Sandy Polishuk (2003)

To Wear the Dust of War: From Bialystok to Shanghai to the Promised Land, an Oral History, by Samuel Iwry, edited by L. J. H. Kelley (2004)

Education as My Agenda: Gertrude Williams, Race, and the Baltimore Public Schools, by Jo Ann Robinson (2005)

Remembering: Oral History Performance, edited by Della Pollock (2005)

Postmemories of Terror: A New Generation Copes with the Legacy of the "Dirty War", by Susana Kaiser (2005)

Growing Up in The People's Republic: Conversations between Two Daughters of China's Revolution, by Ye Weili and Ma Xiaodong (2005)

Life and Death in the Delta: African American Narratives of Violence, Resilience, and Social Change, by Kim Lacy Rogers (2006)

Creating Choice: A Community Responds to the Need for Abortion and Birth Control, 1961–1973, by David P. Cline (2006)

Voices from This Long Brown Land: Oral Recollections of Owens Valley Lives and Manzanar Pasts, by Jane Wehrey (2006)

Radicals, Rhetoric, and the War: The University of Nevada in the Wake of Kent State, by Brad E. Lucas (2006)

The Unquiet Nisei: An Oral History of the Life of Sue Kunitomi Embrey, by Diana Meyers Bahr (2007)

Sisters in the Brotherhoods: Working Women Organizing for Equality in New York City, by Jane LaTour (2008)

Iraq's Last Jews: Stories of Daily Life, Upheaval, and Escape from Modern Babylon, edited by Tamar Morad, Dennis Shasha, and Robert Shasha (2008)

Soldiers and Citizens: An Oral History of Operation Iraqi Freedom from the Battlefield to the Pentagon, by Carl Mirra (2008)

Overcoming Katrina: African American Voices from the Crescent City and Beyond, by D'Ann R. Penner and Keith C. Ferdinand (2009)

Bringing Desegregation Home: Memories of the Struggle toward School Integration in Rural North Carolina, by Kate Willink (2009)

I Saw It Coming: Worker Narratives of Plant Closings and Job Loss, by Tracy E. K'Meyer and Joy L. Hart (2010)

Speaking History: Oral Histories of the American Past, 1865–Present, by Sue Armitage and Laurie Mercier (2010)

Surviving Bhopal: Dancing Bodies, Written Texts, and Oral Testimonials of Women in the Wake of an Industrial Disaster, by Suroopa Mukherjee (2010)

Living with Jim Crow: African American Women and Memories of the Segregated South, by Anne Valk and Leslie Brown (2010)

Gulag Voices: Oral Histories of Soviet Incarceration and Exile, by Jehanne M. Gheith and Katherine R. Jolluck (2011)

Detained without Cause: Muslims' Stories of Detention and Deportation in America after 9/11, by Irum Shiekh (2011)

Soviet Communal Living: An Oral History of the Kommunalka, by Paola Messana (2011)

No Room of Her Own: Women's Stories of Homelessness, Life, Death, and Resistance, by Desiree Hellegers (2011)

Oral History and Photography, edited by Alexander Freund and Alistair Thomson (2011)

Place, Writing, and Voice in Oral History, edited by Shelley Trower (2011)

Oral History, Community, and Displacement: Imagining Memories in Post-Apartheid South Africa, Sean Field (2012)

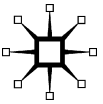
Second Wind: Oral Histories of Lung Transplant Survivors, Mary Jo Festle (2012)

Second Wind

Oral Histories of Lung Transplant Survivors

Mary Jo Festle

palgrave
macmillan



SECOND WIND

Softcover reprint of the hardcover 1st edition 2012 978-0-230-34091-6

First published in 2012 by
PALGRAVE MACMILLAN®
in the United States—a division of St. Martin's Press LLC,
175 Fifth Avenue, New York, NY 10010.

Where this book is distributed in the UK, Europe and the rest of the world, this is by Palgrave Macmillan, a division of Macmillan Publishers Limited, registered in England, company number 785998, of Houndmills, Basingstoke, Hampshire RG21 6XS.

Palgrave Macmillan is the global academic imprint of the above companies and has companies and representatives throughout the world.

Palgrave® and Macmillan® are registered trademarks in the United States, the United Kingdom, Europe and other countries.

ISBN 978-1-349-34366-9 ISBN 978-1-137-01150-3 (eBook)
DOI 10.1057/9781137011503

Library of Congress Cataloging-in-Publication Data is available from the Library of Congress.

A catalogue record of the book is available from the British Library.

Design by Newgen Imaging Systems (P) Ltd., Chennai, India.

First edition: March 2012

10 9 8 7 6 5 4 3 2 1

For Bob and John
and all those
who know lung disease and organ transplantation

Contents

Figures

Acknowledgments

Special thanks go to the following people who were interviewed for this project:

Kitty Adair, conducted by Allison Riley, November 20, 1998 [telephone].

Frank Avila, conducted by Andrew Oak, Burlington, North Carolina, November 4, 2002.

Randall Benifield, conducted by Kristen Nastasia, Durham, North Carolina, November 13, 1998.

Harold Blaise, conducted by Sondra Van Essen, Mebane, North Carolina, November 19, 1998.

Steve Brunson, conducted by Melissa Pace, July 2, 1997 [telephone].

M. L. Bryan, conducted by George Baker, Jr., November 20, 1998 [telephone].

Thomas Bullard, conducted by Larry McSwain, Elon, North Carolina, October 24, 2000.

Steven Bunsen, conducted by Kristen Nagy, November 5, 2002 [telephone].

Matt Byrd, conducted by Genienne Taormina, Chapel Hill, North Carolina, October 23, 2000.

Jimmy Carroll, conducted by Daniel Jackson, November 7, 2002 [telephone].

Tim Choquette, conducted by Lindsey Clarke, Durham, North Carolina, November 7, 1998.

Sharolyn Converse, conducted by Dena Gregory, Raleigh, North Carolina, November 7, 1998.

Dr. Joel Cooper, conducted by Mary Jo Festle, Philadelphia, Pennsylvania, February 16, 2009.

David Courtney, conducted by Morgan Kelso, November 13, 2000 [telephone].

Karen Couture, conducted by Derrick Krout, November 8, 2002 [telephone].

Danelle DeCiantis, conducted by Annie Evans, November 20, 2000 [telephone].

Pauline DeLuca, conducted by Stacy Morin, Raleigh, North Carolina, November 1, 2000.

Kathleen Feeney, conducted by Sarah Starkey, October 29, 2002 [telephone].

Tom Fereday, conducted by Jennifer Bradshaw, Sterling, Virginia, November 25, 1998.

Bob Festle, conducted by Julie Gill, November 24, 1998 [telephone].

Elizabeth Fleuren, conducted by Beth Haynes, Elon, North Carolina, November 11, 1998.
Karen Fitchett, conducted by Zach Smith, November, 1998 [telephone].
Kathryn Flynn, conducted by Glenn Long, Hillsborough, North Carolina, November 16, 1998.
J. Wayne Foster, conducted by Karen Mullis, Burlington, North Carolina, November 11, 1998.
Rosalie Gallogly, conducted by Melissa Pace, July 7, 1997 [telephone].
Howell Graham, conducted by Melissa Pace, Wilmington, North Carolina, July 16, 1997.
Melodie Greene, conducted by Courtney Wells, Cornelius, North Carolina, October 27, 2000.
Ruth Hall, conducted by John Stephen Bolger, King, North Carolina, November 7, 2002.
Dr. James D. Hardy, conducted by Mary Jo Festle, Jackson, Mississippi, March 17, 2001.
Don Hawkins, conducted by Shannon Carpenter, October 28 and November 24, 2000 [telephone].
Kelly Helms, conducted by Elizabeth Harper, November 10, 1998 [telephone].
Brian Hinton, conducted by Peter Cavanagh, Graham, North Carolina, November 15, 1998.
Paula Huffman, conducted by Anna Story, Norfolk, Virginia, October 31, 1998.
Lori Hughes, conducted by William York, Lawndale, North Carolina, November 1, 2002.
Lynn [prefers last name not be used], conducted by Inga Bajalyte, Durham, North Carolina, October 19, 2002.
Jasper Martin, conducted by Chris Champagne, Madison, North Carolina, October 30, 2000.
Cheryl Maxham, conducted by Emily Linz, Manassa, Virginia, October 31, 1998.
Charla Parker, conducted by Thom Cleary, Durham, North Carolina, November 13, 1998.
May Parker, conducted by John Rockefeller, Durham, North Carolina, November 13, 1998, and conducted by Amity Lutes, Lexington, South Carolina, November 28, 2000.
Kimberly Pearce, conducted by Melissa Pace, Chapel Hill, North Carolina, July 10, 1997.
Brett Pearce, conducted by Mary Jo Festle, Chapel Hill, North Carolina, July 10, 1997.
Mary Peters, conducted by Claire Baker, Ferndale, Maryland, November 26, 2002.

William Poplett, conducted by Zack Harrison, Virginia Beach, Virginia, November 12, 2000.
Dare Reitz, conducted by Stephen Bloodworth, Burgaw, North Carolina, November 3, 1998.
Laura Richards, conducted by Amy Clayton, Durham, North Carolina, November 2, 1998, and by Brielle Gould, November 8, 2002 [telephone].
Tracy Raub, conducted by Greer Fenton, November 29, 2000 [telephone].
Judy Ryan, conducted by Melissa Meiskey, Garner, North Carolina, November 9, 2002.
Dana Schmidt, conducted by Kelly Foster, Durham, North Carolina, November 19, 2002.
Joanne M. Schum, conducted by Sarah Fitch, November 8, 2000 [telephone].
Mary Ellen Smith, conducted by Justin Herman, October 31, 2002 [telephone].
Jack Snyder, conducted by Erin Alston, Durham, North Carolina, November 9, 2000.
Frank M. Spears, conducted by John Asmussen, Oxford, North Carolina, November 1, 2000.
Barbara M. Stepp, conducted by Jamie Goebel, Durham, North Carolina, October 27, 2000.
Carol Stimmel, conducted by Tony Vasquez, November 17, 1998 [telephone].
Richard Throlson, conducted by Jessica Lesko, Durham, North Carolina, November 7, 2002.
Jan Travioli, conducted by Erin Witmer, Waxhaw, North Carolina, November 2, 2000.
Tiffany Vuncannon, conducted by Kelly Poisson, Cary, North Carolina, October 31, 2002.
Carol White, conducted by Gretchen Buskirk, Louisburg, North Carolina, November 1, 2002.
A list of other first-person accounts and all the primary and secondary sources used for this book can be viewed at http://festlesecondwind.wordpress.com/.

Series Editors' Foreword

In *Second Wind*, Mary Jo Festle provides a masterful account of the history of lung transplantation, and through oral history interviews, the experiences of those who have undergone them in the period since the 1960s. This book also offers insight into the role of family members and caregivers. Her work is informed by the passion of one whose family has had firsthand knowledge of the subject, as well as by a scholar's ability to translate complicated medical issues into understandable terms for the layperson. By so doing, Festle demonstrates the value of oral history for humanizing complex issues.

This volume contributes to the increasing application of "narrative medicine" to the treatment of the ill, which permits patients to share their experiences and affords physicians the opportunity to *listen* in contrast to simply analyzing scientific data. As a consequence, it encourages a holistic treatment of patients, which sees a person as more than his symptoms. Like oral history, "narrative medicine" allows individuals to explain their own experience. Thereby, both approaches may have a salutary effect on the narrator.

Also, with respect to methodology, chapter seven, "Quality of Life after Transplant," reveals that oral history interviews may more effectively uncover the essentials of quality of life than frequently used statistical surveys that try to measure it quantitatively. As Festle suggests, oral history provides "a fuller, more textured, more subtle understanding of recipients' lives after transplant." The free-flowing, probing, open-ended approach of an interview proves invaluable for this purpose.

By employing interviews conducted by university students in a seminar dedicated to "Oral History of Lung Transplantation," this volume also provides an excellent example of the effective use of oral history in teaching and making history an active method of learning.

As a consequence, *Second Wind* is an important addition to the Palgrave Studies in Oral History series. It is our entrée to the history of medicine; it serves as a fine model for instruction; and it contributes to the methodological questions concerning the series. It joins the more than two dozen books covering a wide variety of topics, both within the United States and globally, already published in

our effort to bring the best of oral history to scholars, students, and the general reader.

Bruce M. Stave
University of Connecticut

Linda Shopes
Carlisle, Pennsylvania

Introduction

At the time when my brother John Festle was born in 1966, doctors encouraged parents to treat children with cystic fibrosis (CF) as normally as possible, and this fit in with our family's mode of operating. As soon as he could, John did everything his two older brothers and sister did—playing baseball in the alley, ping-pong in the basement, and gin rummy with my grandparents next door. Every day he tolerated my parents pounding on his back and chest for respiratory therapy, took lots of pills, and slept in a noisy mist tent; but John's coughing, therapy, and insatiable craving for pretzels were a part of a routine his siblings didn't think much about. I recall this from the memory of a child, of course, but it seemed like everyone acted as though the disease was not a big deal. When a birthday came around, it was actually a bonus; we could use the condenser from his mist tent to blow up balloons. His disease didn't stop John from normal schoolwork or playing baseball, basketball, golf, and volleyball well. He was smaller than many boys his age, but playing against older siblings had insured he would be well-coordinated, savvy, and competitive. Others may have wondered about his frequent coughs during a game, but they didn't distract him. While he was in high school, the Chicago Cubs chose John to serve as their batboy, and for two years, he capably performed the cleaning, supply, and errand duties of that job while fiercely protecting team secrets. Besides being an athlete, John was also an entertainer. He had a quick wit and sarcastic sense of humor, which I didn't want to be the target of. He dressed stylishly, perhaps trying to distract people from noticing how thin his limbs were. In many ways, John was a pretty typical and likable young guy.

John's life became increasingly complicated by cystic fibrosis, however. Though he didn't reveal much about his illness to others, he was aware of his body's changes and in tune with its needs. He knew when it was time to switch antibiotics and which drugs worked best for him. He needed to consult with CF specialists regularly, and he had a very friendly, teasing relationship with many of the doctors and nurses. During his adolescence, he had to be hospitalized for a couple of weeks at a time to combat his worsening lung infections. Those "tune-ups" helped improve things temporarily, but they became more and more

frequent. He slept late in the day and lay around a lot when he wasn't working at his job at a golf driving range. I wasn't sure if that was because he was getting sicker or if he was just being a typical teenager. After he finished high school, he wasn't sure what he wanted to do with his life. Perhaps this aimlessness was affected by his illness but it's hard to know, because while our family was very matter-of-fact about daily aspects of his disease, we didn't talk much about the scary prognosis, which suggested he'd only live into his teens or young adulthood. John attended college for a couple of years, then dropped out. Increasingly, he became eager, even desperate, for respiratory therapy, since it was the only thing that made him feel a little better. He needed it more times a day than my mother could provide, even with her years of practice and endurance, so others pitched in. John's temper got shorter as his energy waned. Even though he was very bothered by cigarette smoke, he was able to serve as a groomsman at his brother's wedding. Then in 1990, he came back from a doctor's appointment with disturbing news. Although he had planned to start classes at a new college, the doctor told him that he would not be attending that semester, nor ever, because he was entering the last stages of his illness. There wasn't anything else his CF doctors could do for him, but there was an outside chance he could try for a lung transplant.

Although we talked about it, I don't have a record of John's response to this news. I do recall how I felt: stunned and dismayed. Intellectually I had understood the probability that John would die young and I had feared that moment for years, but I still found it hard to believe that that my 24-year-old younger brother would soon die. Equally shocking was the possibility of a lung transplant. In 1990, the procedure sounded to me like science fiction. I knew nothing about organ transplants at all, much less lung transplants, though somewhere I harbored a vague Hollywood image of dramatic, risky, high-tech surgery that would miraculously cure him. I was dimly aware of the possibility of rejection. Naturally, I had many urgent questions: Was it really possible to undergo a lung transplant? What was the experience like? What were the risks? How long would he live? Would a lung transplant be worth it? How would he cope with this?

Initially I asked those questions as a desperately worried family member, and despite never having set foot in a medical library before, I searched through medical journals trying to find answers. John didn't end up getting a transplant, but years later our younger brother Bob did. (Their stories are resumed in the epilogue.) In the meantime, though, my curiosity and training as a historian kicked in. I wondered about when, why, and how people figured out they could replace one person's diseased lungs with lungs from a dead person. It seemed like an amazingly complex procedure, one involving a tragic death in one location, a quick decision on the part of a grieving family to donate organs, a choice about who on a waiting list should receive the donor lungs, surgery to take them out, transportation of the lungs to a different location, and finally a long operation to implant them. Once I could look at lung transplantation with some distance

and from the perspective of a historian, I realized that for decades others had been asking the same questions I had. In the early 1960s, there were only a few people with lung disease who knew about and seriously considered the risky transplant procedure offered by just a few surgeons. In 1990, when my brother John was wondering about its risks and benefits, a couple of hundred people in the United States had actually received lung transplants. Today lung transplants are fairly common; in 2009 over 1,600 people in the United States had one. But people considering transplants often still wonder if it is worth it. A transplant involves a long process of getting evaluated, spending time on the waiting list, and adapting to a new lifestyle with a foreign organ. People's outcomes vary. When Danelle DiCiantis described the effect of her transplant in 1999, she said, "Picture yourself seeing in black and white your entire life, then just waking up one day and being able to see in color. That's how dramatic the difference is." Laura Rothenberg, on the other hand, suffered a great deal after her transplant in 2001. "I'm happy I made it a year," she wrote, "but it is not the year that I'd dreamed of: complication, after complication, after surgery, after surgery, and rejection and lymphoma . . . My whole life, I've been searching for something to fix me. And it hasn't." These are sobering words to contemplate for the over 2,000 people who are on the waiting list.[1]

It is not only potential candidates who ask whether lung transplants are worthwhile; the number of stakeholders with an interest has grown over time. Surgeons, pulmonologists, nurses, and therapists have always had to decide whether or not to encourage patients to take the risk. In addition, anyone who considers organ donation has a legitimate interest. Unlike kidney transplants, which can use organs from living donors, lung transplants rely almost exclusively upon organs donated from people who died. Thus the public's approval of the procedure is crucial. Some observers characterize transplants as amazing advancements and medical teams as compassionate miracle workers. However, other recent commentators view surgeons more skeptically or see transplants as symptomatic of much that is ailing modern medical practice in the United States; while millions lack access to basic health care, specialists use flashy, risky, expensive, and complex procedures in order to fight death at all costs, even if those treatments don't always significantly lengthen patients' lives.[2] Lung transplants are certainly expensive; a single lung transplant in 2008 cost around $450,000, and a double lung transplant $657,000.[3] Historically insurance companies and government officials have been key players who made decisions about whether to pay for transplants. Even though organ transplants are common today, questions about their value are still relevant in the context of the nation's health care crisis. As states face large deficits, lowered revenues, and rising health care expenditures, they look for ways to cut costs, and organ transplants are sometimes a target. Arizona's legislature passed a health care cost containment plan with a provision that starting in 2011, its Medicaid program would no longer cover seven

types of organ transplants, including lung transplants.[4] Rationing of health care is likely to remain a significant social and political issue, one that poses difficult decisions with life and death consequences. How should we decide whether a medical procedure is worthwhile? If patients gain an additional year of life, does that constitute "success," or should we expect longer? Should we also consider the *quality* of that added time?

This book explores these questions and starts from the premise that in order to evaluate the value of lung transplantation, it is crucial to listen to the perspective of people for whom the procedure was developed. It is a historical work that spans the period from the early 1960s through 2010. Although it describes the experiences of early recipients, the patient experiences it examines in the most depth are those of people who were lung transplant candidates and recipients between mid-1990s and early 2000s. *Second Wind* approaches their stories analytically, synthesizing them, along with other types of evidence, in order to address the following fundamental question: "What factors affected people pursuing lung transplantation?" The answer to that question is complex because people differed in their particular diseases and individual circumstances. Still, their stories reveal that as a group they shared many personal and psychological challenges. That is, being a lung transplant candidate or recipient was a significant and continuing factor in one's life. Although these people faced some of the same struggles as those who had other types of life-threatening diseases, they also had many experiences that were different because of the ways organ transplantation is a unique medical procedure. Their unusual experiences included having to wait a long and uncertain amount of time for their medical treatment, enduring false alarms, pinning their hopes on an organ from an unknown person who died tragically, and living with a suppressed immune system after transplant. These circumstances forced transplant candidates to deal with difficult feelings, consider carefully how they wanted to live, and rethink their identities. Although individuals made choices about how to cope with their unusual circumstances, as a group they shared some strategies, including notable ones related to community formation. Not everyone who started the process actually underwent a transplant, but for those who did, it proved to be a life-changing experience with ongoing implications for identity, health, and daily life.

Lung transplant patients were also affected by numerous phenomena that occurred well beyond their personal and local circumstances. Lung transplantation is a medical procedure rooted in historical context, and the experience of people with end-stage lung disease was different for people in different eras. The ever-changing state of medical knowledge, especially related to surgical techniques, immunosuppressive methods, and patient selection and care, was one fundamental factor that directly touched them. In addition, lung transplant candidates were affected by the supply of donor organs, which depended in part upon fate and in part upon acceptance of the procedure by the general public, medical

personnel, government officials, and insurance companies. Patients were also impacted by national political, legal, and organizational events related to organ transplantation in general and to lungs specifically. At times, there was intense debate about organ transplantation, particularly about its ethics. Stakeholders asked important questions: When is it appropriate to use an experimental medical procedure on someone who is very sick? Is organ transplantation "successful"? Is organ transplantation ethical? How should donor organs be obtained? How should scarce donor lungs be allocated? Who should decide? These questions recurred, though the answers to them changed between the mid-1960s and 2010. Whether or not transplant candidates and recipients were aware of them, these "macro-level" sociomedical factors—medical knowledge, the supply of organs, social acceptance, and national political and organizational events—had a significant impact on their lives.

This book also argues that lung transplant recipients' stories are worth listening to for reasons beyond simply assessing the worthiness of the procedure. Recently scholars in medicine, the social sciences, and the humanities have asserted the value of what they call "illness narratives" and "narrative medicine" to remedy some problems with contemporary medical practice. They observe that practitioners are trained to value abstraction and objectivity, and pressured by the demands of managed care, spend too little time with their patients and lose sight of their individuality and humanity. They believe doctors' primary interests in disease pathology, diagnosis, and action may prevent them from hearing and honoring patients' individual goals and experiences of suffering. Proponents of narrative medicine observe that telling stories is a universal way in which people share their experiences. Formally telling one's story can be beneficial for ill people.[5] It can give voice to one's body, help make sense of and give meaning to devastating experiences, and possibly even improve one's health. Having one's individual story heard and understood can validate, empower, create community, and sometimes even instigate change. Doctors, nurses, and therapists can be especially important listeners. Advocates of narrative medicine assert that by listening carefully to patient narratives—not just about their symptoms but also about their individual suffering, successes, hopes, and needs—health care professionals can practice more humane, ethical, rewarding, and effective care.[6]

My goal is for readers to find the narratives meaningful, authentic, and accessible. This book tries to avoid simplistic stereotypes of patients as either pitiful victims or courageous heroes; instead, it shares their varying reflections about physical, psychological, and metaphysical issues, reflections that may be thoughtful, humorous, painful, fascinating, mundane, or moving. Lung transplant "insiders" (both medical personnel and patients and their loved ones) share knowledge and experiences that may initially seem foreign to others who haven't waited for "the call," kept track of lungs' forced expiratory volume, or feared organ rejection. "Outsiders" may discover, however, that while the experience

of lung transplantation is unique, patient stories are not completely alien. Many people have chronic diseases or disabilities, have undergone treatment for serious illness, have lived with trauma, loss, or poor health—or they or their loved ones will experience one of these things—and thus they may easily identify with the people and challenges featured in this book. Americans often feel uneasy around people who embody their fears of loss of independence and control, so hearing stories of suffering can sometimes be difficult, but listeners may help the storytellers by bearing witness to their stories. Finally, listeners themselves might also benefit.[7] I believe any of us, even if we are currently healthy, can identify with and learn from lung transplant candidates and recipients. At their foundation, the stories are simply human and thus potentially meaningful to anyone.

Overview of the Book

This book has two different types of chapters. Chapters two and eight analyze the "macro-level" sociomedical events in the history of lung transplantation, including early experimentation in animals, the first efforts in people, and what needed to happen medically, politically, and administratively before it could become a widely used procedure. Lung transplantation is an international field, and important research and experiments took place around the globe, but this book focuses on the United States. Because key events took place just across the border at Toronto General Hospital, occasionally the geographic scope is somewhat wider. Where relevant, as in the development of new immunosuppressive methods, legal and ethical issues related to organ donation, development of the United Network for Organ Sharing, and the politicization of transplantation in the 1980s and 1990s, these two chapters interweave stories from the larger world of organ transplantation. They proceed in chronological order, with chapter eight following the story up through 2010 and including the new lung allocation system.

Readers who are more interested in the experiences of "ordinary" transplant candidates and recipients can find them in the remaining chapters. These chapters describe living with end-stage lung disease (chapter one), considering and being evaluated for a lung transplant (chapter three), waiting for and eventually getting the call that a lung or lungs came available (chapters four and five), and post-transplant issues related to recovery, immunosuppression, identity, thinking about donors, and quality of life (chapters six and seven). The organization of these "experience" chapters is also chronological, but in the sense of following the typical stages that an individual patient goes through. While many of the patients' experiences described in these chapters undoubtedly mirror those of people with lung disease and transplants today, many of these accounts date from the mid- to late 1990s and early 2000s. As the history of transplantation shows,

medicine is a dynamic field, and specific treatments, procedures, and drugs have likely changed during the time it has taken to write this book. I hope, though, that the fundamental truth of the experiences is accurately portrayed and remains authentic.

A Note about Methods

Uncovering the historical and sociomedical story of lung transplantation involved research in articles from medical journals and texts. Part of my task as a historian was to "translate" the highly technical language of these texts so that it is both accurate and accessible to people without medical knowledge. The "macro-level" story of lung transplantation also required research in government documents, newspapers and news magazines, organizational press releases, scholarly books and articles, works of popular culture, and interviews with and autobiographical works by key participants. Full citations of all the sources are included in the endnotes. Interested readers can find a complete bibliography of sources online at http://festlesecondwind.wordpress.com/.

To understand the experiences of illness, I looked not to medical records but to individual narratives.[8] *Second Wind* relies heavily on first-person accounts, including 58 oral history interviews, primarily with transplant candidates and recipients. The interviews were supplemented by information gleaned about individuals from autobiographies, newspapers and magazine coverage, personal and organizational websites, and organizational newsletters. Historians must approach all types of sources with a certain skepticism and critical eye, whether those sources are formal and scientific or informal and personal. We know that in reporting results, researchers might gloss over failures and uncertainties, and that stories in published media accounts can contain errors. With first-person chronicles, we know that everyone telling their own story must choose which parts of their experience to emphasize and which to omit; they might forget things or even (intentionally or unintentionally) be untruthful. Whenever people talk about themselves, they adjust their stories to their particular audience; in this case they may have considered whether that audience included lung or organ transplant community "insiders" or "outsiders" such as the general public. Lung transplant candidates and recipients would likely speak differently to a doctor, therapist, donor family, or someone with end-stage lung disease. They might write their stories with an eye to promoting organ donation or selling copies of a published work. They likely would express things differently in more formal writing than in a newsletter or website. Although written first-person accounts are different from those given in oral interviews, I have used them in similar ways, by using quotations that seemed authentic, insightful, and typical, and by being aware of the context in which they were created. While I approached

the written first-person accounts cautiously, I viewed them as valuable primary source evidence for illuminating people's perspectives.

Oral history is an art, not a science, and its practice for this book resulted in what I hope is powerful testimony. The people who were interviewed for this book included seven candidates waiting for lung transplant, 46 recipients of a lung transplant (one of whom was my brother Bob), four caretakers, and two surgeons. Many of the interviewees volunteered to share their time and experiences after I sent out a request through a Second Wind Lung Transplant Association member email list. While there is some diversity and depth, the pool of interviewees cannot be considered a representative sample. Most were from or were treated in North Carolina or the mid-Atlantic states; however, a few were from or were transplanted elsewhere, including Missouri, Nebraska, Florida, Texas, Illinois, New York, and Massachusetts. Supplementing the interviews with other first-person accounts broadened this base a bit. Most of the interviews were conducted by Elon University third- and fourth-year undergraduate students enrolled in a course titled "Oral History of Lung Transplantation." In this interdisciplinary seminar, which I taught on three separate occasions, we read about medical, psychological, historical, and ethical aspects of organ transplantation, and then studied the ethics and practice of oral history, guided by the principles and standards of the Oral History Association. Each student arranged an interview designed to last one and a half to two hours. Before the interview, each interviewee was given a description of the project and a consent form, and the research project was approved by Elon University's institutional review board. The class as a group discussed good common topics to investigate, including what it was like to have lung disease, consider transplantation, get evaluated, wait, get called, recover from surgery, and live with a transplanted lung; but each individual student was responsible for preparing questions and conducting his or her own interview. The students were encouraged to craft open-ended questions and to follow up based on their respondent's answers. Because of the unique experiences of the narrators and the differing interactions between them and the interviewers, each interview was distinctive. Afterward, each student carefully transcribed the tape-recorded interview, trying to accurately convey the speaker's words to the typed page.[9] Interviewees signed release forms giving the interviews to the public domain, and tapes and transcripts were deposited in the Oral History Program archives at Elon University.

To write this book, I immersed myself in the interviews, listening, reading, and rereading while looking for common themes. I followed this same process with the other types of first-person accounts. I tried to be open not just to the themes I expected and that leapt out to me but also to things that surprised or even disturbed me. I was looking for experiences, feelings, and attitudes that were repeated regularly as well as unusual ones that illuminated common dilemmas, moved me, or otherwise seemed significant. My process involved extracting

quotations on certain topics so that I could examine them together as a group. The interviews were not formally coded, but I was very careful as I analyzed, well aware of the power of words. While they were primarily created by the transplant candidates and recipients and their interviewers, I realize that in gathering and analyzing the interviews, I have put my interpretive stamp on them.[10] I selected which quotes would be included in this book, choosing those which seemed to most aptly describe a situation or feeling. I had to exclude many quotations that may have been equally powerful or persuasive. I am the one who chose which themes to highlight, and I likely overlooked ones that I should have included. If we were to redo the interviews or do additional ones, there would be other areas we'd ask about, but of course we didn't know then what we know now.[11] I have worried that interviewees or their families might be disappointed in the way I used their words. After they receive their transcripts, people sometimes are distressed to see that they spoke in an ungrammatical fashion—even though in conversation, we all speak informally. It is also possible that since I may have only used a couple of quotes from a two-hour interview, a person might be disappointed with the particular ones I chose. I can imagine someone protesting, "You mentioned I had diarrhea but not how much I appreciated my caretaker!" For those sorts of selections, I offer a heartfelt apology, and at the same time want to say that I am extremely grateful to those who were willing to share both happier experiences and ones that might be considered difficult, unusual, embarrassing, or painful. Not everyone is able to or wants to remember or talk about personal matters that are frightening or traumatic. In addition, historians don't hide behind anonymity or pseudonyms; they use the real names of their respondents. Thus being willing to speak on the record was an act of courage and generosity by these narrators.

I'm also sensitive to the fact that by only using excerpts from interviews, I didn't allow the full complex individual story of each interviewee to be told. The process of trying to tell collective stories is necessarily reductionist. Because I focused on highlighting common themes, at times a reader might wonder what ultimately happened to a particular person waiting for transplant who was described in chapter four. It was hard to decide whether to produce an edited book of transcripts or the synthetic type of book I opted for because both types are valuable. Historians are trained to try to make generalizations while keeping in mind the existence of exceptions, and that is why I chose to write a book that tries to step back to provide some perspective and more general observations. Fortunately, there are some fascinating autobiographies by lung transplant recipients that offer readers the chance to delve deeply into one person's individual and complex story. In addition, Joanne Schum has compiled a large collection of short first-person accounts.[12] I hope that I have used the primary sources and my "authority" wisely.[13]

Oral history methods proved especially valuable in discussing lung transplant survivors' quality of life. Post-transplant quality of life became an important

focus of study starting in the 1990s as scholars and various stakeholders explored whether expensive medical procedures were justified. Although quality of life is by definition a subjective phenomenon, thus far the fields of medicine, psychology, and social work have tended to rely upon quantitative survey-based data to evaluate it. These are useful and help the field to make generalizations about whether transplants are worthwhile, but they also have limitations, which are described in chapter seven. Oral history interviews nicely complement the quantitative data, while at the same time alleviating some of the problems with surveys. Since they are characterized by open-ended questions, oral history interviews allows people to provide fuller and more detailed description and to supply their own definitions of quality. While oral history also has limitations, this book shows that listening to recipients speaking in their own words more richly conveys the intensity of feelings and experiences that add up to the *quality* of their lives. Their stories of daily routines, small successes, painful disappointments, profound lessons, overwhelming joys, and significant fears deserve to be heard.

Acknowledgments

From the strange looks I get when I mention the subject, I'm aware that few people know anything about lung transplantation, much less its history. Even those in the medical field consider lung transplant a sort of lesser-known "stepchild" of organ transplantation. Not surprisingly, then, few scholars have written specifically about lung transplantation. Nonetheless, I had a wealth of material to call upon as I pondered this history. As the endnotes demonstrate, I have been influenced by many authors in many different fields, including medicine, oral history, bioethics, psychology, disability studies, political science, anthropology, sociology, and medical humanities. They have thoughtfully explored policies, ethics, coping, relationships, death, donation, quality of life, narratives, identity, and other issues, often as related to other organs or the larger field of organ transplantation. Although until now no historian had written an extensive history of lung transplantation, there are books on the history of heart transplantation, kidney disease and transplantation, CF, blood transfusion and the "prehistory" of organ transplantation, and the controversial heart-lung transplant for Jesica Santillan; there are also articles written by medical personnel about lung transplants.[14] I appreciate the many ways other scholars influenced my thinking, but take full responsibility for this book's unique perspective and analyses. I hope *Second Wind* proves valuable for relating both the micro-level experiences of individuals and the macro-level sociomedical history of lung transplantation, and that it does so in a style that welcomes an audience of medical personnel and the lung transplant community as well as historians, other scholars interested in organ transplantation, and the general public.

Many people made very direct and significant contributions to this project. Thanks go first of all to the many individuals who volunteered to talk with me or my students about their experiences. The students and I were profoundly touched by their generous sharing of time and experiences. We learned much from their honesty and insights. Even though I never met many of them, working so closely with their words and thoughts made me feel quite connected to the interviewees. Some particular interviewees showed extra support for the project, including Joanne Schum and Karen Couture, who have written their own books on lung transplantation, Howell Graham, whose story helped persuade me this project might work, and Kathryn Flynn, who has been both a guest speaker for my classes and a friend. I also appreciate the fact that two prominent surgeons who made enormous contributions to lung transplantation, Joel Cooper and the late James Hardy, took time to share their insights and experiences with me. I am grateful to Marc Mitchell and Laura Neill of the Department of Surgery at the University of Mississippi Medical Center for providing helpful access to James Hardy's materials. In addition, I appreciate the three groups of students who were willing to enroll in an unusual course and learn new things about organ transplantation, oral history techniques, and life in general. They were smart, hardworking, earnest, and fun to teach and learn with.

This project would never have been finished without the support of a number of grants, including a sabbatical and a senior faculty research fellowship from Elon University. I appreciate the committee members and the administrators who had faith in this project and awarded me these gifts of time and funding for research trips. I am also grateful that I teach at an institution that values interdisciplinary work and allowed me to teach a course like "Oral History of Lung Transplantation." The personal interest and encouragement of my colleagues in the Department of History and Geography and across campus have meant a great deal to me. Very practical help came from Elon's reference librarians, and Lynn Melchor in particular, who can find and retrieve any book or article, no matter how obscure, from anywhere in the world. Celeste Richards, Pat Long, and Marnia Gardner assisted with oral history matters, and Melissa Pace Garrison served as a helpful and industrious partner in a summer undergraduate research experience. Janet Myers, Peter Filene, Jean Schwind, Jim Bissett, Clyde Ellis, Heidi Frontani, and David Fletcher made suggestions on things I'd written, as did anonymous readers on a number of occasions. Carolyn Stuart invited me into the worlds of disability studies and team teaching, and our conversations have stimulated much thinking. I also appreciate the sage advice of series editors Linda Shopes and Bruce Stave. I explored some of the ideas in this book in previously published articles and appreciate the permission of the journals for reproducing some of that material. These include: "First Try at a Second Chance: The Pioneering Lung Transplant," *Journal of Mississippi History* 64, no. 2 (Summer 2002): 81–106; "Qualifying the Quantifying: Assessing the Quality

of Life of Lung Transplant Recipients," *Oral History Review* 29, no.1 (Winter/Spring 2002): 59–86; and "'Enemies or Allies?' The Organ Transplant Medical Community, the Federal Government, and the Public in the U.S., 1967–2000," *Journal of the History of Medicine and Allied Sciences* 65 (January 2010): 48–80.

My family has been a continual source of support. I will always miss my brothers John and Bob, but am thankful for our time together and their ongoing inspiration. Bob energetically encouraged this project, often joking that he should be prominently featured and offering to be my agent. My brothers Tom and Jim and their whole families have supplied love and humor to sustain me, and my mother JoAnne has expressed the pride and enthusiastic interest only a mother can show for years-long scholarly pursuits. Barbara Z. Taylor has done too many and too important things for me to enumerate publicly in less than a full book, but I will say that most notably for her constant love, patience, insights, support, and kindness, and secondarily for her critical editing and technical support, I am forever indebted.

CHAPTER 1

End-stage Lung Disease

When Jan Travioli was 31 years old, she had a good job with Bank of America, close friends, and had recently put a down payment on a condo. She had been noticing she felt short of breath when exercising, but assumed she was out of shape. Then one day while taking a walk, she felt like her lungs were going to explode. "It just hit me overnight," she recalled. She consulted with her regular doctor, who "just kind of pacified me" and suggested "it was all in my head." Travioli insisted the problem was real, so he referred her to a cardiologist, who "diagnosed me pretty quick" with primary pulmonary hypertension (PPH), which is high blood pressure in the lungs that eventually builds up so much it causes heart failure. A rare disease, it was not surprising that Travioli and her family knew nothing about it and were "in shock" when they realized its severity. She was lucky in a couple of ways, though, to have a doctor that recognized the rare condition and to get diagnosed at a time when a new medication called Flolan had recently become available. "It kept me alive," she reported. "If I was without the drug for five minutes, I could tell." Flolan worked well for her for about a year, but then the disease resumed its deadly path. Soon doing her job became difficult since she was always short of breath; her supervisors let her work from home for a while, but eventually that became impossible and she had to go on disability. She became unable to make the payments on her condo, and her mother moved from another state to help buy the condo and care for Travioli.[1]

Almost six decades earlier, in April 1942, a little boy was born one month premature, weighing five pounds and ten ounces. "W.M.," as he is referred to in published medical records that preserve his anonymity, had an obstruction of the bowel at birth. The case records note that although his appetite was "always

ravenous," he did not gain weight. His stools were "frequent, large, greasy, and offensive." His parents brought him to doctors when he was 21 months old because he was not developing normally, was very thin, and had a large abdomen. His feces contained a lot of fat. Treated with a high protein diet, W.M. improved, but a few years later, he stopped gaining weight and developed a cough. He was admitted to the hospital "cyanosed [bluish in color], distressed, and extremely dyspnoeic [short of breath]," and he died a few weeks later. His autopsy uncovered overexpanded lungs with areas of collapse. His trachea and bronchi were filled with thick yellow pus. His pancreas was characterized by advanced fibrocystic change. W.M. was a little over three years old when he died.[2]

Jan Travioli and W.M. were among the millions of Americans who grappled with debilitating lung diseases in the twentieth century. Their lives differed substantially, not only because they were unique individuals but because they had different diseases. W.M. was born with what doctors today would immediately recognize as cystic fibrosis (CF), while Travioli had PPH. These diseases tended to affect people at different stages in life, cause varying physical problems, and take a different course. Along with emphysema and pulmonary fibrosis, these were two of the four main lung diseases for which doctors would one day turn to lung transplantation. Each disease had its own story of how it was identified and treated, and the state of medical knowledge about it necessarily affected the differing treatments that were available for individual patients. The narratives of people with these lung diseases illuminate differences, but also common threads, especially in one phenomenon shared across diseases: a struggle for life-giving oxygen.

Cystic Fibrosis

Until around the middle of the twentieth century, babies like W.M. mystified doctors, and those who we now know had CF typically died in infancy or early childhood. In the late 1930s, after studying autopsies of children who died with respiratory and digestive problems, Dorothy Andersen of New York Babies Hospital suspected that their problems were part of a single disease.[3] Because they all had cysts (fluid-filled sacs) and scar tissue (fibrosis) replacing most of the normal tissue of their pancreas, Anderson named the disease "cystic fibrosis of the pancreas." Pancreatic insufficiency in the babies with CF meant that they lacked important digestive enzymes that break down food and thus died in part from malnutrition.[4] Recognizing the existence of the disease, though, was a far cry from understanding the underlying disorder, much less being able to treat or cure it.

Scientists gradually learned much more. Cystic fibrosis is a life-shortening, inherited disorder, which can affect people of any ethnicity but occurs somewhat

more frequently in people of European descent.[5] The most commonly inherited life-shortening disease, by the mid-1990s CF affected one in every 2,500 births and over 30,000 Americans had it. The disease is caused by a defective gene and 1 in 31 Americans is an unknowing, symptomless carrier of it. This gene is responsible for production of a protein that helps regulate how much sodium chloride (salt) moves across cell membranes. This improper regulation results in a buildup of a thick and sticky mucus that obstruct ducts or tubes in a number of the body's systems.[6] The salt glands, exocrine glands, reproductive system, kidney, and liver can be affected, and people with CF have delayed physical development. The two most seriously affected areas, however, are the respiratory and digestive systems. Blockages in the pancreas result in poor absorption of food and those in the intestines can lead to cramps, stomachaches, and constipation. In the lungs, salt, fluid, and electrical abnormalities lead to inflammation, infection, and the clogging of the airways with mucus. Relentless lung damage eventually prevents the body from eliminating dangerous carbon dioxide and from sending crucial oxygen to the body's organs, ultimately causing death.[7]

Understanding how the disease works meant great improvements in the lifespan of people born with cystic fibrosis. In 1959, two researchers developed a sweat test that reliably diagnosed the disease. Beginning in the 1950s, doctors experimented with ways to offer patients the enzymes that their bodies failed to manufacture, meaning they could gain nutrients from their food and become much healthier. New antibiotics also gave physicians a varied arsenal with which to attack the constant, life-threatening infections plaguing patients' lungs. In addition, respiratory therapists designed a host of exercises, called chest physical therapy or postural drainage, which involved pounding on the patient's chest, back, and sides in a range of positions to try to force coughing and move mucus out of the lungs. By the mid-1960s, children with CF could be diagnosed early and treated by top pediatric centers using a comprehensive program of enzymes, antibiotics, diet, respiratory therapy, and careful monitoring. By 1983, patients routinely exceeded their doctors' expectations for their life expectancy; half of the CF patients in the United States lived to at least the age of 20.[8] "When I was diagnosed at four I wasn't supposed to live past 12," said Matt Byrd. "And then when I turned 12, the doctors said 16, and then after 16, he said possibly 18, and then at 18 he just threw his hands up and he said he's not even going to try [to predict] because I was just doing so well."[9] Despite the improvements, John Lloyd-Still declared in a textbook on the disease in 1983, "For patients and their families, CF remains a grim sentence, usually prolonged through an unhappy adolescence to a sad, inevitable end."[10]

The lives of siblings Kimberly, Kristie, and Brett Pearce illustrate the degree to which Lloyd-Still's dire description was only partially true. Twins Kimberly and Kristie were bubbly cheerleaders who loved softball, gymnastics, and skiing. Brett claimed they all had a very normal childhood.

> There were really no differences between my sisters and myself and the rest of the neighborhood kids. We had relatively normal lives, especially through elementary school. I was never very sick. I would go to gym class, I'd run the fifty yard dash with everyone, I'd do the pushups and the pull-ups, play capture the flag, dodge ball. Most kids couldn't tell the difference between me and anyone else. I was actually one of the better athletes when I was younger.[11]

There were differences, however. Four times a day each child swallowed a handful of medications set out by their mother. She couldn't perform chest physical therapy on all three of them in the morning, so they took turns taking a special bus to school early so one could get treatment from a therapist there. They all had the deep, loud, and productive cough characteristic of CF, so fierce it sometimes caused them to double over. They all had an enormous appetite. Brett laughed as he remembered an amazed friend who watched him consume "an entire box of Apple Jacks" for breakfast and how a waitress thought Kristie was joking when she ordered two steaks and two baked potatoes for dinner. The disease eventually took a more serious toll on all three of the siblings, but they differed in how early and how badly. Kimberly was not hospitalized until she was in fourth grade, but when Kristie was 12 years old, she was planning her own funeral and buying Christmas gifts for her family because she correctly anticipated she would die before then. "She was just always sicker than I was," recalled Kimberly, who lost her best friend. Brett recognized Kristie's impact on his perspective on life; he was impressed that she exhibited concern for her family while she herself suffered. Her death, he said, had "shown me what's really really important. If I'm sick, and feeling really depressed about having to go into the hospital, and I'm going to miss whatever—you know, the basketball game or something—[I realize] when it really comes down to it, it's three weeks in the hospital and afterwards I'll be out again and I don't need to complain about it. There are worse things that can be happening." As Kimberly's health deteriorated, her mother decided to move the family from Michigan to North Carolina in the hopes of getting her and Brett on a list for a lung transplant. Well enough to attend college, Brett was the luckiest of the siblings. He managed in part by being attuned to his body's needs. "You get used to the signs," noted Brett. "I can tell the difference . . . between an asthma cough, a CF cough, an allergy cough, and a cold. I can call my doctor and say, 'I'll be calling you in a couple weeks because I feel an infection starting now . . . ' And most of the time I'll be right." Twenty years of dealing with discomfort, difference, loss, and frequent medical interventions gave Brett a maturity beyond his years while still having the sense of humor and interests of a typical college student. In describing the impact of CF on his life, he used an image from math class. "My health is like a sine wave: I have peaks of feeling very healthy and valleys of feeling very sick, and they alternate. I'll feel very healthy the day I get out of the hospital, I'll decline until I have to go into the hospital, then I'll feel

very healthy again once I get out of the hospital. Despite that there's a constant motion of that, the overall health has declined over the years."[12]

In a number of ways, the Pearces' stories reflect the characteristics of others who lived with CF. Their childhoods frequently belied Lloyd-Still's predictions of unhappiness and abnormality. "I had a fun childhood," declared Tim Choquette. "I felt pretty normal. My disease wasn't showing up at the time so I was just like any regular kid running around, having fun." Rosalie Gallogly ran track, winning all-city honors in the 440 and 880. "I had a normal childhood I would say until puberty," she asserted. Like Brett, Carlene Weber went to college, then she worked as a financial analyst and subsequently completed a Ph.D. Philip Wenrich actually passed a physical exam from an unsuspecting doctor, which allowed him to be a police officer for six years.[13]

There are a number of possible explanations for these CF patients' assertions of having had normal childhoods. First, because there are hundreds of different mutations of the responsible gene, each case was unique. Some people had earlier respiratory involvement than others; some had more serious digestive problems than others. That meant that like Kristie, some children still died of the disease, while others lived into their thirties or longer. Especially in retrospect (after they became seriously ill), their childhoods could indeed seem idyllic and "normal." Another explanation is that children lacked perspective on what was "normal." Howell Graham said that he was 13 or 14 years old before he found out that he had to do certain things that other people didn't have to do. Laura Scott Ferris had the same experience. "I didn't know any different," she said. "And I was happy." Their parents frequently had a different perspective, however. Although 13-year-old David told an interviewer, "School is quite normal. I go to an ordinary school and do everything that other children do," his mother said, "School causes quite a problem."[14] Naturally, children with CF wanted to be considered normal. To do so, some lied about the reason for their constant cough, saying it was a cold or asthma, dressed in ways to downplay their thinness, hid their treatments, or refused to tell friends they had the disease.[15] Tim Choquette admitted:

> If you go to the mall with your friends, and everybody else walks up and down the mall three times, and you're huffing and puffing trying to keep up with them, you feel different. But I never let it stop me. In other words, I would really bust my butt to keep up with everybody and I would try not to let anybody else know that I was having problems. So I tried to present the most normal aspect of myself that I could to other people.[16]

Try as they might, in fact children with CF weren't quite "normal," but they often approached their differences philosophically. They incorporated drugs, a special diet, and an hour or more of therapy into their daily routines and characterized them as minor irritations. Although absences from school and

hospitalizations were more intrusive, Tim Choquette even compared his situation favorably to other people in the hospital.

> They have to stay there, and they're stuck in bed. I'd get the drugs two or three times a day for like maybe an hour or something, and then the rest of the time I could just hang around. I mean it hurt me socially because I had to be away from school or away from my friends for two or three weeks at a time, but it could have been worse . . . I grew up in the situation. In other words, it was like second nature. I never really liked it, but . . . I'd basically just chill out and talk with the therapist, or whoever, you know, have fun, and try to make the best of it."

A positive attitude helped. Eighth-grader Isa Stenzel wrote in her journal, "I wish I didn't have these stupid IVs and these damn hospitalizations," but she and her sister, who also had CF, figured out ways to have fun in the hospital, bowling with lotion bottles, painting t-shirts, and writing a booklet about their time there, which they sold for a dollar. At a week-long summer camp for kids with CF, the Stenzels joined others in making jokes about their disease (such as CF being short for coughing fits, clubbed fingers, and constant farting) and taught one another a philosophy for coping: "Embrace life. Recognize its fragility. It is better to love and lose than never to have loved at all . . . It's quality-of-life that matters more than quantity."[17]

Clearly growing up with a chronic disease gave them maturity and a perspective different from their peers.[18] Many even tried to acknowledge a positive side to having the disease. "You kind of look at things a lot differently from other people," observed Frank Avila. "[Like] breathing, for instance, you don't take that for granted." Bob Festle agreed. "I think having CF taught me a lot of self-discipline, taking care of myself, and independence. I think I grew up a lot sooner than a lot of people, and so I was very happy with the way that I turned out." On the other hand, he did assert that he "wouldn't necessarily wish that on anyone else." Laura Scott Ferris echoed that thought, describing CF as "a cruel disease that sought to rob me of my breath, my dignity, of myself. Throughout my life it has been my greatest enemy. It has also been my greatest teacher."[19]

Despite a "seminormal" childhood for many, things often got harder for CF patients in adolescence. "When you're ten years old, you don't care," said Shelby Parker. "[But] by about 14, your body is changing and you suddenly care about what you look like." In high school, Carlene E. Weber "found students then to be small-minded and often cruel to those who were different." Danelle DeCiantis resented that she couldn't go on sleepovers because it would mean missing her therapy and that some kids made fun of her clubbed fingernails.[20] Laura Scott Ferris was miserable during adolescence as her peers' bodies matured and hers didn't. "How unfair could life get? Not only did I have a deadly disease,

but I was flat[-chested] besides." Health concerns also often accelerated during their teens. Like Brett Pearce, who no longer took gym class, Matt Byrd noticed that he could not play soccer nearly as long in twelfth grade as he had in tenth grade. Rosalie Gallogly no longer won the 880-yard dash. "By the time I was out of high school, walking up hills began getting very hard." Frequent infections began to take their toll, leading to more frequent hospitalization.[21]

Growing up often meant the implications of having the disease began to hit home. It might take awhile to believe the prognosis, however, as Howell Graham reported.

> The first time I ever saw an ad on TV [about CF] when I was 14 or 15, they said it was a fatal disease and it killed so and so. And I'm sitting there thinking… "I don't have that. I must have a different thing than that, because I'm not going to die." I just kind of lived my whole life like that. Like this thing's never going to get me, and I was going to be fine. As I got older and got more problems, I started to get a little more of an understanding of it.[22]

Tom Fereday recalled the exact day when his outlook changed. Up late one night in the hospital, he started sneaking looks at CF patient files.

> I kept seeing "deceased." And I'd think, "This is weird." So I'd start asking the nurse. I'd say, "All these people are dying." And she said that the average life expectancy was 15 at that time. I was 21, and I said, "Jesus, I'm not even close to dying." It didn't make sense to me, so at that point I started looking through what CF was and tried to learn as much as I could. I don't know if that was good because then I really got a dose of reality.[23]

The combination of greater understanding and declining health was frightening. "I would have points where I couldn't control myself and I would be crying and stuff," recalled Danelle DeCiantis. "It wasn't all like that through high school, but there were some times when I was really scared." Laura Rothenberg wanted to be a typical college student but she was getting sicker and some of her friends were dying. She got upset whenever she thought about the future, knowing she would never grow into old age. In her journal, she wrote, "I think about death every day."[24]

Physical problems mounted. One of the worst was difficulty breathing, which Matt Byrd tried to describe. "It's just like putting your fingers over the holes of your nose and trying breathing through your nose. And that's it—it was just real short of breath all of the time." Everyday activities became difficult, according to David Balsam, who said he could not as much as "walk down a hallway without weaving due to lack of oxygen" and felt his lungs were overburdened by the mere weight of an overcoat. Howell Graham explained, "I would get out of breath just

brushing my teeth—if you can imagine that." Rosina Ferranti-Mehal recalled that in her decline, "I kept getting fevers of 105.5 and I couldn't breathe. I felt like I was suffocating and I'd panic."[25]

Doctors could try different antibiotics, and more therapy, but little else. At some point the patients required supplemental oxygen, which meant hooking a tube over their heads and into their nostrils. Often at first they used it only at night, but eventually it was needed more frequently and at higher and higher levels. Sometimes they also used a feeding tube at night to try to get more nutrition. Shelby Parker's feeding tube made her feel nauseous, and she felt crabby and self-conscious about her oxygen hose. She didn't sleep soundly, and simply could not do much. "I feel bad, and it takes me all day to feel better. I can't really describe it. It's just yuck."[26] She was emotionally stressed, too, worrying about how her father was handling her deterioration. She began thinking about the way in which she wanted to die. Shortly thereafter, she did die.

While the moment of death couldn't be predicted, usually the spiral pointed clearly downward. Many patients fought to the very end, while others found themselves welcoming the release. "I am not happy, my health sucks and sometimes I want to die," declared Joni Murphy. Sometimes their families shared that sentiment. Although Shelby Parker's father was overwrought about her imminent death, her mother said, "I'm not afraid for Shelby to die. I don't think she's afraid to die. It's living like this that I have problems with. I have a hard time seeing her in distress." Howell Graham certainly hated what had happened to him. "I was miserable dealing with this day in and day out and not being able to breathe. I got to where I didn't even have a life . . . towards the end. My life . . . just sucked. It was so bad it was to the point where I wasn't sure that I wanted to go on like that. To go from what I had been to as sick as I was . . . I was really wondering if it was worth it to me." Speaking of CF, Graham concluded, "It's a horrible disease. I would not wish it on anybody."[27]

Primary Pulmonary Hypertension

In 1979, Mary Gohlke sat in a cardiologist's office, hoping for an innocuous explanation for the wheezing, shortness of breath, and incredible fatigue she'd been experiencing. Instead, her doctor told her that she had PPH, a rare terminal illness for which at that time there was no effective treatment. "I could scarcely breathe for a moment," she recalled, as numbness spread throughout her mind and body. She managed to ask how long she might live. After hearing the answer, "the anger began to build slowly but steadily until I was about to burst, as violent as I've ever been in my life." She wanted to smash things. "I've got two kids to raise and you're telling me I have five years to do it?"[28] As the prognosis sank in, Gohlke felt frustration and grief, especially sad about the times she would miss

with her sons. Then during one long night in the hospital, she felt something different.

> I was *afraid*. I knew I was going to die, and it was absolutely terrifying. My chest was tender, and the beating of my heart hurt. It was a clock saying, "You're dying, you're dying," each beat repeating the awful litany. It would be a long, long time before I could confide my terror to anyone, even my husband. I learned something else that night, something only the terminally ill know. I learned the haunting loneliness. It's a loneliness that can't be helped by other people. You can share anything in life with others, but in the end, you die alone.[29]

Mary Gohlke shared with cystic fibrosis patients many of the feelings experienced by the terminally ill, but there were differences in terms of the symptoms, causes, and treatments of their diseases. There were also psychological differences. Most people with CF were diagnosed in childhood and had years to grow accustomed to their illness, its prognosis, and the medicalized lifestyle that accompanied it. Many people with primary pulmonary hypertension, on the other hand, were not diagnosed until they were adults. While the rare disease can strike anyone, it affects women more than men, particularly young or middle-aged women. Although they often had symptoms for a couple of years before they were accurately diagnosed, it felt very sudden. "A few months ago, I was just a fat, lazy mom with an asthma problem," said Mickey Moran. "Now I sit here with a tube coming out of my chest and an incurable disease. I crawl to the bathroom and have to have people wait on me. How did this THING take over my life?"[30]

Often struck in the prime of life, PPH patients had a lot to lose. Like Gohlke, Louise Pennewell was a 43-year-old professional and mother. She had happily worked 50 hours a week, enjoying her success and relationships with colleagues and customers. Unfortunately, PPH forced her to quit her job, meaning a critical part of her identity was gone. "I have not filled this void. The friends call less and less, and the void seems bigger. I miss the feelings of accomplishment. I miss feeling valued for the work I do. I miss knowing the answers for my coworkers' problems, and sharing the solutions." The disease also had a detrimental effect on Pennewell's role as mother. "As a single parent, I want to give [my daughter] the sun and the moon! I realized today, as we got her bike out, that I haven't the energy to help her graduate from her training wheels. I can't take her swimming and be the one to hold her back [up] while she learns to float. It is the littlest things that bring me to tears."[31]

The psychological and emotional implications of the disease were clearly difficult, but so were the physical effects. PPH causes the cells of small arteries in the lungs to become irritated and form fibrous material, which narrows the opening of the arteries. As the blood vessels constrict, they carry less blood. Pressure then

builds up in the arteries, including in the pulmonary artery, the vessel that leads from the heart to the lungs, making the heart work harder. With less blood circulating through the lungs to pick up oxygen, the patient becomes dizzy, exhausted, and short of breath. Many experience chest pain, fainting spells, and swollen ankles and legs. If the pressure remains too high for too long, the right side of the heart becomes enlarged. Eventually heart failure develops.[32]

Primary pulmonary hypertension is both rare and mystifying. Although first described about 100 years ago, it was only identified as a disease in the 1950s.[33] Perhaps as few as two people per million have the disease, and even in the 1990s, many physicians had never seen it. That meant patients were frequently misdiagnosed. "I kept going to the doctor who told me I was depressed and overweight," Alix Flipse recalled. "He gave me Prozac and kept increasing my dosages. I asked what about the fainting, and he said it was panic attacks. He said there was no way of knowing if I would faint again, that it was up to me and how I dealt with life." Finally at one visit her regular doctor wasn't in, and the replacement said right away, "This isn't depression, this is your heart. Then came all the other tests until finally I was told Pulmonary Hypertension." Shirley Jewett's physicians wondered if she suffered from chronic fatigue syndrome, Epstein-Barr, allergies, or depression, and mainly treated her symptoms. Without a definite diagnosis, she felt she was going crazy. The small number of diagnosed cases also meant that researchers and pharmaceutical companies spent less time on exploring treatment options than they did for more common diseases. In 1987, when three women started the Pulmonary Hypertension Association, there were fewer than 50 known cases. That proved to be a hardship on newly diagnosed patients. "I didn't know anything about it," remembered Jan Travioli. "I felt very isolated when I was diagnosed."[34]

The disease's causes are not understood. Ten percent of sufferers may have a genetic form of the disease, but for most, the cause is unknown. In the late 1960s, there was a sudden tenfold increase in PPH in Europe, attributed to diet pills. There was a similar outbreak in the United States in the 1990s in people who used diet pills containing fenfluramine or dexfenfluramine ("Phen-Fen"). Some people also suffered from what was known as secondary pulmonary hypertension, which meant that their pulmonary hypertension was triggered by another, known problem, such as asthmatic bronchitis, blood clots, collagen vascular disease, or congenital heart disease.[35] Melanie Greene was born with a heart defect in which a hole between the heart's two pumping chambers permitted blood to flow abnormally. Randall Benifield's problems also originated with his heart. When he tried to pick up something heavy, he said, "I turn a nice shade of purple." Cases varied a great deal. While usually adults develop the condition, Jessica DelCimmuto had to go on supplemental oxygen when she was three months old. ICU nurses jokingly referred to spells that caused her to collapse and turn blue as "Smurf attacks."[36]

Gradually medical researchers developed some promising treatments. Calcium-channel blockers prevented arteries from constricting in about one-quarter of cases, and anticoagulants helped some others. In 1995, the FDA approved a synthetic version of a naturally occurring steroid, prostacyclin, known by the brand name of Flolan, that decreased symptoms in a high percentage of patients. For Jan Travioli, who got flushed and severely short of breath without it, "It was my lifeline." Unfortunately, using Flolan could be daunting. A freeze-dried powder that had to be prepared daily, it had to be administered intravenously through a catheter leading directly to the heart. "I had to carry a pump around with me. I had to mix medication every day. This thing was intravenous, it was 24 hours a day. It was really hard to get used to," explained Jan Travioli.[37] In addition to the hassle of wearing a Walkman-sized medication cassette everywhere, there were side effects to the drug, and the catheter could break, get plugged, become dislodged, or develop infections. In addition, Flolan was very expensive. Because she was diagnosed 16 years earlier, Mary Gohlke never had the option of Flolan. And unfortunately for some people like Travioli, the drug only worked for a short period. In 1998, the average survival time for pulmonary hypertension from the onset of symptoms was two to three years.[38] Although much progress had been made by the mid-1990s, the disease had been "known" an even shorter time than cystic fibrosis, and as with CF, there was still much to be learned.

Idiopathic Pulmonary Fibrosis

Many people have suffered from lung disease of unknown origin, which American doctors called idiopathic pulmonary fibrosis (IPF). "Idiopathic" means unusual or unknown; pulmonary refers to the lungs; fibrosis refers to scarring. The very tiny air sacs of the lungs are called alveoli, and it is through them that oxygen is transferred into the bloodstream so that it can be delivered to the body. It is through the same alveoli that carbon dioxide exits the bloodstream. The interstitium is the tissue wall between the alveoli. Normally, this interstitium is a thin tissue layer with just a few cells in it, but in people with IPF something irritates the lungs. What it is that irritates them is often unknown, perhaps sometimes an autoimmune disorder or a virus. Regardless, it seems likely that the body tries to fight off the irritation with white blood cells and that these white blood cells damage the tissue of the interstitium, resulting in scarring. This stiffens the lungs, making breathing difficult.[39] "In this disease the lung soon becomes like a brick," according to surgeon Joel Cooper. "Instead of being spongy and soft it becomes increasingly very hard and fibrous. In fact, on microscopic section, it's almost unrecognizable as a lung."[40]

Kelly Helms was the last person you would have expected to develop lung disease. As a child she had been very athletic, swimming competitively and playing basketball, and as an adult she worked full-time and loved fitness so much that she taught aerobics in her spare time. At 26, Helms was happy, energetic, and excited about the future, yet she coughed and coughed. At first everyone assumed she was suffering from asthma, but her chest x-rays alarmed a doctor, who suspected Hodgkin's disease and ordered her into the hospital. "Here I was at work one day, and the next day I'm in the hospital, and they think I have cancer. It wasn't like a gradual progress. It was like boom! My life was just turned upside down in a matter of 24 hours."[41] The eventual diagnosis of IPF was surprising, she noted, "because it usually strikes older adults in their 50s. They traced my family history and everything, and they still do not know why I was stricken with this lung disease at such a young age." Although she never knew the cause, Helms could effectively describe the experience of the disease, and did so in terms similar to Matt Byrd's description of CF.

> The symptoms are really just massive shortness of breath. Your lungs become really fibrotic, like leather, so you can't get air in. It's like you try and get air in and it just hits a wall, because all your air sacs have become like leather. Most peoples' lungs move in and out and they're flexible. Mine became really structured and stiff, so I would try to get air in and couldn't get it in. I always tell people to try to close your nose off and breathe in through a straw, like a really tiny cocktail straw. And how difficult that is, that's what just breathing normally was like for me.

No one knows for sure how many people have IPF. There may be 50,000 currently diagnosed in the United States, with an additional 15,000 new cases developing each year. This may translate into a rate from 7 to 10 cases per 100,000 persons. About 5 percent of the cases appear to run in families, suggesting a genetic cause for some. Men get the disease somewhat more frequently than women. Idiopathic pulmonary fibrosis is just one of approximately 200 diseases—collectively known as interstitial lung disease—in which lung scarring is found. In many of these cases, the causes are known, and these include exposure to substances such as asbestos or silica or chemicals, connective tissue diseases, and other diseases such as sarcoidosis, eosinophilic granuloma, and lung cancer. Cigarette smoking, chronic aspiration due to acid reflux, exposure to certain dusts, and certain viruses may be risk factors for IPF.[42]

Regardless of the cause, the prognosis is not good. Once the scarring occurs, no surgery or medication can remove or dissolve it. In recent decades doctors used corticosteroids or immunosuppressants to reduce the inflammation that may lead to the scarring. These treatments seemed to help some people (though with side effects), but no effective treatment for IPF has been identified that can

lengthen survival or significantly improve the quality of life for patients. In the mid-1990s, the average survival rate after diagnosis was four years, and most patients died of respiratory failure. Specialists concluded, "IPF progresses in a relentless and insidious manner."[43]

Chronic Obstructive Pulmonary Disease

In stark contrast to idiopathic pulmonary fibrosis, the main cause of chronic obstructive pulmonary disease (COPD) *is* understood: in 80–90 percent of the cases, it is smoking. Chronic obstructive pulmonary disease is a term used for two conditions, emphysema and chronic bronchitis. In both cases, long-term irritation of the airways (usually caused by smoking) results in white blood cells releasing enzymes that damage the alveolar walls. The walls lose their structure, become weakened, and collapse. This causes air to be trapped in the lungs and prevents the normal exchange of oxygen and carbon dioxide between the alveoli and the blood. As elasticity of lung tissue is lost, the lungs become distended, unable to expand and contract normally. Breathing gradually becomes more and more difficult. "Emphysema is like breathing in as far as you can and living with your chest in that position for the rest of your life," explained surgeon Joel Cooper. "That's what happens to these patients—their lungs are fully expanded and they can barely breathe." In an x-ray of someone with severe emphysema, "It looks as if someone took a tire pump and inflated this [person's] chest."[44] COPD is a widespread disease. By the 1990s, COPD was the fourth most common cause of death in the United States, killing almost 120,000 people annually. Almost 14 million people had the disease, somewhat more men than women, most of them over 50 years old.

Tobacco has had a long history in the United States. Indeed, from the founding of the British colonies, tobacco was a central part of American society, bringing pleasure to users and high profits to growers. Cigarettes (as opposed to other forms of tobacco) became popular around the turn of the twentieth century, aided not only by their addictive ingredients, but by creative and aggressive new advertising campaigns. Throughout much of its history, people extolled tobacco's benefits. Folklore decreed that tobacco could aid many ailments, and in the twentieth century, American manufacturers advertised that cigarettes protected throats from irritation, aided digestion, helped weight loss, and guarded against colds. Individual physicians in the 1930s endorsed particular brands; the American Medical Association declared that the benefits of tobacco in relieving tension outweighed its dangers; generals attributed part of American troops' success in both world wars to the influence of free cigarettes. By the middle of the twentieth century, smoking was firmly entrenched in American culture. Presidents, movie stars, athletes, journalists, and people

from all walks of society regularly smoked cigarettes, including about half of American adults.[45] For decades, though, chest physicians had observed linkages between smoking and respiratory problems, and by the middle of the twentieth century, scientific evidence showing the deleterious effects of tobacco use was accumulating. Despite a campaign by the industry to disrupt the investigation, the surgeon general of the United States issued a report in 1964 that concluded smoking was a cause of lung cancer and laryngeal cancer in men and an important cause of chronic bronchitis. The report also noted a relationship between emphysema and cigarette smoking. A year later, Congress forced tobacco manufacturers to put a warning label on every package of cigarettes. Meanwhile, the tobacco industry promoted new types of cigarettes, implying they were healthier, and established a research institute which tried to convince the public that disagreement existed about whether smoking was hazardous. Despite being aware of convincing evidence to the contrary, tobacco industry giants argued for decades there was no conclusive proof that smoking was addictive or that it caused lung disease.[46]

By the time the surgeon general issued the report, it was too late for some people. "I started smoking when I was very young and at that time there was no such thing on a pack of cigarettes [as] 'bad for your health,'" reported Glenda Jones. "I do realize that no one made me smoke, but then again, I didn't know they could or maybe would kill me either." Indeed, Jones' own doctor smoked. "[He] smoked himself and to him smoking was no big deal. He did not encourage me to stop smoking, and I guess he thought that I didn't want to hear all of that about cigarettes being bad for you."[47] Although word of smoking's dangers eventually spread, many people did not take the warnings to heart. Wayne Foster smoked 15–20 years. "Over the years, Dad said, 'Don't you kids smoke. You'll regret it in years to come.' Of course I learnt that now. Being a kid you don't realize those things."[48] Chain-smoker Cheryl Maxham started smoking in her teens, but assumed that because she was very active, it was not a problem. "I did water-skiing and I played softball. I waitressed for 17 years, so I was constantly running, never idle. Smoking never really bothered me." To the degree she was thinking about it, her thoughts were illogical. "I never thought that much about it. I knew it wasn't good for you, but everybody smoked; it was not a big deal."[49] Only later did a debilitated Maxham realize that the cigarettes took their toll silently at first.

Many people understood the danger but still had great difficulty quitting the habit. Diagnosed with chronic bronchitis at 33, Donna Wall already had high blood pressure and episodes of shortness of breath. Her doctor had been warning her for years to quit smoking, but "Evidently everything was put out of my mind, it couldn't have been what I wanted to hear." She attended five different smoking cessation programs and a hypnotist, but "Nothing worked, as I was not able to say I want to quit smoking with conviction. It is insidious, addicting and

had taken [my] energy and vitality." After repeated hospitalizations, she formed a new plan.

> You will laugh and so do I now but at the time it was horrific. I made myself sit down and write "I hate cigarettes" over and over and over, [h]oping my mind would believe it . . . After a week of writing my hundred sentences of why I hated smokes I put them down. Three times my husband had to get them out of the garbage; three times I broke his heart, but the fourth time I threw the pack out the upstairs window in front of him and said, "I will never ask for them again." He was relieved and delighted. I was miserable.[50]

Not everyone who smokes develops COPD (only 10–15 percent do) or lung cancer, and no one knows why some do and others do not. In addition, a small percentage of people who have not smoked or been exposed to second-hand smoke develop COPD. Alpha-$_1$antitrypsin deficiency is an inherited disorder and people with it lack a protein (alpha-$_1$antitrypsin) made in the liver that protects the lungs from an enzyme that digests damaged or aging cells. The alpha-$_1$ protein stops the enzyme from going too far and attacking healthy lung tissue.[51] Alpha-$_1$ sufferer Karen Fitchett described the process in nontechnical terms.

> It's like a little Pac-man. There's a Pac-man that comes out into your lungs and eats bad tissue away. Well there's another little guy that's protein that comes out to tell the Pac-man when to stop eating so it doesn't eat good tissue. I lack the guy that tells the other guy when to stop eating. So the Pac-man just keeps eating away the tissue, good tissue and bad.[52]

A pulmonary specialist confirmed that in someone with the disease, the lung "looks like Swiss cheese, like something's been chewing on it."[53]

People with alpha-$_1$antitrypsin deficiency develop emphysema at a younger age than most COPD sufferers, and although it is a fairly common genetic disorder, their cases often mystified doctors. "At 24, I was basically given my death sentence," said Laura Richards. "[I felt] terrible, and I had nowhere to turn. There is a national alpha-$_1$ association now; there wasn't any back then. I felt very alone, just really very alone."[54] It took Mary Peters 10 years to find a doctor who recognized her symptoms for what they were. Unfortunately, by that time she was told she had only 18 months to live. May Parker was also misdiagnosed. Told that her repeated problems were spontaneous bronchitis and sinusitis, she accelerated the course of her disease. "They told me you have to stop smoking. I go, 'Yeah, yeah, yeah,' and I'd quit for four weeks, get better, and start smoking again." Before she was tested for the disease, she was "bleeding from the rectum, bleeding from my mouth, my feet were swollen," her lung capacity was down to 11 percent, and she was near death.[55]

Physicians recognized emphysema and chronic bronchitis over 200 years ago, but since the causes were not understood, the treatments were often misdirected. In the late nineteenth century, doctors believed chronic bronchitis could be prevented by avoiding exposure to dampness, wind, polluted air, and drafts. They also prescribed expectorants and compressed air baths. During the twentieth century, surgeons tried new fixes. Some tried to compress the distended emphysematous lung; others took the opposite tack, trying to give the expanded lung more space to breathe. Unfortunately, these methods failed, and usually made the patient even more short of breath.[56] Other efforts included depriving a patient of his/her lung nerve supply, designing an abdominal belt to restore the position of the diaphragm, and excising a body of vascular tissue in a procedure called glomectomy, which is now considered "one of the most unphysiologic, controversial, and infamous operations in all of surgical history."[57] Some people whose emphysema is caused by alpha-$_1$antitrypsin deficiency can be helped by replacement therapy of the protein. For most people with COPD, though, the main treatment has been to slow the progression of the disease by stopping the irritation of the lungs (smoking), and the earlier that happened, the longer patients tended to live. Doctors can prescribe bronchodilators to reduce inflammation and muscle spasms, and they eventually realized they can alleviate some suffering by providing supplemental oxygen, but once lung damage has occurred, it can't be reversed.[58]

Common Effects of End-stage Lung Disease

Whether they had cystic fibrosis, primary pulmonary hypertension, idiopathic pulmonary fibrosis, chronic obstructive pulmonary disease, or another, more rare lung condition, whether its cause was genetic, environmental, unknown, or smoking-induced, and whether it became problematic in childhood, middle age or in one's sixties, people with end-stage lung disease had some things in common. First, whatever other symptoms they might have had, all shared the experience of being short of breath. "It's hard to describe it to someone that's never experienced it," said Kathryn Flynn. "Struggling with breathing is an incredibly difficult thing. It's probably one of the hardest things there is." Kelly Helms said it was a frightening feeling. "You know how panicky you feel when somebody puts their hand over your mouth and you can barely breathe? That's how people with lung disease feel 24 hours a day. All that anxiety and panic, because you can't get air."[59]

The inability to breathe easily led to all sorts of other losses. It didn't just affect health and energy levels, but ultimately a person's basic identity. "Your whole life, everything changes about you," asserted Bill Poplett. B. J. Hoilman

agreed. "As your shortness of breath increases, you incur more losses," including independence, self-confidence, body image, occupation, mobility, hobbies, relationships, and innocence. Each loss was serious, and involved adjustment. "When you become ill, the things that once made up your life begin to fall away," asserted Tiffany Christensen, who observed the phenomenon in herself and others. "Usually, this causes a crisis of self that I call The Illness Identity Crisis."[60]

Often losing one's job came fairly early in the process. At first, Frank Spears tried to just cut back on his hours. "It dwindled down to two or three days a week, two or three hours a day, and that was all. And then at the last, work was beyond me." Donna Wall hoped she could just take some time off to recover, but eventually had to recognize that she was permanently disabled. "The depression was overwhelming. What will I do[?] I've worked all my life. Even though my interests were many and hobbies were numerous, my feeling was of complete loss at that time." Unemployment could cause worries about money, too. As one person put it, "In terms of using up my finances, continuing living is a real concern of mine."[61]

Lung disease hampered one's ability to perform everyday functions. Bill Poplett could no longer be involved with his daughter's baseball team and watched his wife take over many of his usual errands. He felt he was "not able to actually be a real father or husband. All this has a direct impact on your psyche." Harold Blaise similarly missed being able to contribute to the household. "I'd love to just get out and clean my car. There's no way I can even do that; I just don't have it in me . . . You just can't do 99 percent of the things you could do before, and that really plays out to where you're frustrated." Eventually, walking even the shortest of distances became difficult. "Small inclines began to look like Mt. Everest," observed Karen Couture. "And stairs? They were out of the question."[62]

Supplemental oxygen became necessary and sometimes wheelchairs as well. When first offered a wheelchair, Gene Weinstein refused, saying, "It will affect my identity. I'm not ready for it yet." He felt people didn't see him as a "whole person" when they knew he was sick, and once he did use a wheelchair, he found that people spoke to him as though he were intellectually disabled. No one liked being dependent upon oxygen, either, even if it brought some relief. Gradually more and more was required just to survive, and no matter how far the tube from the oxygen machine stretched, one felt tethered to it. In fact, Weinstein called the oxygen tube "the python."[63] Modern, lighter-weight, portable oxygen tanks made it possible to leave the house for a few hours at a time. Still, Cheryl Maxham disliked "living stuck to an oxygen tube, taking it with you wherever you go, and the hassles it causes." But it was more than just the cumbersome nature of the machine. "I was embarrassed to take my oxygen out in public. I didn't want people to know I was on oxygen. So I didn't do

anything, I didn't go anyplace. Each day I was dying." Charles McNeill noted succinctly, "Going to the mall in a wheelchair and tied to an oxygen tank is not cool for a 19 year old."[64]

Progressive lung disease also took a toll on relationships. Since "it's a lot of hassle to get ready and to go someplace," patients easily became isolated and depressed. That could put even more stress on their loved ones as well. Thomas Bullard had grown up with lung and heart problems, so he felt "It was probably harder on my immediate family, my wife and two boys [than on me]. I think the children had to do a lot of growing up in a hurry."[65] Sometimes the strain brought family members closer, but it could also have the opposite effect. Laura Richards and Shari Converse both attributed the breakup of their marriages in large part to their terminal disease. And it could affect other relationships as well. "People forget you when you are sick," explained May Parker. "They don't mean to, I'm not saying anything bad about them because they have their lives and all, but when you're away, people forget." Converse added that illness could be threatening to some people. "And you just don't see those people quite so much anymore."[66]

"The scary thing about lung disease is you're very, very very slowly deteriorating and there's not a thing you can do about it," said Rod Kane. Even for a tough Vietnam veteran like Kane, this powerlessness caused "a sense of terror and hysteria."[67] Crises inevitably occurred. Randall Benifield coughed up enough blood to fill up a Coke bottle, Paula Huffman had "these incredibly horrible coughing spasms" where the mucus "gets caught in your throat and it strangles you," and Sylvia Edwards blacked out, feeling like she was drowning.[68] "Nothing stays the same with this disease," complained Roger Stevens.[69] What one could count on, though, was deterioration. Patients' health problems became cumulative. A lack of oxygen made them fatigued, and even eating became a challenge. "Sometimes I just get so out of breath from eating, I don't bother," admitted Laura Richards. Losing weight made them more fatigued. A medicalized life became inevitable. "My new routine evolved around pills, breathing treatments, and oxygen twenty-four hours a day, seven days a week," explained Sylvia Edwards. "My visitors included a visiting nurse, a respiratory therapist, and a physical therapist." Roger Stevens appreciated the oxygen tanks that saved his life, but also the oxygen delivery men who were one of his only links to the world outside his home. Simply surviving took all Stevens's energy. "All I seem to do is take medicine and drink. Oh, and give myself shots now. And have a wicked time breathing." There came a point when patients became unable to care for themselves. Like Jan Travioli, Kelly Helms needed her mother to move in to help her. Tiffany Christensen hated how much became out of control. "As a sick person, you can feel like you spend your life at the mercy of others; waiting for them to bring you food, medicine, oxygen; being pushed in a wheelchair

at a speed and route not determined by you . . . Vulnerability is one of the most emotionally painful parts of illness."[70]

* * *

People with end-stage lung diseases such as CF, PPH, IPF, and COPD had individual lives, which, like their lung diseases, differed. They struggled with different symptoms developed at different ages and stages of life. Based on the medical field's understanding of their condition at a particular moment in history, they might have had some or not very many treatment options to slow their deterioration or alleviate their discomfort. Whichever progressive lung condition they had, however, they eventually encountered debilitating symptoms and a series of losses. A psychologist termed life with progressive lung disease an "emotional strait jacket" because people "cannot become angry, depressed, or happy, or experience any other emotional change, without risking shortness of breath. They tend to be extremely nervous and tense, often not knowing when their next breath will come."[71] As the American Lung Association said in its fitting slogan, "When you can't breathe, nothing else matters." Probably everyone who cared for someone dying of lung disease wished they could do more. Certainly pulmonary specialists wanted to. As David Bates declared in 1970, "Any physician who has had the sad task of caring for a patient suffering from advanced [lung disease] must on occasion have wished that human lung transplantation could offer some hope to these unfortunate patients."[72]

CHAPTER 2

Sociomedical History of Lung Transplantation, 1963–2000

When her doctor told Mary Gohlke that no treatments were available for primary pulmonary hypertension (PPH) and that she probably had only a few years to live, she said it was "the loneliest moment of my life." But the 5-foot, 90-pound Gohlke was a fighter. When she read in 1980 that Stanford University researchers had been performing heart-lung transplants with some success in animals and were ready to begin human trials, she volunteered to take part. "I want to live," she told surgeon Bruce Reitz, "whether it's for five minutes, five days, or five years. I want to be able to live, to breathe, to feel good." Reitz welcomed her as a candidate, but was brutally honest, explaining that although his animal subjects were doing well, human beings were different from monkeys. He could not estimate her odds for success but anticipated it would be a difficult path. Only three heart-lung transplants had ever been performed in human beings, all a decade earlier. One recipient lived less than a day, another eight days, and the third twenty-three days. Reitz warned her that rejection of the organs, infections, and side effects from post-transplant drugs were very real dangers and would remain so for however long she might live. Because it was quite possible that she might not survive the surgery, Reitz wanted to wait until she was at the brink of death before doing the transplant.[1]

Gohlke considered herself lucky to live at a moment in history when a heart-lung transplant could be offered to her. Before such a moment had become possible, though, medical pioneers needed to learn much about surgical techniques, methods to suppress the body's immune system, and patient selection and care. In addition, they had to gain acceptance for their procedure from the medical community, the government, and society at large. Although surgeons had been

trying lung transplants since the mid-1960s, such approval was not automatic in 1980. Earlier failures had soured many people on the prospects. Indeed, a proposal to do a heart-lung transplant raised practical and ethical questions, the same ones raised when lung transplants were first considered for human beings in 1963: Could such a transplant work? Where would donor organs come from? When is it ethically permissible to try an experimental procedure in a human being? How sick should a patient be before a lung transplant is attempted?

Mary Gohlke was unusual because she actually was offered a transplant in 1981, but she was like other Americans who hoped for one in that her chances were affected by sociomedical factors outside her personal circumstances. Macro-level factors such as the state of medical knowledge, acceptance of the lung transplant procedure, the supply of donor organs, and national legal and organizational matters all affected the opportunities available to individual patients. Sometimes these factors were related to the general field of organ transplantation, but sometimes they were unique to lung transplantation, which posed special problems. Difficult ethical issues and practical, administrative, cultural, financial, and political challenges would all make "success" surprisingly elusive for lung transplantation in its early history.

* * *

In the period after World War II, the transplantation of solid organs seemed increasingly possible. Advances in blood banking, surgical techniques, anesthesiology, treatment of infections, and immunology, and greater support for scientific investigation inspired researchers in labs all over the world to perform animal experiments transplanting livers, hearts, kidneys, and lungs. Certain challenges were common to all types of transplants: obtaining and preserving a suitable donor organ; keeping the patient alive while removing his/her diseased organ; attaching a new organ in the recipient; and getting the donor organ to function effectively as part of a complex system in a new body. After passing those hurdles, researchers faced a very serious problem: preventing "rejection" of the new organ. The body's immune system, which attacked foreign entities such as bacteria and viruses, also attacked or "rejected" a grafted foreign organ, usually destroying the transplanted organ within a matter of weeks.[2] Even if researchers discovered a way to prevent rejection in animals, there was no guarantee that it would work in human beings. Thus at some point transplant surgeons would face an ethical issue as well: when it would be appropriate to try the procedure in a sick person.

The first "success" in the transplantation of solid organs in human beings came with kidneys, and even that was limited. The recipients lived only a few weeks, and many criticized the surgeons for undertaking such a risky endeavor. In late 1954, the first long-term success came when surgeons used a donor kidney

from a man who was the identical twin of the recipient. The recipient lived eight years, presumably because his immune system did not recognize the genetically identical kidney as foreign and therefore did not attack it. While this case proved a kidney transplant could restore good health, it did not solve the rejection problem. Indeed, some of the methods researchers tried to prevent rejection even killed the recipients.[3]

Transplanting lungs in human beings would pose particular challenges not associated with other organs. Anatomically, the structure of a lung is complex, involving the pulmonary artery, the pulmonary veins, and the bronchus (the main airway passage leading to the trachea), requiring many surgical connections and making it difficult to maintain an adequate blood supply. The respiratory system depends on the exchange of gases between the air and the blood, which takes place across a very delicate, easily damaged membrane. In addition, surgery involves cutting nerves that affect coughing, the respiratory system in general, and other systems as well. Lungs are big but quite fragile, which meant that it could prove quite difficult to obtain healthy donor lungs. In certain situations, the heart or kidneys of a dead person could be donated, but the lung was frequently marred in some way. "An improper touch alone will destroy it," noted one physician. In addition, donor lungs often harbored infections, which made them potentially deadly, since the immune system of recipients would be suppressed in order to combat rejection. Although recipients of any type of organ transplant faced this danger, it was worse for lung recipients, since every breath they took would expose their new organ to airborne viral and bacterial dangers. "Nowhere in the field of organ transplantation are the challenges greater than in transplantation of the lung," claimed William Cook. "To take this complex, delicate, and violently reactive organ from one body and place it successfully in another must certainly represent one of the greatest achievements in contemporary medical science."[4]

Early Lung Transplant Experimentation in Animals

Researchers around the world who dreamed that lung transplantation would one day save the lives of people with lung disease started with experiments in animals in the 1940s and 1950s. In the Soviet Union in 1946, Vladimir Demikhov gave a heart-lung transplant to a dog that survived for over nine hours, and a year later his transplanted dogs lived up to a month. Cold War barriers meant few in the west knew of Demikhov's accomplishments until the 1960s. In France, Henri Metras did equally pioneering work developing surgical techniques to address problems with insufficient blood supply to a new lung. Five of his dogs lived an average of 20 days post-transplant. After the operation, the dogs breathed

well; had clear lung x-rays; and ran, yelped, and barked normally. After about 8 days, however, the dogs became short of breath and reluctant to move. After 10–12 more days, they died.[5] In subsequent years, investigators in Pennsylvania, Washington, Mississippi, Illinois, Georgia, New York, and Minnesota in the United States joined the efforts. By the 1950s they had proven that a lobe or whole lung could successfully be implanted and that it could support an animal's respiratory needs, but they had not yet resolved issues pertaining to nerve structures and blood vessel attachments. Nor could they solve the basic problem of rejection. If researchers simply removed and then reimplanted a dog's own lung, it would live twice as long as a dog with a lung grafted from another dog. Inevitably, a dog's immune system recognized and destroyed an organ that came from a different dog.[6]

In the early 1960s, lung transplanters found cause for hope in methods used by those transplanting kidneys and livers. The drug azathioprine helped dogs given kidney transplants live up to five times longer. Unfortunately, the amount that was saving animals proved toxic to humans, killing the first two recipients. Smaller amounts proved safer. Then in 1963 surgeon Thomas Starzl combined azathioprine with a synthetic steroid called prednisone to "almost miraculous" effect, achieving vastly improved survival time for human recipients of liver and kidney transplants.[7] Lung transplant researchers experienced some improvement, too. Despite some of his dogs dying early, in 1962 David Blumenstock achieved the longest ever survival time for dogs with new lungs, including 172 days for one dog. In Minneapolis, surgeons performed lung transplants in baboons. Although only 11 of the 20 baboons survived reimplantation, 8 of them lived for two years with normal lung function, raising hopes that lung transplantation in primates, including human beings, might be easier than in dogs.[8] In Mississippi, James D. Hardy (figure 2.1) performed a series of experiments comparing various types of immunosuppression and found that azathioprine exceeded other methods. Hardy had been quite active in animal research on lungs, hearts, and kidneys. "It would be hard to impart," he said, "the huge excitement and challenges the pioneers of transplantation felt in the 1950s and 1960s."[9]

Beginning in the late 1950s, Hardy and his colleagues at the University of Mississippi Medical Center performed lung transplant experiments on more than 400 animals, mostly dogs, but also some apes and pigs.[10] First they worked on simply removing and reimplanting the same lung, making sure they got the surgical techniques right. Then they focused on how to maintain normal respiration when the nerve connections to the brain were severed. They also tested how long a dog's lungs could be separated from its donor's blood and oxygen supply, with their best effort resulting in two hours. Finally, they transplanted organs taken from different dogs, and they quickly encountered problems with rejection. Their dogs treated with azathioprine did best at warding off rejection,

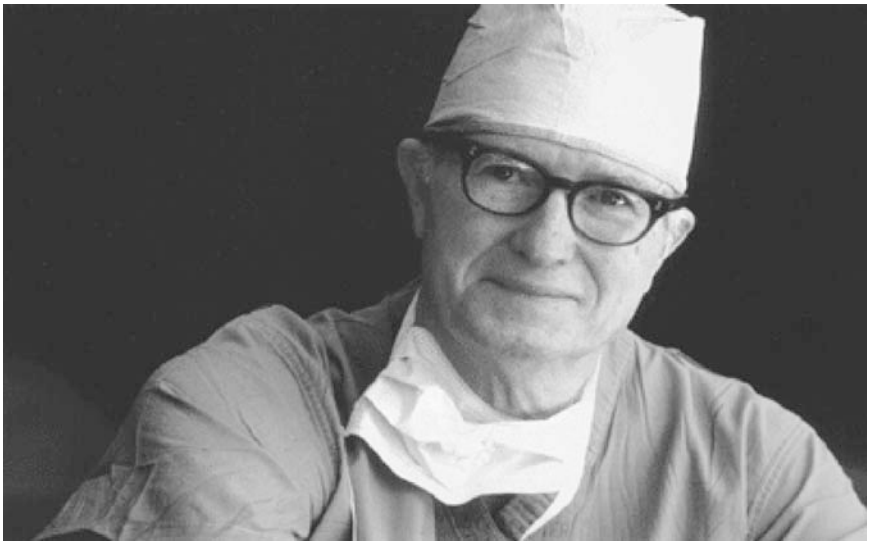


Figure 2.1 Dr. James D. Hardy, first surgeon to perform a lung transplant in a human being. Courtesy of the University of Mississippi Medical Center.

living an average of 30 days, with some surviving for months. Hardy published his findings, reporting that the drugs currently available for suppression of the immune response were more effective than those in the past, but left "much to be desired."[11] Although a few months represented improvement, it wasn't long-term survival. In a May 1963 article, Hardy concluded that experimental progress thus far did "not yet justify sacrifice of even a minimal amount of lung function in a [human] patient" with chronic lung disease. Indeed, "wide clinical application must await resolution of the . . . basic rejection problem."[12]

Despite admitting the poor chances for long-term survival in a person receiving a lung transplant, Hardy intended to try one. He insisted there could be some special situations in which a lung transplant could be useful even *prior to* success in staving off rejection. In one case he had observed, a man with a bowel obstruction vomited while being given anesthesia and subsequently died from inhaling stomach acids into his lungs. Giving the man a single lung transplant, Hardy claimed, even if the lung were rejected in a few weeks, might have allowed enough time for the man's other native lung to recuperate and for him to survive. He argued that "in such otherwise hopeless cases . . . cautious attempts are morally justified." Hardy realized that an unprecedented operation would be better received if he gave people time to get used to the idea. He announced his intentions at surgical conferences starting in December 1962 and met with the dean of his medical school. He and the dean agreed to a set of conditions that had to be satisfied for Hardy to proceed. First, the patient had to have a probably fatal disease, so that if results were poor, his/her life would not have been significantly

shortened; second, there had to be a reasonable possibility the patient might benefit from the transplant; third, the removal of the person's lung must not result in a loss of any functioning lung tissue; and fourth, it should involve the transplantation of the left lung, since that was technically simpler. Over the next year, Hardy considered a number of candidates.[13]

The First Lung Transplant in a Human Being

In 1963, John Richard Russell was a physical wreck. He was 58 years old and had spent six years of a life sentence in Mississippi's state penitentiary for accidentally shooting and killing a 14-year-old boy. He had endured six recent bouts of pneumonia, no longer responded to the infirmary's antibiotics, and had lost 26 pounds. He awoke on sweltering summer nights, coughing up bloody sputum until he was blue in the face. Every movement made him horribly short of breath and he was terrified of suffocating.[14] Prison officials sent Russell to the University of Mississippi Medical Center on April 15, 1963, where examinations confirmed he had only about one-third of a healthy person's breathing capacity and that his vital organs were not receiving enough oxygen. He had cancer in his left lung, which was collapsed and worthless. A lifetime of smoking had also caused emphysema in his right lung. On top of everything else, he had signs of kidney disease.[15]

Hardy thought Russell was a good candidate for a lung transplant. It made sense to try to beat Russell's cancer by removing his left lung, but once they did that, his emphysema-ridden right lung might not be capable of supporting him. If a transplanted lung functioned as well as it did in dogs, it would take over his respiration and offer some relief for however long he might live. Hardy worried about Russell's kidney problems, but he knew he met the criteria: Russell was very seriously ill; it was his left, non-functioning lung that needed to be removed; and he could benefit from the operation. When Hardy approached him about undergoing the procedure, Russell talked with his wife and three children. Russell's main concern was whether the operation would help ease his shortness of breath, and Hardy thought it would. According to Russell's wife, Louise, "He said he didn't know whether it would turn out all right. But he didn't say once he was afraid…I didn't want him to go ahead. But he said he wanted to do it."[16]

About a week after Russell agreed, around 7:30 p.m. on June 11, 1963, a man having a massive heart attack was rushed to the University of Mississippi emergency room. Doctors furiously tried to resuscitate him, but failed. Thoracic resident Martin Dalton was in the hospital, and recognized that the deceased patient might be a potential organ donor. He talked to the family, who consented to donation. Dalton began the procedures they'd discussed to preserve

the lung, keeping it ventilated with an endotracheal tube, and injecting the heart with heparin to prevent clotting, and he arranged for two adjoining operating rooms. He excitedly called Hardy, who rushed to the hospital. Although they found that the donor lung had a worrisome amount of fluid in it, they proceeded, with Dalton removing it and carrying it in a metal basin to the operating room next door.[17]

Hardy and Watts Webb opened Russell's chest around 8:30 p.m. As expected, they found Russell's left lung collapsed, but they also saw that the cancer had spread beyond the left lung. Now it was certain that neither removing nor replacing the lung would save Russell for an extended life. They removed Russell's left lung, but then were dismayed to find that the donor lung might be too big. As Russell's cancerous left lung had shrunk, so too had the space surrounding it. Shaken but avoiding panic, the surgeons adapted, making space for the new lung, and changing a few of the planned vascular connections. Despite the unexpected challenges, the lung inflated easily. After the three-hour operation, they were exhausted, but as Hardy remembered, "We walked out of the operating room thoroughly pleased with our effort."[18]

Reaching the front desk of the operating suite, the surgeons found a great deal of activity, but it had nothing to do with the transplant. Black civil rights leader Medgar Evers, who had been shot from close range, had arrived in the emergency room with a massive chest wound. The ensuing manhunt for Evers's assassin dominated the state's headlines for the next weeks. While Hardy's unprecedented surgery did make the front page of the *Jackson Clarion-Ledger* newspaper, it did so with only a very short story in a bottom corner, dwarfed by the urgent racial issues preoccupying the local citizenry.[19]

When he awoke after the surgery, Russell was told he had a new lung, and he smiled before falling back to sleep. Hovering over him, his eager doctors were equally pleased. The x-rays were clear, and his arterial saturation rate had risen dramatically. An angiocardiogram confirmed that the transplanted lung was getting a good blood supply. Hardy took Russell off the respirator. When he became aware that he was breathing by himself, Russell opened his eyes wide, and he tried to move his arms. He could barely remember the last time he'd felt air entering his lungs without a struggle, and it seemed miraculous. Over the next days, Hardy administered azathioprine, prednisone, and radiation to suppress Russell's immune system (figure 2.2). After three days, the hospital told reporters that the lung was "still doing well." "He looked great," said Hardy. "I thought we were in for a long run."[20]

Ironically, given all that could go wrong with the first human lung transplant, Russell's main problem appeared to be his kidneys. His renal function steadily declined. They had to put him on peritoneal dialysis, which was not ideal and did not work. Intestinal problems also developed. Russell got weaker, less able to enjoy his ability to breathe easily. Although his lung was still functioning,

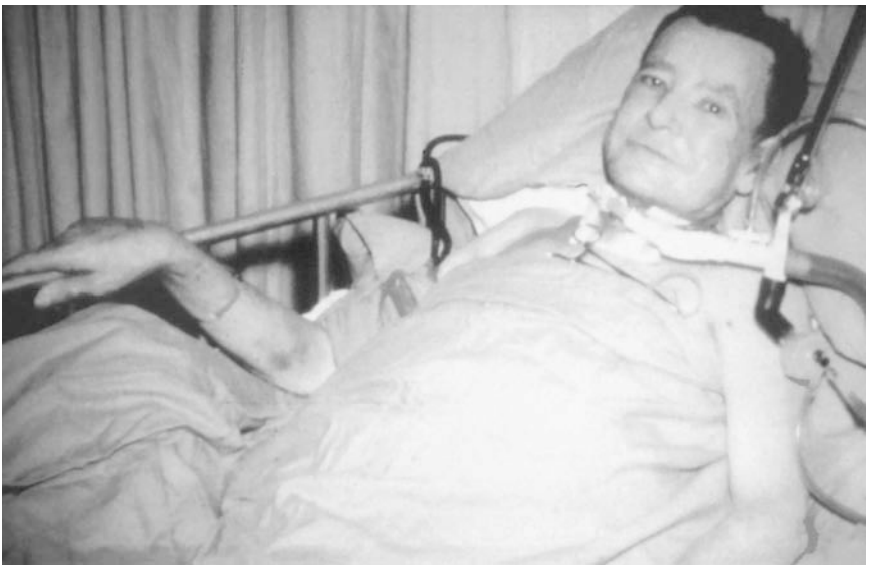


Figure 2.2 John Richard Russell, the first human recipient of a lung transplant, in the hospital after his surgery in 1963. Courtesy of the University of Mississippi Medical Center.

the cancer, infection, and kidney disease took their collective toll, and he died 18 days after his transplant.

Hardy felt disappointed, of course, but also proud of the accomplishment. He had proven that it was feasible to perform a lung transplant in a human being using the techniques perfected in animals. Furthermore, the transplanted lung functioned well, supporting Russell and significantly improving his respiration. Hardy was also pleased with what he saw at the autopsy: the structure of the blood vessels and alveoli looked good, and there was "virtually no evidence" of the cellular infiltrates that had signaled rejection in dogs. Although later examination found some evidence of rejection, at the time Russell's death did not seem to be directly related to the lung transplant. Hardy had found it easier to perform the operation and manage immunosuppression in a human being than in dogs. He declared the effort a "limited but gratifying success" and believed his experience "open[ed] the way to further careful exploration of lung homotransplantation in man."[21]

A few weeks later, doctors at Presbyterian-University Hospital in Pittsburgh followed up on Hardy's trailblazing. George Magovern and Adolph Yates had been doing lung transplants on dogs for two years, and like Hardy, they believed that some transplants could ethically be attempted in order to "bridge the gap between the laboratory and the patient." In late June 1963, Regis Sismour, a 44-year-old father of two, came to the emergency room for the fourth time in a month, comatose and gasping for breath. His death from emphysema was

imminent. When Sismour regained consciousness, Magovern and Yates proposed a transplant, a possibility they had first discussed with him a few months earlier. He agreed to try it. Around the same time, a 33-year-old man suffered a cerebral aneurysm. After unsuccessful surgery, he lay unconscious for 10 days, with no sign of brain function and no hope of surviving. When his heart stopped beating on July 7, 1963, doctors asked his wife for permission to use one of his lungs, and she gave it.[22]

The transplant surgery appeared to go well. When oxygen was pumped into the donor lung in Sismour's chest, Magovern recalled, it "was a beautiful sight. The lung [had been] collapsed to the size of a fist, just a dead-looking purple-blue hunk. Then the air made it expand and it suddenly became a soft pink living thing." A few hours after the operation, Sismour seemed to be doing well, and after a few struggles in the first couple of days, he was able to visit with his family and take short walks. By the fifth day, though, he had difficulty breathing and his x-rays were cloudier. They put him back on a respirator, treated him with antibiotics, and kept hoping, but he died on the morning of the eighth day after surgery. At the autopsy, the entire surface of the transplanted lung was covered with reddish-gray and black mottled pus. The pathologist believed the changes in the lung could have been due to infection (which they had discovered in the donor lung) or to a combination of infection and rejection.[23]

Despite the relatively quick deaths of the first two lung recipients, media coverage tended to portray the first two lung transplants positively. Local and regional newspapers reported the facts of the surgery and later published the proclamation the governor issued commuting Russell's prison sentence and commending his "outstanding contribution to medical progress," which would undoubtedly "alleviate human misery and suffering in the years to come."[24] Hardy told a reporter from the *New York Times* that they had been "absolutely inundated" with requests from publications.[25] *Life* magazine published a congratulatory feature story on the transplant performed by Magovern and Yates, characterizing it as "a noble failure" which "los[t] a life but advance[d] surgery." It acknowledged that the "extraordinary new medical feat" had not been perfected, but predicted someday a patient would walk out of a hospital with a transplanted lung.[26]

Among the medical profession, the reactions were more mixed. The *Journal of the American Medical Association* (*JAMA*) published the results of Hardy's case and included a cautious, positively worded editorial highlighting its significance and agreeing that further human experiments would be in order. However, it appears that the journal asked Hardy himself to write the editorial.[27] In his autobiography, Hardy reported that among many of his *surgical* colleagues, the lung transplant was "accepted, [and considered] a known advance in the field." Because "everybody was transplanting everything in those days," he said the lung transplant was "just at the edge of the envelope."[28] But not everyone was so positive at the time. The *Annals of Internal Medicine* published what Hardy considered "an

arrogant and viciously critical editorial" and another journal mentioned Hardy's work in a sarcastic manner.[29] The extent to which others try to replicate one's work can be an indicator of colleagues' opinions, and over the next four years, there were only eight more lung transplants performed, only two of which took place in the United States. Hardy also received feedback at the Sixth International Transplantation Conference, held in New York eight months after the lung transplant. There he met with an audience he described as "palpably hostile."[30]

Part of the hostility derived not from Hardy's lung transplant, but from a heart transplant he performed seven months after it. This operation was distinctive because it was the very first time a heart had been transplanted into a human being and because the heart Hardy used came from a chimpanzee. Inserting an animal organ into a human being was not unprecedented, but Hardy had not waited very long to assess the results of others' recent kidney experiments with xenotransplantation. In addition, the circumstances of this transplant were far from ideal. The recipient, Boyd Rush, was deaf and mute, and since he was unconscious, Rush himself could not agree to the transplant.[31] Little had been known about Rush's medical history. Many people thought that this heart transplant had been premature, and Rush's death after just 90 minutes only seemed to confirm that notion. These factors help explain the "hostile" reception Hardy received at the transplantation congress. Other professional snubs followed, and Hardy feared he might lose his funding or even his job if he performed another transplant. He heard his heart transplant referred to as "not merely *immoral*, but *amoral*."[32]

Legitimate questions can be raised about Hardy's first lung transplant as well, especially about whether John Russell was a good choice as recipient. Around midcentury, after revelation of cruel Nazi experiments during World War II, the international medical community began serious discussions about appropriate practices for medical experimentation. As a result, American researchers eventually adopted standards requiring full disclosure to subjects about experimental risks, "informed consent," and a system of institutional review boards to approve new procedures.[33] In the early 1960s, some American researchers still used prison volunteers despite the growing belief that prisoners were never truly free to consent.[34] Although Russell signed a consent form, it is difficult to know the degree to which he enjoyed truly informed consent. British physician's 1967 exposé of unethical research practices explicitly condemned Hardy's lung transplant on Russell because he was a prisoner. Hardy's patient selection might also be criticized because of Russell's kidney disease. "A better recipient would have been able to carry it longer, I think," acknowledged Hardy years later.[35]

One can also ask whether 1963 was simply too early to perform a lung transplant. In his own research published a few months before the operation, Hardy had admitted that the drugs available for immunosuppression were insufficient and he knew Russell's body would likely reject the new lung. At times medical

innovators have been criticized for taking advantage of extremely ill patients in order to advance their careers. "When a patient is desperately ill, the physicians and hospital must make a supreme effort," acknowledged surgeon Francis Moore. "But we should not let this concern spill over into an area where our search for a desperate remedy has instead become a desperate search for a chance to try a new remedy."[36] It is difficult to know whether Hardy was rushing to "beat" other surgeons to conduct the first lung transplant. Other surgeons were on the brink of performing such transplants, and a Chicago newspaper reported shortly after the operation that Hardy "won a friendly race" with Edward Beattie of Presbyterian-St. Luke's hospital.[37]

A final question is whether the University of Mississippi Medical Center had the necessary infrastructure for a successful lung transplant. Hardy admitted that the hospital had unreliable blood banking; there was no intensive care unit and only a modest recovery room; the anesthesia program was weak; and 24-hour lab support was limited. In Russell's specific case, the lack of an artificial kidney machine may have made a significant difference. Hardy said later that he was "satisfied we had done it well, to the extent of the circumstances at the time," but in some ways, the time and the place of the transplant were not ideal.[38]

While it can be criticized, Hardy's first lung transplant can also be defended. One of the most difficult issues facing researchers is deciding when the time is right to try a new procedure in human beings. There is no way to avoid all risk. "Sooner or later you've got to get into the patient arena," insisted Hardy. "You've got to move out of the laboratory and into the hospital and use it for some appropriate purpose." Furthermore, Hardy pointed out, the patient who faced imminent death was usually squarely behind a transplant.[39] Indeed, Hardy knew other seriously ill patients who were eager to volunteer. "I am desperate and in need of help," wrote one. "I am fully cognizant of the risks involved in your experiments," assured another. A third declared, "I am very anxious to take the risk if there is the remotest chance that it would work."[40] Although it was likely that the lung would be rejected fairly quickly, Hardy never made unrealistic claims about the chances of long-term survival and had thought carefully about what specific (if rare) medical conditions might justify a lung transplant. Compared to today's practices, a conversation with the dean of the medical school seems a rather casual way to insure ethical standards, but this was at the time when American hospitals were just beginning to form institutional review boards.[41] Although his medical center lacked some infrastructure, Hardy himself had the necessary experience in terms of both surgical and immunosuppressive techniques due to his work with animals and with human kidney recipients.

It is also possible to defend Hardy's patient selection. In this case, it appears that a prisoner arrived at his doorstep because the University of Mississippi Medical Center treated patients from the state penitentiary. While Hardy apparently did not have ethical qualms about using prison volunteers, it is not fair to

compare this transplant to experiments others conducted on large numbers of healthy prisoners. Since Russell met his predetermined criteria, it seems reasonable that Hardy not eliminate him simply because he was a prisoner. All he could do was to be scrupulous about not unduly influencing Russell by promising him a lesser sentence in exchange for agreeing to the surgery.[42] Although it is true that Russell was not an ideal candidate because of his kidney disease, this is not surprising. "When you first start, you operate on people who are a terrible operative risk," explained Hardy. While some say it is wrong to conduct new procedures on people likely to die (since they are so desperate they can be easily taken advantage of), doing an unproven technique could *only* be justified with a patient likely to die. Unfortunately, operating on such an ill patient increased the odds of failure. Quite simply, it is difficult to find a "perfect" candidate the first time an experimental procedure is tried. As one medical ethicist wrote, "In the presence of almost certain death, the physician is sometimes justified in undertaking therapeutic procedures whose chance of success are small."[43] Taking the risk in such a patient, especially when the knowledge that will result from the procedure may help many future patients, may be justified. In retrospect it is clear that the odds for Russell were quite slim, and though his death came as no surprise, his willingness to be the first recipient, combined with Hardy's ambitious work, laid the foundation for all future human lung transplantation.

Dark Years: From 1964 to 1977

In the next couple of years after Hardy's pioneering effort, few human lung transplants were attempted. After Magovern and Yates performed the second one in 1963, none were performed in 1964. Three were done in 1965—one each in Tokyo, Montreal, and in Hines, Illinois. The year 1966 witnessed just one more (in Japan). The next year, 1967, saw four done worldwide, only one of which was in the United States. Undoubtedly the poor results of these operations discouraged surgeons: only one of those recipients lived as long as Russell's eighteen days. Half of them survived seven or eight days, and the rest lived not for days, but hours.[44]

The field of lung transplantation was also affected by the state of affairs in organ transplantation and medical experimentation in general in the United States, both of which suffered from negative perceptions in the mid-1960s. Attempts to put animal organs in people led to criticism that organ transplanters were going too far. In addition, in 1964 word broke of a study at a hospital in Brooklyn where researchers had injected live cancer cells into elderly and senile patients.[45] Not surprisingly, public opinion turned against medical experimentation involving human subjects. Research money became scarce in organ transplantation, and researchers became tentative. "Life did go on," Hardy recalled,

"but it was as if there had been a recent bereavement in the family, for the lung and heart transplants were never mentioned by friends." Hardy performed no more human lung transplants during the next five years.[46]

Things suddenly changed after December 3, 1967, however, when South African surgeon Christiaan Barnard removed the heart of a deceased car accident victim and placed it in the chest of Louis Washkansky. Reporters from all over the world flew to South Africa to cover the "miracle in Cape Town," breathlessly portraying heart transplantation as a radical breakthrough comparable to space travel. They exaggerated its prospects, including the number of people who might be saved by it. Barnard instantly became a celebrity. Louis Washkansky, who lived 18 days after his heart transplant, called Barnard "the man with the golden hands," and reporters deemed him the "greatest physician of the age." Other surgeons rapidly followed Barnard's footsteps. In the United States, Adrian Kantrowitz in New York and Norm Shumway in California, both of whom had been doing animal heart transplants for years, tried them in human beings. Many other surgeons seemed to "jump on the bandwagon," some of them from places not known for transplantation research. In 1968 alone, 101 heart transplants were performed by around 60 different medical teams in 22 countries.[47]

Soon negative voices surfaced again. Some physicians bemoaned the "circus atmosphere" surrounding the procedures and the rise of "surgical show biz." They feared that young surgeons might be lured by "the glamour that surrounds them" and lose sight of the well-being of their patients. They suspected that in rushing to join a "me-too brigade," surgeons had done too many heart transplants, too fast. Four months after Barnard's first transplant, the president-elect of the American College of Cardiology declared rejection was still so serious a problem that heart transplant surgery was like "sending a man to the moon without any hope of bringing him back, just to beat the Russians." Many cardiologists called for a moratorium on the procedure because the outcomes were so disappointing. Although there were a few success stories, there was a dismal 22 percent one-year survival rate, and the quality of life of the typical recipient who lived a few months was poor. Media coverage reflected the increasing skepticism. *Newsweek* reported that medicine was "reassessing transplants" and *Time* magazine asked, "Were transplants premature?" Prominent heart surgeons found themselves on the defensive in front of a Senate subcommittee exploring whether to establish a national committee to discuss medical ethics.[48]

Almost as quickly as it rose, the heart transplant craze slowed. In 1969, surgeons transplanted just 48 hearts, half as many as in the previous year. In 1970, they performed 17, and in 1971, just 9. Most surgeons simply chose to stop doing them, but others stopped less willingly, pushed by the media, patients, and physicians who no longer had confidence in them. In the United States, almost everyone quit except for Norm Shumway at Stanford, and the *New York Times* reported "what amount[ed] almost to a complete world moratorium on heart

transplants."[49] Many considered this good news, including some transplant surgeons who thought too many of their colleagues did the procedure for the wrong reasons and without the experienced team of immunologists, pathologists, and cardiologists necessary for successful immunosuppression and follow-up care. "People were performing transplants who had no idea what they were doing," declared Shumway. "It wrecked the field for a good five years." Indeed, kidney transplant pioneer Joseph E. Murray referred to the period from 1968 to 1970 as "transplantation's darkest hour."[50]

Some of the pioneering surgeons saw the period differently. Although the patients did not survive long, they saw the early struggles as normal. "Nothing works the first time," declared heart transplanter Adrian Kantrowitz. "Progress is made by people who have some understanding of the problem, and enough courage to have the willingness to fail, because failure is part of success, it is part of the scientific process." Hardy had a similar attitude about his first lung transplant. "When you go into a swamp, you don't expect to find paved roads. The pioneers are always taking a risk. If it works, you're brilliant, and if it doesn't work, you're dead."[51] More accurately, of course, it was the patient who died, while the risk for the surgeon was related to his professional reputation. Whether a person views the early lung transplants as premature or as an incremental step forward might depend on one's definition of "success." At first the procedures had been lauded simply because the new organ functioned and the recipient survived the surgery, but others had a higher standard. "I don't think any heart operation can be regarded as successful until the patient goes home," remarked Kantrowitz. Other surgeons defined success as recipient survival of a year or more, while still others expected decent quality of life, not simply a prolonged state of suffering and need.[52] In 1970, it was not at all clear that would ever be attained.

Because they received less notoriety, lung surgeons did not face the same public criticism as heart transplant surgeons, but many were quite discouraged by the state of their field. Although they had performed far fewer transplants, internal criticism echoed that of heart transplants. John Benfield asserted that "too many surgeons were attempting lung transplantation," in some cases without sufficient background experience, institutional commitment, and awareness of the many postoperative skills needed for success. Benfield encouraged his colleagues to step back and honestly assess their record. They found the results dismal. "If one cites the cold fact that 23 lung transplants have been performed [worldwide] and that only 1 patient has survived longer than thirty days…, the picture is discouraging," wrote Benfield and his colleague Charles Wildevuur. "To skeptics it is prohibitive." Fortunately one patient, transplanted in Belgium by Fritz Derom in November 1968, could serve as a beacon of hope. The 23-year-old sandblaster, who had been heavily exposed to silicium dust, overcame two episodes of acute rejection and one of infection, and actually was released from the hospital. He lived for 10 months after surgery with his new lung functioning well

and significantly improving the quality his life.[53] Without him, though, there was no evidence of long-term success. Of the other 22 recipients, only 5 managed to survive more than two weeks. Pioneers like George Magovern openly wondered whether their efforts had been worthwhile. At an April 1970 conference on lung transplantation, a group of 61 doctors "extensively discussed . . . the question of whether or not to proceed further with human trials."[54]

The surgeons recognized that they faced some serious problems. First, because 20 different surgeons in seven different countries had performed the operations (and no surgeon had performed more than two), information was "only partially and sporadically available." Still, they knew the foremost problem was rejection. So far, doctors had either undersuppressed the patient's immune system, allowing the body to reject its new graft, or they oversuppressed it, leading to infection. Unfortunately, they were unable even to definitively recognize rejection, having a hard time distinguishing between the signs of it and infection. The correct diagnosis was critical, "since the treatment for rejection and infection is in many ways directly opposite," and the wrong treatment could lead to death.[55] Another obstacle involved the critical connection between the new lung and the airway leading to it. Specialists suspected that problems with bronchial leakage and narrowing were due to insufficient healing and blood flow at the surgical connection at the airway known as the "bronchial anastomosis." In addition, they needed better methods for preserving a fragile donor lung before it was inserted into the recipient, and some sort of artificial support system to take over a patient's respiration during emergencies. Others worried about imbalance between the patient's new lung and the remaining diseased lung or infections traveling between them. Indeed, they concluded, "there are still many unknowns in lung transplantation." Many believed the problems were insoluble. "There was great discouragement," noted one thoracic surgeon, "and very little interest anymore in doing it." Rather than ban the procedure, however, the group agreed to permit clinical lung transplantation in humans to proceed on a limited basis in carefully chosen situations. Between 1970 and 1978, only 13 more lung transplants were attempted anywhere in the world.[56]

A New Era

By the late 1970s, only a handful of surgeons remained committed to seriously investigating lung transplantation. In North America, Frank Veith, a cardiovascular specialist at Montefiore Hospital in New York, focused on surgical techniques to improve the bronchial anastomosis, identify rejection, and preserve donor lungs, and generally "kept the candle glowing through some dark years."[57] In Toronto, Griffith Pearson put together a transplant team eventually headed by Joel Cooper, a young Harvard-educated thoracic surgeon whose mentors had

pioneered airway surgery.[58] Cooper had been involved in developing an artificial lung machine, known as ECMO for extracorporeal member oxygenation, which could help the body exchange fresh oxygen for accumulated carbon dioxide in the bloodstream for about two weeks. In 1978, the Toronto General team attempted a single lung transplant on Dennis Gustar, a man who had suffered extreme lung damage from smoke inhalation.[59] The surgery seemed to go well, and shortly thereafter Gustar was able to talk and walk. "It was an exciting time," Cooper remembered, but as had happened before, the patient died 18 days after the transplant. Fond of repeating the saying, "Those who fail to learn the lessons of history are doomed to repeat them," Cooper decided to refrain from trying additional lung transplants until his team spent more time in the lab.[60] A third group, at Stanford University in Palo Alto, California, had a different focus. Convinced that single lung transplants would never work, they worked on a transplant that inserted both a new heart and the lungs connected to it. This direction was not surprising, since Stanford had the world's most experienced and respected heart transplantation program. Cardiac surgeon Bruce Reitz headed the group doing heart-lung transplants on animals in the lab.

At this critical time, lung transplantation encountered a stroke of great luck. Discovery of a drug called cyclosporine eventually benefitted not only Veith, Cooper, and Reitz, but transplanters of all solid organs. Cyclosporine came from a fungus found in soil. It contained an unusual amino acid that selectively suppressed production of T-lymphocytes, which play a crucial role in the body's attack against transplanted organs. Besides suppressing the part of the immune system that caused rejection, cyclosporine did so with less destruction to the rest of the body's defenses. By the late 1970s, the Food and Drug Administration (FDA) had approved its experimental use in a limited number of people. The pharmaceutical company Sandoz shared cyclosporine with a number of hand-picked transplant programs in the United States, four performing kidney transplants, two doing liver and pancreas transplants, and four working on hearts, including Stanford.[61] Veith's program at Montefiore was the only place in the United States given cyclosporine for single lung transplants, and in Canada, Toronto General was permitted to use it for lungs as well. The initial results were impressive. For example, in children receiving liver transplants, the one-year survival rate jumped from about 38 to 70 percent. Although the drug was not perfect—it could cause some very serious side effects—its discovery eventually proved to be a watershed. The "penicillin of transplantation" ushered in a "golden era of transplantation."[62]

"We were in the right place at the right time," said Stanford's Bruce Reitz, observing the fortune of being in the middle of animal heart-lung experiments when cyclosporine became available.[63] While fortunate, it was no accident that Stanford was chosen as one of the sites for limited trials given its long track record with heart transplantation and responsible reputation. Stanford's team

members investigated heart-lung transplantation despite its short and sad history. They believed that the three failed transplants done in people in the late 1960s and early 1970s had been premature since at that time no animal that received a heart-lung transplant had survived more than ten days.[64] A decade later, Stanford's team would make sure there was success in the animal lab before attempting anything in human beings.

By fall 1980, Reitz could report that three of their seven monkeys treated with cyclosporine were "long-term survivors." One of the three survivors died 144 days after transplant and two lived for more than two years. Cyclosporine appeared to be powerful and effective, and the Stanford team felt confident that heart-lung transplants would be better than transplanting a single lung or pair of lungs. After all, they reasoned, the heart and lung worked very closely together (suggesting there would be no problem with unequal ventilation or blood supply), the surgery itself was technically simpler, and they could diagnose rejection more easily through biopsies of the heart. After Reitz presented these results, one surgeon in the audience exclaimed, "I believe we have heard the opening of a new era of lung transplantation."[65] Though careful, Reitz predicted human application in the 1980s.

Reitz soon found a good candidate in Mary Gohlke, but how to "manage" the correct timing for the transplant posed both a practical and an ethical issue. By February 1981, Gohlke was so weak she could barely turn over in bed and she experienced frightening blackouts, from which doctors acknowledged she might not regain consciousness. Yet as Gohlke recalled,

> In a macabre waiting game, we both had to hold off until I was truly near death. Because of the experimental nature of the operation and the very real risk that I would not survive it, Bruce [Reitz] was bound by moral duty to make sure that he was not asking me to sacrifice needlessly whatever quality time I had left.

In addition, Reitz had another problem: he did not yet have FDA approval to use cyclosporine for human heart-lung transplants. Incensed, Gohlke told some journalist colleagues that her time was running out and they called politicians and FDA officials trying to find the official response to Stanford's request, which had been lost in a bureaucratic maze. Soon Stanford had approval to proceed, and an astonished Reitz wondered how reporters had cut through six months of red tape in a matter of hours. Gohlke moved to an apartment in Palo Alto, so she would be nearby when donor organs became available, which happened on March 9, 1981, after a 15-year-old boy was hit by a car. Before she had the surgery, she tearfully told her son, "I want you to know how much I love you . . . and no matter what happens, the important thing is that you try. It doesn't matter if you don't always win. It matters that you tried."[66]

The road ahead was an uncharted, difficult one. The four-and-a-half-hour surgery involved diverting Gohlke's blood flow to a heart-lung machine while they removed her diseased heart and lungs and then inserted the new ones. It went smoothly.[67] The day after the operation, Gohlke was able to breathe without a respirator. In the months after the surgery, though, she suffered from pain, nausea, lack of appetite, inflammation of her joints, rectal bleeding, tremors, herpes, extra hair growth, rejection, and horrible hallucinations from the drugs. At one point her lungs stopped working and she had to be put on a ventilator. For two months after the surgery, Gohlke was constantly monitored in an isolation room, where every visitor wore a gown, mask, and shoe covers. Even as most of her physical problems got resolved, she was depressed, withdrawn, anxious, and unmotivated. Although she was released from the hospital after 85 days, she had to be readmitted a few times. Eventually she was well enough to return home to Arizona, and although she wasn't able to do the job she'd done before her illness developed, she could cook, shop, write, entertain, and care for her family. She felt very grateful for the chance to watch her sons grow up and for the supportive efforts of Reitz and the devoted nurses at Stanford. In an autobiography she wrote four years after the transplant, she said that if she needed to, she would agree to another transplant in a second, "because the way I know it now, living is better than dying . . . a lot better."[68]

It marked a new era. Although Gohlke had struggled, from the medical perspective, it was a major success. "Fundamentally, we wanted to know whether we would get the same long-term results that we did in animals," Reitz said. "We know now it does work in human beings, and that's the No. 1 question." Reitz attributed Stanford's success to its experience in primates, the physical advantages of combined heart-lung replacement, and cyclosporine. While cyclosporine made it possible, he admitted the drug was not perfect. Four of Stanford's 29 heart recipients had developed lymphomas from it and they'd had to decrease the amount they used, realizing there was a fine line between its therapeutic and toxic effects.[69] Reitz's team performed three more heart-lung transplants in 1981, and two of the patients were long-term survivors. Word spread of this miracle in national newspapers and magazines, resulting in Gohlke receiving over 2,000 cards and letters. The medical world learned the details through Reitz's professional reports, and the procedure was hailed in the *JAMA* as a "milestone." Gohlke would eventually live over five years after the heart-lung transplant. Cardiac surgeon Norm Shumway saluted her as "one of the genuine heroines of modern medicine."[70]

The reaction from the Toronto and New York teams to this success was mixed, though. Pleased that a transplant involving lungs helped suffering patients, at the same time they worried that if it persuaded people that heart-lung transplants were the only way to proceed, Stanford's achievement might actually harm the prospects for single lung transplantation. Their efforts differed; while Cooper

and Veith were concerned primarily with people with lung disease, Stanford's cardiac surgeons focused on patients with heart problems. Veith and Cooper fervently believed single lung transplants eventually would be better both practically and ethically, since using a heart when it wasn't needed would waste precious organs. "We feel that the heart-lung is the operation down the line for people who must have a new heart and must have new lungs," said Cooper. "But there has to be a better way for someone who [just] needs lungs . . . " A bit of jealousy probably crept in as well. "We've been at it awhile," admitted Veith. "We'd like to make it work."[71]

To catch up, the Toronto and New York teams looked to their labs. After the autopsy on Dennis Gustar showed that the anastomosis had come apart, Cooper's group targeted the problem with the bronchial connection. Cooper suspected this was not due to rejection but to poor wound healing and that immunosuppressive drugs might be responsible.[72] In a series of experiments, researchers eventually isolated prednisone as the culprit that was slowing healing. In addition, they worried about the lack of oxygenated blood that was making it to transplanted lungs; this shortage occurred because it was impossible for surgeons to reconnect all the tiny blood vessels. To address this obstacle, Cooper's team came up with the innovative idea of wrapping the bronchus with the omentum. The omentum is a long apron of fatty tissue that hangs off the stomach and large intestine and is rich in blood vessels. Its purpose is unclear, but doctors knew that sometimes it migrates to an infected area of the body and reestablishes blood supply. When the team from Toronto General put an omental wrap around the reattached airway in their dogs, it sped up bronchial artery circulation to the donor lung, improved bronchial healing, and added some protection against potential air leaks. Finally, they found that using cyclosporine made it possible to delay administering prednisone and made rejection's manifestations milder and more easily reversed. Veith concluded, "For the first time this drug has made therapeutic lung transplantation a real possibility."[73]

Bolstered by a better way to insure sufficient blood supply, connect the airway, and combat rejection, Cooper's team proposed that Toronto General Hospital cautiously reactivate its human lung transplantation program. He suggested strict criteria: prospective patients must have a short life expectancy, no other alternative but a lung transplant, and harbor no conditions such as chronic infection, kidney problems, or heart failure that would complicate the situation. Cooper also proposed that their first recipients should have pulmonary fibrosis, because that disease avoided some of the problems posed by other common diseases. Hospital administrators gave permission for four transplants and set up a three-member committee composed of physicians unassociated with the transplant program in order to evaluate the choice of patients and their outcomes.[74]

About a year and a half after Stanford did Gohlke's heart-lung transplant, Cooper got a call about an Atlanta gardener, James Franzen, who was near death

due to poisoning from paraquat, a toxic weed killer. Franzen's doctor hoped that Cooper could keep him alive on the ECMO machine while they used dialysis to clear the paraquat from his bloodstream and found a new lung to replace one of his badly damaged ones. On August 29, 1982, they got the news that the family of someone who had died from a gunshot wound in Atlanta agreed to let his body be flown up to Toronto so his lung could be donated. (At the time they believed lungs could not be outside the donor body for more than two and a half hours, so they transported the donor's whole body to the recipient hospital.) With extremely high hopes and a "rush of emotion," a team of about 30 people cooperated to give Franzen a new right lung.[75] In the days after the surgery, though, some of the paraquat that had been stored in his muscles moved into the new lung. (Since paraquat victims did not usually live that long, doctors had not known that would happen.) Rather than give up, the team performed another lung transplant. Although he was alert after that one, Franzen got weaker and weaker, unable to sit up by himself or breathe on his own. Two and a half months after his original transplant, Franzen suffered a massive stroke and died. Franzen's family took the news hard, as did the exhausted Toronto transplant team. At the announcement of Franzen's death, Cooper's voice faltered and tears welled in his eyes as he stated that Franzen "showed really enormous courage." Fellow surgeon Thomas Todd recalled, "The despondency was enormous."[76]

Before it became clear that Franzen would not survive, Frank Veith's team at Montefiore performed a similar single lung transplant on another young male landscaper who had inhaled paraquat. Scott Wilson was "as close to being dead as he could be without being dead," reported Veith. The procedure took six hours and involved five surgeons, three anesthesiologists, two pulmonary specialists, and fifteen nurses and technicians. At the end of the week, Wilson was in critical condition but awake, responsive, and watching television. That didn't last long. Wilson died about seven weeks after the transplant.[77]

In addition to profound disappointment, lung transplant proponents felt pressure. Their rivals at Stanford suggested single lung transplants should not be performed, and another commentator publicly criticized the Franzen case, saying, "They are putting him through all this agony, but you know and I know and *they* know he's going to die anyway."[78] Veith complained that the skepticism from his colleagues made it even harder to obtain good-quality donor lungs from hospitals, which was a serious problem since lungs were so fragile that only about one of every ten or fifteen available donors had suitable lungs in the first place.[79] They also worried about finding patients willing to take a chance on a single lung transplant instead of a heart-lung transplant. Cooper recalled, "People were starting to say, 'Why are you doing lungs? It's never going to work.' " The Toronto team knew they would only have a few chances to do the very expensive transplants. Cooper believed that if they tried again and failed, "then for another 10 or 20 years lung transplants would be finished."[80]

Nonetheless, Cooper felt hopeful. After all, they had kept Franzen alive with good lung function for three months—a good outcome compared to the past—and Franzen had died from complications of his poisoning, not the transplant. Cooper had also learned an important lesson from Franzen's experience: to avoid such desperately ill, fragile, ventilator-dependent patients. Naturally, the pioneering surgeons had performed "deathbed rescues" because they did not want to deprive patients of any valuable time they might live with their native lungs. But Cooper concluded this had been a mistake. His next transplant would be on a somewhat healthier patient, someone with end-stage pulmonary fibrosis, but not quite so near death, because he believed such a recipient had a better chance of surviving. Because they had knowledge, experience, excellent hospital resources, and a "wonderful" cooperative team, Cooper declared, "We felt we were ready."[81]

"Success" with Single Lung Transplants

In the late 1970s, Tom Hall, a Toronto hardware salesman, began experiencing coughing, fatigue, and shortness of breath. After five years with pulmonary fibrosis, Hall's lips and nails would turn blue after the slightest exertion, and he was completely dependent on supplemental oxygen. An energetic man, he hated being tethered to an oxygen tank. When his pulmonary physician told Hall he would die in less than a year, his wife remarked that she wished they did lung transplants. His doctor replied that surgeons at Toronto General had tried but not yet succeeded. Hall asked for a referral. When they met, Cooper told him honestly that only 44 single lung transplants had ever been attempted and that most patients hadn't survived more than a few weeks. Hall said that he'd be grateful to have the opportunity to be number 45. The Toronto team saw Hall as a perfect candidate except for his age. At 57, he exceeded the age 50 they had set as an upper limit. Hall argued that his will to live mattered more than his age, and the team eventually agreed. Indeed, they were pleased with both his physical condition and his inner strength.[82] Still, the team proceeded carefully. "The doctors were all very frank with me about the dangers," explained Hall, and the hospital ethics committee, made up of people unassociated with the transplant group, reiterated them. Hall persuaded them that he understood. "I knew the chance I was taking, but I was willing to trade quality of life for quantity of life . . . I could see in the time remaining to me that I would probably end up lying in bed gasping for breath. And that isn't the way I wanted to go. So the operation for me was the answer."[83]

After three months of waiting for a donor organ, Hall got his single lung transplant on November 3, 1983. The almost ten-hour surgery went well, but then Hall had a number of scares. In one, he felt anxious and breathless for

reasons that baffled his doctors (perhaps related to nerves having been cut). Another time they knew he was not getting sufficient oxygen and had to reinsert the breathing tube for three days. Ten days later, suspecting that he was experiencing rejection, the doctors treated him with prednisone.[84] Although his oxygen levels soon returned to acceptable levels, the ups and downs demoralized Hall, who recalled that at one point,

> My spirits went down. I gave up. Had there been a way of just dying at that point, I would have—if I could have controlled it. It was just such a disappointment after going through everything and you get that great life and say, "By God! I have made it, I have lived." And then all of a sudden you are back down. You are back where you started from.[85]

Hall made it through this low period, left the intensive care unit, and was weaned from supplementary oxygen.

Soon the main concern was not his lungs, but the rest of his body. Weak from a long period of immobility before surgery, Hall's unused muscles had atrophied. It required two nurses to drag him down a hallway. So after six weeks, they released Hall to a rehabilitation center where they started him on an exercise program that pleased Cooper with its "astounding" results. The level of oxygen in Hall's bloodstream was normal even while exercising. Three months after the surgery, Hall went back to work. It was historic: the first time a single lung recipient had ever been able to resume the normal routines of life. "It just feels great to be off the oxygen," said Hall. "I feel great, wonderful." Hall went on to live for over six years after his transplant, and in his free time volunteered to speak on behalf of organ donation.[86]

Although Hall's lung transplant had been pathbreaking, there was no immediate fanfare. The first public announcement came six weeks after the surgery, when Hall left the hospital, and even then, the team remained low-key. "The time we really made the hoopla was when he had been out of surgery for one year," Cooper recalled. "We said, 'Okay, now we can call that successful; now we are willing to tell people about it.'" Tom Hall exhibited a similar sense of humility, saying he didn't think he deserved any attention. "I just lay there," he remarked. "The doctors did all the work." When it was suggested he had been brave, Hall pointed instead to the woman who lost her son and husband in an accident and still made the decision to donate organs.[87] Cooper also made sure credit was shared; the author of the medical journal article describing the transplant was listed as "the Toronto Lung Transplant Group"; nurses, research fellows, and lab technicians were publicly thanked; and they characterized their achievement as "modest compared with those of so many previous investigators whose experimental and clinical contributions have now made success possible."[88]

Though Hall's transplant made them more confident, Cooper opted not to do a second transplant immediately so the team could focus on taking good care

of each recipient. On November 30, 1984, almost a year after Hall's transplant, they proved Hall's case had not been a fluke. The next recipient was Monica Assenheimer, a 35-year-old woman whose pulmonary fibrosis made her painfully thin, short of breath, and dependent on a wheelchair. Like Hall, she was "highly motivated" and understood the risks. Assenheimer viewed the surgery as a public service, declaring, "I have always wanted to do something for mankind." Assenheimer also faced obstacles; the donor lung was too big, and surgeons had to remove part of it. At one point she needed ventilator assistance as she fought rejection. At another, her doctors were flummoxed about what treatment might help her, and made a guess that ended up working. Six weeks after the surgery, Assenheimer was discharged to a rehabilitation unit. About six months after the transplant, she worked a full day and was "almost 99 percent back to normal."[89] She lived for five and a half years after the transplant and became an enthusiastic spokesperson for the procedure.

During these early cases, the Toronto doctors closely examined their results and looked for ways to improve. The surgeons honed their procedures; Hall's operation took about ten hours, and Assenheimer's just six. When things worked well, they tried to figure out why. For example, they speculated that things had gone relatively smoothly for Hall in part because he was from the Toronto area, close to the transplant center, and could spend his waiting time in his own home (instead of the infection-ridden hospital) surrounded by loved ones who could support him. They also theorized that patients would recover better if, like Hall, they were as healthy as possible before their surgery. For that reason, once they accepted Assenheimer as a candidate, they had her move to Toronto and begin a rehabilitation and nutritional program—even though it seemed absurd to expect much exertion from someone who could barely breathe and move. It worked: before the surgery, Assenheimer gained ten pounds and doubled her exercise tolerance. After witnessing Hall's emotional roller-coaster, the program required that candidates have at least one family member stay with them in Toronto. They began warning patients of the frightening breathlessness they might feel when taken off the ventilator, and that they would experience emotional ups and downs. In addition, they added a psychologist and psychiatrist to their medical team and initiated a weekly support group for those on the waiting list.[90]

Like others before him, Cooper contemplated the issue of how to evaluate the single lung transplant procedure.

> I had to decide: What is success? When could we call it a victory? To me, a victory wasn't just getting [the recipient] out of the operating room; it wasn't getting out of the hospital, although that was an important step. It was improving the quality of life in sufficient duration and benefit to justify the procedure, the cost of the procedure, the resources, the wear and tear on everybody. And what was the metric? I felt that if we could accomplish two good years of life, in my mind, that would spell success.[91]

Between November 1983 and early 1986, the Toronto group performed a single lung transplant on eleven people. Two of the recipients died fairly early, but the other nine were discharged from the hospital. Eight of them were still alive in May 1986—at 44 months (Hall), 31 months (Assenheimer), 20 months, 17 months, two at 6 months, and 5 months—and had returned to a normal lifestyle with consistent, sustained improvement in lung function and physical performance. Although they acknowledged the procedure was still risky, the Toronto group thought they had proven it was no longer "experimental." Others appreciated their work. An editorial in *JAMA* called the procedure "extraordinarily successful" and said it should be more widely used.[92] Frank Veith told Cooper, "I would like to have done it, but you made my day." Applications to the program increased.[93] By offering people who were near death a year or more of additional life, the Toronto single lung transplants contrasted sharply with the earlier outcomes, and by most people's definitions, represented success (figure 2.3).

Many factors explained the success of the Stanford and Toronto transplant programs. In both cases, they were led by tenacious, talented surgeons, who

Figure 2.3 Surgeon Joel Cooper (seated) in 1988 with early lung recipients (left to right) Tom Hall (first successful lung transplant, 1983), Patsy Ruff (double lung transplant, 1987), Ann Harrison (first successful double lung transplant, November 1986), Monica Assenheimer (second single lung transplant, November 1984), Doris Matthews (second double lung transplant, January 9, 1987), and Kathy Urish (third double lung transplant, February 1987). Courtesy of Joel Cooper.

coordinated competent and dedicated teams made up of surgeons, immunologists, anesthesiologists, hematologists, experts in respiratory illnesses and infectious diseases, respiratory and physical therapists, intensive care and ward nurses, nurse coordinators, psychiatrists and social workers, and lab technicians. They needed the resources and support of their own hospitals, referring physicians, and nonmedical people to procure organs.[94] The teams investigated the stubborn problems of bronchial healing and rejection by dedicating years to experiments in the lab, and only when they had achieved *long-term* survival with their animals did they try transplantation in human beings. They made the decision prudently about when and how to do so—in just a handful of cases that they could closely monitor—and insured that the patients who agreed to undergo the experimental procedure had a firm understanding of the risks. They chose their patients carefully, and those patients felt they were concerned about them, not just about conquering a medical frontier.[95] While members of the teams may have been ambitious and competitive, their behavior contrasted sharply with the carnival-like heart transplantation craze of the late 1960s.[96] Thus research, persistence, teamwork, and solid ethics all help explain why heart-lung and single lung transplants became viable in the early 1980s, but good timing mattered too.[97] Without cyclosporine, which became available in the early 1980s, it is unlikely that anyone could have done much better than Hardy did in 1963. Still, the two teams earned the opportunity to be among the few fortunate early users of cyclosporine precisely because they had invested great effort in lung transplantation experimentation in animals when others had doubted it would pay off. Finally, success was also attributable to the patients who took great risks. For some of them, like John Richard Russell, James Franzen, and Scott Wilson, it did not pay off. But others benefitted from their courage. "Looking back, it is evident that each recipient contributed in a very real sense to the development of the program," noted Thomas Todd. "They contributed to our knowledge whether they died before we recognized the lesson learned, or whether they survived because the lesson was learned in sufficient time to assist in their success."[98]

Growth and Politicization of Organ Transplantation

By the mid-1980s, surgeons knew lung transplantation was feasible, but the field faced significant challenges. Some were medical. They did not know what would happen to lung transplant recipients more than a few years after their surgery or whether transplants would work on people with other diseases. While cyclosporine was a vast improvement, they struggled to accurately diagnose rejection and manage immunosuppression. Their techniques for the preservation and retrieval of organs were "rather primitive." Other obstacles included finding

ways for patients to pay for lung transplants and finding enough donor organs.[99] In these last two areas, lung transplanters resembled the transplanters of other organs. Now closer to the mainstream of organ transplantation, lung transplantation would be affected by a new set of issues, which were not simply medical, but legal, social, political, ethical, and administrative. To build upon their success, innovators would need to continue their medical endeavors, but also venture outside their labs, operating rooms, and clinics.

Organ transplantation differed in important ways from other medical treatments. Unlike in radiation, angioplasty, brain surgery, or drug therapies, the crucial element was something that was quite valuable and scarce: a human organ. Usually (and almost always for lung transplants) this key ingredient had to come from a person who died in very specific and relatively rare circumstances. Since most Americans believed that organs should be freely donated (rather than taken or purchased), organ transplantation required that the general public understand and support the treatment. Gaining this support would take time. As they had been with kidney transplants and with blood transfusion earlier in the century, the first reactions to solid organ transplants in the late 1960s tended to be very positive. Surgeons were portrayed as heroes, as were grieving families who generously provided the gift of life for someone on the brink of death. A January 1978 Gallup public opinion poll that showed 70 percent of Americans were willing to donate their organs.[100] Governmental agencies moved to encourage organ donation. By 1972, all 50 states had decreed that a driver's license could serve as a legal document indicating the desire to be an organ donor in case of unexpected death.[101]

Yet there was also some concern about this new and different medical procedure. The very fact that transplants seemed to be "cheating death" disturbed some people. "This kind of artificial prolongation of life is a crime against nature," said one man. Another asked, "Is it right to take vital organs from one patient and give them to another?"[102] While many people were pleased that a faulty organ might now be replaced, some worried that the human body was being diminished, or objectified, by considering it as simply a collection of replaceable parts that could be switched out when they stopped working. Some people wanted reassurance about practical matters, such as whether donation would delay a funeral, while others were curious about what it all meant, especially about identity. Would a male organ recipient's skin get softer once he had a woman's heart? Would a person be affected by receiving a kidney from a donor of a different race? A body of science fiction, movies, and novels explored the implications. Although all the main religions in the United States declared organ donation permissible and even laudable, some people also wondered whether donors would be desecrated by the removal of their organs after death.[103]

Acceptance of the concept of "brain death" especially took time. Traditionally people had assumed that a person died when his or her breathing and heartbeat stopped, but the meaning of death was confused by medical technologies.

By the 1950s, respirators could keep an unconscious patient's lungs breathing and heart beating artificially—even after there was no chance whatsoever of that patient's revival off of the respirator once the brain could no longer send neural signals to the rest of the body to prompt respiration and circulation. Spread of the new technology forced discussion of when it was appropriate to switch off the machines and declare a patient dead. In 1968 a prestigious Harvard Medical School committee pronounced that doctors should adopt new "brain death" criteria for determining the moment of death.[104] The Harvard Committee argued for acceptance of these criteria for two reasons: first, to ease the burden on the families of brain-dead patients, hospitals, and those patients in need of hospital beds occupied by brain dead patients; and second, to insure that there would be no controversy in obtaining organs for transplantation. Transplant surgeons were pleased with the committee's decision because it would mean both more donor organs and better quality ones. To others, though, a diagnosis of death on the basis of a permanently nonfunctioning brain seemed radical and disturbing, especially because of the organ transplantation justification.[105] The procedures for declaring death, said one ethicist, should not be "distorted by any reference to someone else's need for organs." The public perception of transplant surgeons seemed to shift in a negative direction. They were seen as untrustworthy, "vultures, waiting for a convenient death to bring life to their patients."[106] *Coma*, a bestselling 1977 novel and then a popular Hollywood movie, imagined a corrupt set of transplant doctors profiting from a black market in organs by taking advantage of innocent people wrongly diagnosed as brain dead. A lung transplant advocate observed, "*Coma* probably set transplantation back five years!"[107]

When life ends was not simply a medical or a philosophical issue, but a legal one. In most states, the law gave the responsibility of declaring death to physicians, so after the Harvard Committee's declaration, many transplant programs thought they were on safe ground in using brain dead donors. Some well-respected heart surgeons encountered legal difficulties, however. In one case, doctors at the Medical College of Virginia were sued for the wrongful death of a man whose heart and kidneys were donated after doctors and the coroner had turned the ventilator off because he was brain dead.[108] Eventually the doctors were acquitted, but during the four years the case slowly moved through the justice system, the doctors—pioneers in heart transplantation—discontinued their transplants. To alleviate legal confusion, some states passed a law recognizing brain death, but others did not, resulting in the bizarre circumstance that a person could be considered dead in one state but not in another.[109]

Confusion reigned for a decade or more. Unless medical personnel took the initiative to explain matters, some individuals felt perplexed because their brain-dead loved ones appeared to be alive while a ventilator pumped oxygen into their bodies.[110] Eventually, though, some of the skepticism and confusion declined. Consensus was achieved among physicians and other medical staff were

trained in how to handle the situations. Hospitals set up reassuring procedures, preventing any member of a transplant team having anything to do with the diagnosis of death of a potential donor. In 1981, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research authoritatively gave its approval to the concept. It concluded that proof of an irreversible absence of functions in the entire brain, including the brain stem, provided a highly reliable means of declaring death for respirator-maintained bodies. The commission asserted that clear and uniform legal guidelines were needed. Supported by the American Medical Association and American Bar Association, most states passed the Commission's suggested language very quickly.[111]

Clarity about brain death was one necessary stage in the maturing of organ transplantation in the United States, but other steps were needed as well. Cyclosporine led to enormous optimism and a huge jump in the number of solid organ transplants. In the late 1970s only 2 hospitals in the United States had performed heart transplants, but by 1985, over 50 had. The American Heart Association thought this rapid growth caused "chaos."[112] At this point, the field had a choice: to continue the decentralization in which very independent and competitive transplant centers did things in their own ways; or to develop a more cooperative and standardized *system*.

The sentiment for coordination grew. In the early years of organ transplantation, surgeons occasionally made informal agreements with colleagues elsewhere to share a donor organ they themselves could not use. Over time agreements became more formal, and nonprofit entities called organ procurement organizations (OPOs) sprang up to concentrate on the finding, procuring, and transporting of organs for transplant. Farsighted leaders believed the field could be improved with national (rather than simply regional) sharing of both organs and data. In 1969, with a computer system funded by the Public Health Service, physicians from nine transplant centers formed the South-East Organ Procurement Foundation (SEOPF) to insure that any hospital that had a kidney to share could locate a good match for it. After distant transplant centers requested the service, in 1977 SEOPF formed a nationwide organization, the United Network for Organ Sharing (UNOS). By 1982, about 87 percent of the transplant centers in the country participated in the UNOS system. Meanwhile, in Pittsburgh, the North American Transplant Coordinators Organization developed a 24-hour telephone service to match donor and recipients for organs other than kidneys.[113]

It would take time to create a truly coordinated system. Centers increasingly shared donor organs, but they differed in their willingness to do so.[114] UNOS provided national waiting list information, but there were no standardized practices or policies, especially related to allocation. Someone had to decide which hospitals received donor organs and on what basis, and which individual patients received them. These were difficult decisions that meant life or death

for individuals. In making them, surgeons considered physical issues such as size, blood type, and tissue type (which was not universally agreed upon as crucial). But how should they decide between those candidates who matched donor organs? Should the patients closest to death get the organs? The ones who had waited longest? The youngest? The most "worthy"? By the mid-1980s, participation in the growing national network was voluntary and inconsistent. "In practice, ad hoc rules and 'old boy' networks distributed America's organs," observed policy analyst Jeffrey Prottas. "'Every surgeon a king, and every city a kingdom' [was] the rule."[115]

Things changed in the mid-1980s when transplantation became politicized. In late 1982, Charles and Marilyn Fiske, the especially dogged parents of a girl dying of liver disease, contacted medical organizations, television stations, and politicians trying to publicize Jamie's desperate need. Millions celebrated when a donor organ was found for Jamie.[116] In July 1983, President Ronald Reagan made a personal appeal in a national radio broadcast on behalf of another gravely ill child awaiting a liver transplant. The Fiske case and the president's unprecedented plea for organ donation brought great attention to the cause but also calls for improvements to the system. Some complained that media appeals on behalf of a few "poster children" were not fair when thousands of equally needy people waited. They said people should not have to have special influence in order to obtain an organ.[117] Responding to the concern, Congress began considering a greater governmental role in transplantation. Each year there were 20,000 potential organ donors but less than 3,000 organs available for transplant, Representative Henry Waxman declared, and action was needed to fix the nation's fragmented system.[118] Representative Al Gore wanted improved efficiency and more fairness and sponsored a bill that proposed the federal government contract with a nonprofit organization to coordinate a national network that would set standards and policies based on up-to-date scientific data. Gore insisted that the federal government had a legitimate role to play because it already subsidized all kidney procurement through its End-Stage Renal Disease program. The government could help promote equity, as it had in kidney dialysis and transplantation, where before government oversight the recipients had been predominantly young, white, college-educated males. Gore asserted, "Only the Federal Government can best provide the glue and the conscience from which a national system can be formed."[119]

Federal legislation proved to be a popular idea. Ironically, the few who opposed it included President Reagan, who despite his sympathy for individuals needing transplants believed the federal government should stay out.[120] Transplant personnel, though somewhat nervous about government oversight, wanted the many benefits the government seemed to be offering, including possible Medicare coverage for heart and liver transplants, subsidies for immunosuppressant drugs, and greater coordination of information and organ sharing. They

realized the government had already facilitated the growth of organ transplantation and were reassured that under the plan medical experts would continue to make most of the decisions about policies. Congress passed the bill on October 19, 1984, and as the vote in the House demonstrated (396 to 6), it did so with enormous bipartisan support.[121]

The National Organ Transplant Act outlawed profit from the purchase of solid organs and decreed that the Secretary of Health and Human Services (HHS) should contract with a nonprofit organization to be the nation's Organ Procurement and Transplantation Network (OPTN). The OPTN would maintain a national list of individuals who needed organs and a system to match them with available organs, and coordinate the procurement, testing, and transportation of them. The law told HHS to contract with a scientific registry to maintain and analyze transplant data. Finally, it established a national task force to make recommendations about medical, legal, ethical, economic, and social issues related to organ transplantation.[122]

The 25-member national task force on organ transplantation shaped the future direction of the field.[123] It asserted that organ transplants have a "special nature" due to their reliance on organs donated by the public. As a result, donated organs should be seen as *a national resource* and every aspect of the transplantation process should be just and transparent and the public should have a voice in the development of fair policies. The task force recommended that a single national system for organ sharing be established with *uniform policies and standards* by which all must abide. Selection of recipients should never include favoritism or discrimination on the basis of race, sex, or ability to pay. Instead, allocation should be based on medical criteria that were *publicly stated* and *fairly applied* and should take into account a patient's need and probability of success. Allocation policies "should be determined by a broadly representative group" that included patient, community, and ethical perspectives in addition to medical professionals. To avoid discrimination based on wealth, the task force recommended that government and private health insurers should cover heart and liver transplants and immunosuppressive therapy. (In response to those who criticized organ transplants as a poor use of resources, the task force insisted they were as effective as other life-extending procedures.) The task force also recommended improvements in transplant programs and OPOs. Finally, the committee noted that despite strong public approval of organ donations, many grieving families were never asked to donate, so it suggested ways to increase the number of organs that were donated.[124]

President Reagan's administration resisted implementation of the National Organ Transplant Act, but Congress enacted it and some of the task force's recommendations nonetheless.[125] Congress passed laws in 1986 and 1987 that provided outpatient immunosuppressant drug coverage for up to one year following

a transplant, tightened up the organ procurement system, and gave HHS more responsibility over OPOs and policies adopted by the nation's network.[126] Congress also required that hospitals notify an OPO regarding all potential donors and inform the families of potential donors about the option to donate. It would take a long time for busy hospital staff to implement these new policies, but analyst Jeffrey Prottas characterized the laws as marking an "ethical revolution." Congress mandated the medical profession's assistance in organ procurement, its actions implying "that organ donation is primarily a social issue, legitimately under the direct purview of public bodies, and not solely a medical question subject to the professional judgment and ethics of physicians." Although the federal bureaucracy did not fully implement the oversight Congress desired during the Reagan and George H. Bush administrations, the national government had been given broad power over organ transplantation.[127] Congress had set in motion the beginnings of nationwide change.

The Department of Health and Human Services eventually awarded the contract for the nation's organ procurement and transplantation network to the United Network for Organ Sharing.[128] Gradually UNOS developed standards for transplant centers and OPOs related to the acquisition, preservation, transportation, and allocation of organs. By 1987, UNOS was handling over 150 calls each day to match organs to candidates.[129] Eleven standing committees established UNOS policies. Regarding allocation, UNOS guidelines deemed that organs should be allocated locally first, and if there was no one in the local region of the donor who matched, they should be shared in a wider geographic region. Beyond that, each organ had its own guidelines. For lungs, UNOS proposed that *the length of time a patient waited* should be the main criteria. That meant the first candidate who had been put on the waiting list who matched a donor organ in the local area would receive it (in a first-come, first-served system).

Although the new guidelines meant individual surgeons would have less power over allocation, many appreciated them. "The beauty of the system we now have is that we don't have to play God, we don't have to make choices," said Keith Reetsma. "The only thing we consider is medical necessity and nothing else."[130] UNOS leaders hoped that developing voluntary guidelines with a lot of input would result in cooperation from transplant personnel, but not everyone liked or abided by the policies. Despite the desire of Congress and the national task force for consistency, many OPOs and transplant centers insisted on developing their own policies. UNOS permitted this practice. "At the outset, the exceptions were invited to swallow up the rule," observed Prottas. Despite some complaints, UNOS leaders thought there had been "considerable progress in achieving equity." In 1990, its president told Congress that UNOS was "not perfect, but still maturing."[131]

Maturation of Lung Transplantation from the Mid-1980s through the Mid-1990s

While the nation was building the administrative and legal infrastructure to make organ transplantation more efficient, fair, accepted, and widely practiced, medical specialists in lung transplantation were trying to help their field mature. "Neophytes" in the area donor acquisition, in their early single lung transplants in 1983 and 1984 Cooper's team had been transporting the whole bodies of donors to Toronto.[132] This practice inconvenienced the family of the donor and put lung transplanters in competition with the transplanters of kidneys, hearts, and livers, who sent a surgical team to harvest only the organs they needed at the donor site and then quickly transported them back to the recipient hospital. Although lung transplanters' early efforts in distant retrieval were awkward, as when a surgeon filled a garbage bag with ice to reinforce a leaky box holding donor lungs, they soon developed better protocols.[133] From the transplanters of other organs, they learned to better protect the graft by inserting cold preservation solution directly into the donor's blood vessels. New techniques extended somewhat the length of time fragile lungs could be preserved and dramatically improved the function of transplanted lungs.[134] OPOs helped coordinate efforts so that it became routine to extract both lungs and the heart from the same donor for separate transplants, meaning each individual donor could now save more lives. Still, managing two separate operations in distant locations required pinpoint coordination. Surgery on the recipient couldn't be delayed too long, but couldn't start too early, either. "The timing has to be just right," Joel Cooper explained. "It's a bit like jumping out of a plane with a parachute and hoping it's going to open."[135]

In the mid- and late 1980s lung transplanters also branched out to apply the procedures to conditions other than PPH and pulmonary fibrosis. Cystic fibrosis (CF) and chronic obstructive pulmonary disease (COPD) both posed unique challenges. With CF, surgeons worried about the extensive scarring of the old lungs, which made them very difficult to remove, and the rampant infections of the old lung that might infect the new one. Nonetheless, Bartley Griffith of Pittsburgh performed the first heart-lung transplant for someone with CF in November 1983. In addition to the anticipated challenges, he had difficulty in maintaining the correct levels of cyclosporine of their CF patients' bloodstream (because their disease caused problems in absorption). Soon, though, dozens of patients had heart-lung transplants and enjoyed a one-year survival rate of 78 percent.[136] Surgeons had also avoided patients with COPD, believing that a single lung transplant would result in an imbalance in blood supply and air flow. In spring 1988, however, Herve Mal in France proved that single lung transplantation could provide COPD sufferers with substantial benefits, and COPD rapidly became one of the most common conditions treated by lung transplant.

Eventually it became clear that people suffering from other more rare conditions could also benefit.[137]

Other frontiers were soon conquered. When in 1984 a Stanford patient encountered serious problems with rejection three years after his transplant, he became the first person ever to receive a second heart-lung transplant. That meant other centers would have to grapple with the ethical dilemma of whether it was fair to retransplant someone when other patients waited for a first transplant. Another frontier was age; surgeons began to offer transplants to adolescents, toddlers, and even infants.[138] In the late 1980s, Vaughn Starnes also developed a technique for implanting just a lobe of a lung from a *living* donor into a child. Some parents of children with CF welcomed this option, but the procedure could only be done in very specific circumstances and raised serious ethical concerns about endangering a perfectly healthy person. Although surgeons continued to test where the lung transplant procedure would work, they explored carefully, cognizant of pressure to produce "good numbers" (survival rates), not only for the sake of their patients but to insure the survival of their programs and convince the government and insurance companies that the procedure was worthy of coverage.[139]

Double lung transplantation proved to be the most significant innovation of the mid-1980s. Members of the Toronto team began experimenting with double lung transplants on primates in the lab before much of their profession had even accepted single ones.[140] They believed patients with COPD and CF would be better served by two new lungs but that they did not need a heart-lung transplant.[141] Although they jokingly called the new procedure, "heart-lung, hold the heart," its official name was "simultaneous en bloc bilateral lung transplant." When they felt confident they had developed "a good operation," they published the description of the technique. They were surprised and disappointed when Magdi Yacoub in London, who had not done lab research on double lung transplants, became the first to use it on a human being in late 1986.[142] Shortly thereafter, Cooper's team performed its first double lung transplant on Ann Harrison, a 42-year-old woman with alpha-$_1$antitrypsin deficiency. Within six weeks, Harrison was walking more than a mile and reported, "I can't believe how deeply I can breathe." Harrison lived about 14 years after the transplant. The Toronto team performed the bilateral procedure on another 12 patients with different diseases. Because some of them had problems with blood supply and airway healing, Cooper's new team at Barnes-Jewish hospital in St. Louis changed the double lung technique so that it was safer and simpler, more like inserting the two single lungs sequentially.[143]

Now presented with three different operations—a single lung, heart-lung, and double-lung—transplanters debated which was best. Heart-lung programs insisted that keeping the heart and lungs together made sense because it was simpler and proven, provided better blood supply, and made rejection easier to

diagnose.[144] For the first few years after the Stanford program's success with Mary Gohlke, this procedure had more adherents. But from the moment it did Tom Hall's transplant, the Toronto Group maintained that single lung transplants had advantages for certain diseases. Some recipients could easily survive on one good lung and already had a good heart, so there was no need to risk cardiac-related complications by giving them a new heart. In addition, by doing single lung transplants, the number of people who could benefit from transplantation could potentially be tripled (since they could use two separate lungs and the heart in three different recipients). For diseases not helped by a single lung transplant, heart-lung opponents said the double lung technique could still save a heart for someone who really needed one.

Sensitive to criticism that the heart-lung transplants wasted a heart, heart-lung teams innovated again, developing something called a "domino" procedure. In this procedure first performed in April 1987 in London, doctors gave one patient a heart-lung transplant (with the connected heart and lungs from a single donor), and then the living recipient's native heart was given to a different patient who was awaiting a heart transplant. "The heart-lung is less risky to the patient whose own heart is in good condition," explained one surgeon, and "the domino procedure allows us to save two lives with one donor." In the United States, the first such domino transplant was performed a month later by Bruce Reitz, who had moved to Johns Hopkins. Reitz's three surgical teams removed the healthy heart from 28-year-old Clinton House, who had CF and had been waiting for a transplant for a year, implanted it into 38-year-old John Couch, and then put the heart and lungs from a deceased donor into House. House and Couch were both happy with the arrangement, but others questioned the complicated arrangement for both psychological and scientific reasons.[145]

After a few years, consensus grew about which procedure was best for what. Domino transplants were abandoned as heart-lung transplants gradually lost ground to double and single lung transplants. After becoming comfortable with a method for taking biopsies of the lungs and realizing that it was possible for a patient to reject a heart and lung separately, even Stanford doctors decided single and double lung transplants provided "maximum use of scarce, valuable resources."[146] Gradually programs pushed the envelope even further and discovered that many sufferers they thought needed two lungs could benefit from just one new lung. Eventually, there were very few heart-lung procedures being performed, usually only for PPH cases that had severe right heart dysfunction. By the mid-1990s, CF and PPH patients usually received double lung transplants while those with end-stage COPD and pulmonary fibrosis often received single lung transplants.[147]

Medical knowledge about lung transplantation had grown by leaps and bounds in the 1980s. The lessons built upon one another. Better preservation of donor lungs meant better bronchial circulation and healing and easier

postoperative care. Better methods of diagnosing rejection meant it was easier to distinguish it from infection and provide more effective treatment for each. By the mid-1990s, lung transplantation had proliferated. In 1993, there were over 500 single lung transplants and over 300 double lung transplants performed worldwide with the number growing each year. By 1996, 90 medical centers in the United States performed the surgeries.[148] The rapid growth meant surgeons were now spending so much time in the operating room that they had turned over many of their previous tasks in evaluation and preparation of patients to specialist nurse coordinators. Though not without risk, the procedures were becoming more routine, and experience was paying off with improving survival rates; 76 percent of patients transplanted in 1994 lived one year, and 46 percent for five years. "We've got the survival rates to a point I never believed possible," observed Cooper in 1992. One scholarly review concluded, "Lung transplantation has matured past its developmental stage and has moved into the stage of improving long-term results. It is no longer considered 'experimental.' "[149]

The government agreed. Noting that the procedure had evolved to achieve "a favorable risk-benefit ratio and acceptable 1- and 2-year survival rates," in February 1995 the Department of Health and Human Services announced that in certain circumstances Medicare would cover lung transplantation.[150] This was especially good news since private insurance companies often followed the lead of Medicare, and because before that decision, many financially strapped patients had appealed in vain to their insurers. While the procedure would still be very expensive, the government's decision made transplantation a realistic possibility for many more people. A spokesperson for the American Lung Association observed, "A lot of people with lung disorders are feeling very hopeful."[151]

Although by the early 1990s medical professionals knew that lung transplantation could be a helpful treatment, they also knew that it was not perfect. For individual patients, the procedure was risky and difficult and did not cure all of a patient's problems. "We tell people that having a transplanted lung is not giving up your illness for perfect health," said Cooper. "It's trading one disease for another, trading what you've got for the disease we call being a transplant patient."[152] For the field, two serious problems loomed. First, an increasing number (ranging from 20 to 50 percent at different centers) of longer-term survivors were developing bronchiolitis obliterans, an insidious syndrome sometimes called chronic rejection that led to a decline in lung function and then death. Bronchiolitis obliterans had become, as one team put it, "the major conundrum of lung transplantation." The second major problem was that there were not enough donor lungs available. Even with improved preservation techniques, only about 20 percent of cadaveric donors provided lungs suitable for transplantation. As a result, there were twice as many people on the waiting list as there were lung transplants performed and 15–20 percent of those on the list died while waiting. In a sense both these problems suggested the very success of

lung transplantation—because they were signs of longer survival rates and high demand. A member of Toronto's team accurately predicted, "Lung transplantation is here to stay."[153]

* * *

Timing was crucial in the development of lung transplantation. Lung transplantation as a field could only succeed once researchers had put in enough time in the lab to gain sufficient knowledge about surgical techniques, immunosuppression methods, and recipient care. An individual patient (like Mary Gohlke or Tom Hall) had to hope that the chance for a transplant came at a time when his or her life expectancy was extremely short, but not so late as to be too weak to survive the surgery at the moment a donor lung came available. Organ transplantation as a whole could not flourish beyond a small number of lucky individuals until a legal framework and organizational infrastructure in UNOS made widespread sharing of donor organs possible, which necessarily took time. Nor could organ transplantation thrive until the general public became aware of the possibility of life-saving transplants and trusted that the process was safe and fair for recipients and donors alike. This acceptance took time and the process involved many more people than doctors expected. In the 1980s, organ transplantation became politicized, which was not surprising given that it needed organs from people who died, was characterized by shortages, posed difficult ethical decisions, and depended so fundamentally on the public. Congressional representatives, federal bureaucrats, organ procurement agencies, UNOS staff members, and insurance representatives became important actors in the drama of lung transplantation, almost as significant as the generous donor families, dedicated medical personnel, and deeply ill candidates. While an individual patient may not have been aware of it, many sociomedical and historical factors influenced the availability of lung transplants.

Despite the political, legal, administrative, and medical challenges, by the mid-1990s lung transplantation had become widely practiced in the United States. True, there was still much to learn, and the procedure's very success led to other problems, but the changes that occurred since James Hardy first attempted a lung transplant in John Richard Russell in 1963 were remarkable. Instead of asking whether a lung transplant could work in a human being, doctors wondered how they could find enough donor lungs, how those organs should be allocated, who should run a national organ system, and how transplants would be paid for. Even the pioneers were awed by how rapidly the progress came after the first two decades of failure, uncertainty, debate, and ethical dilemmas. "I once heard someone describe a miracle as something which leaves you with an abiding sense of astonishment," said Joel Cooper. "At least for me, transplantation is that way. It's still miraculous."[154] Many individual people with end-stage lung disease hoped that it would prove that way for them, too.

CHAPTER 3

Making the Decision and Being Evaluated for Transplant

> I'm confused about transplants. When's the right time? What should I do? Whom should I listen to? Is it worth risking my life to live a different life? Or will that just be difficult in different ways?[1]
>
> —Laura Rothenberg

"What about a transplant?" asked Pauline DeLuca as she discussed her treatment options for sarcoidosis with her pulmonologist. He answered that at that time, transplantation was not an option for people like her. Some years later, when DeLuca was in her mid-forties, her health took a serious downturn so that the smallest exertion caused extreme shortness of breath, forcing her to quit her job. A stress test showed her heart was being damaged. The good news, however, was that by that point, surgeons had tried lung transplants on sarcoid patients and had success comparable to that for people suffering from some more common diseases. The efforts of the pioneering medical teams, United Network for Organ Sharing, and Congress meant that in the year 2000, her doctor could broach the possibility of a lung transplant with her. "Oh my God," she reacted, noting that his words were a "wake up call that this is serious." The news that she was sick enough for a transplant took a little time to sink in, but DeLuca maintained, "Once I got used to that idea, I was all for it." She quickly concluded, "That's it. Let's do it." Her husband and older daughter were more hesitant, she recalled, saying, "No, no, no, no, no, you don't want to do that." They tried to slow her down, insisting she needed to gather more facts before deciding. She replied, "Listen, I'm the one who's living like this. I'm the one who's willing to take the chance that I could be healthy again and have a quality of life—even if it's only

for three years or two years. All I do is sit around all day with an oxygen tube up my nose." Her family eventually came around to DeLuca's point of view, and she proceeded to undergo a difficult evaluation process that led to acceptance by a lung transplant program. She felt fortunate she had the option. "The timing was right," observed DeLuca. "If this had happened five or ten years ago, there wouldn't have been an option. I would have died."[2]

The decision to attempt a transplant was much harder for Laura Rothenberg, a young woman who had just graduated from high school. As someone who had grown up with cystic fibrosis (CF), she knew others who had undergone transplants and not lived long. "Getting a transplant means that I could possibly lose my life altogether," she wrote in her journal. She knew her doctors said she was sick enough to be considering a transplant, but she felt uncertain. "I have to go into this believing that I have no other choice and I'm not sure that I'm quite there yet." Part of her felt she should fight her disease by getting a transplant, but "diving into the unknown" scared her. Although outsiders might have found her medical history daunting, for Rothenberg it was routine. She knew her body, her medications, her disease, her "family" of caregivers in her local hospital. A transplant would mean new medical issues and treatments (including steroids, which she feared would make her ugly) in a new hospital with different doctors and nurses. It would mean admitting she was extremely sick. It would even alter her identity. "I have always said that I would never trade my life for one without CF . . . My lungs are just as much a part of my life as my glasses or my hands. I am the coughing girl." Despite her hesitations, Rothenberg underwent evaluation for transplant and eventually decided to go for it. Being accepted by the transplant program took longer than expected as she waited for approval from her insurance company, and "waiting for the waiting to begin" offered more time to question again whether it would be worth it.[3]

The stories of Pauline DeLuca and Laura Rothenberg illustrate two ends of the spectrum in how people with end-stage lung disease approached the decision of whether to attempt a lung transplant. The relative ease for DeLuca and the difficulty for Rothenberg resulted from their different diseases, ages and stages of life, reactions of loved ones and doctors, and personal outlooks. Their reactions also illustrated some shared challenges: deciding about transplantation meant facing one's prognosis, considering how willing they were to leap into the unknown, and grappling with the slippery issue of timing. As DeLuca noted, she was fortunate to be alive at a moment in history when the option for a lung transplant existed. But timing mattered in other ways as well. Even if they believed transplant to be a good choice, neither they nor their physicians could know when the timing was right to go on the waiting list. And as Rothenberg witnessed, deciding was simply the first stage in what could be a long process, one that was largely out of their control and offered no guarantees.

Hearing the Prognosis

The first step toward transplantation was a conversation. Occasionally it was a patient, such as Steve Bunsen, incapacitated by alpha$_1$-antitrypsin disorder, who initiated the discussion.

> I asked the doctor up there about the possibility of a transplant, just coming off the wall. I had no idea what I was even talking about. I said, "I am probably somewhere out in left field," and he said, "No, you're on third base, but home plate is a long ways away."

Bunsen's question came in 1988, just five years after Cooper's first successful lung transplant, so his doctor didn't consider it realistic.[4] Many doctors remained skeptical for a few more years or longer. Frank Avila noticed that only one of his physicians thought a transplant was necessary; Bob Festle's usual doctors had not spoken to him about the possibility, but when a different "young and new" one looked at the results of a lung function test, she immediately mentioned that transplantation might prove to be his only chance to survive for long. As transplant success rates improved dramatically in the 1990s, pulmonary physicians increasingly brought up the topic with patients who had lung capacity below 30 percent and had no other options. Kathleen Feeney's doctor said, "You know, we talked about that before, and we said, 'Sometime down in the future.' I think the future is now. I really think that the long-term solution is transplant."[5]

Responses to the news differed, but for many, their first response was disbelief. "WHAT? I need a what???" was Marilyn Hom's reaction. Lynn Coleman recalled similarly, "I almost fell off the examining table in shock."[6] For some people the news was too shocking to deal with right away. Kathryn Flynn remembered that when her extremely rare lung condition (eosinophilic granuloma) had finally been diagnosed, "a doctor who I had never seen before walked into my room and asked me if we had discussed my lung transplant. My husband and I were stunned. This was the first suggestion that I would have to resort to such a drastic measure. We asked him to leave." Don Hawkins's denial was so strong that when he received a call from a transplant center to make an appointment for an initial screening, he "had entirely forgotten" his doctor mentioning it. In a "complete daze," it took Gladys Shepard nearly a week before she could even mention the subject to her husband. Not surprisingly, many patients described the news as "mind-boggling" and "overwhelming." Charles Tolchin said in his mind he was a "normal person . . . not someone who was so sick that he needed a transplant," and that his doctor's words had "jarred my self-identity."[7]

Others, though, found the conversation to be positive. Told repeatedly by doctors that he "wouldn't live long enough to grow old," hearing the news made

Scott Collien feel "relieved and scared at the same time." When Mary Ellen Smith's doctor soberly reminded her that her disease was progressive, that it would soon be end-stage, and that there was nothing else he could do for her other than recommending transplant surgery, she didn't get upset. "As a matter of fact I was very excited." When Sharolyn Converse almost died, her doctors initially thought she was in the final stages of lymphangioleiomyomatosis (LAM) and would die almost immediately.

> So they were really glad I wasn't. I remember them saying, "Hey, you can get on the transplant list because now you have time." So it was more of a positive thing than a negative thing. Really the enormity of it hit me later. After I first found out about [transplantation], it was like a straw to grab on to.[8]

Doctors in the mid-1990s would recommend transplantation only if life expectancy was less than two years, so for a patient, the conversation about transplantation meant facing the fact that one's death was imminent. "Mentally the hardest thing for me," confirmed Carolyn Boyd, "was to come to terms with the fact I was dying." Discussing that she had reached the "end stage" was difficult for both Mary Peters and her doctor.

> She was kind of not looking at me in the face, but I didn't get that it was an uncomfortable topic for her. And she said, "You ought to think about a lung transplant," and it took me by surprise. I had no idea, and all I thought was that she was trying to tell me I was going to die. So I started crying and I told her, "Oh, I'm not ready for that yet."

Although intellectually Mike Yurkiw knew the outcome of his disease was inevitable, he "desperately wanted to believe this wasn't true. Who is ever ready to accept it?" Kathleen Feeney had been ignoring the severity of her CF, even begging her doctor to delay going into the hospital for a couple of weeks so she could finish her college final exams. He responded that if she didn't enter the hospital that day, she wouldn't make it to those exams. "It was like getting a two-by-four between the eyes," she remembered. "Whoa! I guess I'm pretty sick."[9]

Making the Decision

There were many factors that patients considered as they pondered whether to pursue transplantation. Obviously one crucial factor was their perception of their health. For someone like Dana Schmidt, who was on a respirator when her doctors brought up the transplant option, being told she was in the end stages of her disease was no surprise.[10] Other patients, however, were skeptical

of the prognosis. Charles McNeil remembered the conversation where his doctor observed that his hospitalizations were longer and more frequent, and that there were no new antibiotics to try, and no options besides transplantation. " 'NO WAY,' I told him. After all, I wasn't that sick—was I? Sure, I was having trouble getting up in the morning, showers were wearing me out, and I couldn't walk very far without resting, but I can live like that, RIGHT?" Similarly, when Jimmy Carroll's general practitioner suggested he think about transplantation, he protested, "That's for people who are virtually at death's door, and I don't feel like I'm there." Sometimes patients did not appreciate the gravity of their situation. "I guess I just didn't realize how sick I really was," admitted Karen Pierce. "This was a process over time. I just kept getting worse [and] as you do get worse, you just adjust to what you can and can't do, and it seems very normal for you."[11] But sometimes people had good cause for questioning the prognosis. While doctors could administer objective tests for lung functions, and could observe typical patterns in the course of disease, there was no foolproof method of predicting *exactly* when lungs would finally give out.[12] A patient named Lynn had much more faith in her body's resilience than her doctors.

> The first time they mentioned transplant to me . . . my lung functions ha[d] been bopping around the mid to high 20s for probably five years. When they first mentioned it to me, I was like, "Ha, you got to be kidding me. I don't need this. I am nowhere near ready for this. You are being nuts."

Lynn turned out to be correct, surviving a couple of years longer than expected. After a few years of hearing her doctors repeatedly suggest transplant, she consented to go on the waiting list, but even then Lynn had not decided to be transplanted if the opportunity arose.

> I would go to a transplant clinic and a surgeon would come in and say, "Are you ready to do this?" and I'd say, "No, I don't need this." You know, I was *sitting* around with my oxygen, kind of panting away, but thinking, "Hey, I'm working two days a week; I go to rehab three days a week. I don't need a transplant." My lung functions were probably at about 18 percent. Everyone thought I needed a transplant but me. The hardest thing about . . . needing a transplant for me was not doing it prematurely. I just did not want to do it too soon . . . What's the right time?[13]

Even for patients who accepted their prognosis, timing was clearly a critical issue to consider. "For me the question was never, 'Yes or no?' but more, 'When?' " explained Annabel Law. "I remember thinking I should get as much 'mileage' out of the old damaged set of lungs before embarking on a very uncertain alternative that certainly carried no guarantees."[14] These patients and their doctors were

maneuvering a delicate high-wire act, trying to balance many unknowns, including how long their own lungs would hold out, when a new lung or lungs might become available, and how well the new lung(s) would last. Placing too much faith in one possibility could well shorten one's life. Unfortunately, due to the success of lung transplants, more were performed, more people hoped to have them, and the waiting list grew ever longer. Those shifting sands meant it was even more difficult to predict the correct timing. So although Jimmy Carroll's pulmonary doctor agreed with him that Carroll was not yet "at death's door," he warned him about the length of the waiting list and that a couple of his patients had died before they had reached the top. A skeptical Carroll agreed to speak with specialists about the option, which, he said,

> I was happy to do, but I just knew they were going to laugh and say, "No, you're not even near ready." And so I mentioned it to them, and to my surprise they said, "Yeah, we think it's a great idea to put you on the list, and then you're accruing time, and maybe you'll never need it. But if you do, then you've got the time, and when the time's ready, you're at the top of the list and ready to go."[15]

Many other doctors began recommending their patients get listed as soon as their lung functions met transplantation criteria so they had the option of saying no to a transplant, but when they were ready to say yes, transplantation truly was an option.

Patients did not want to get transplanted too early, either, as Lynn explained.

> I felt a lot like there was a time clock on the other end [after transplant]. I thought I won't have so much time, because . . . this is what the statistics said. What scared me was that there was a [limited] life expectancy attached to this. I think it is five years at 50 percent right now, so after five years there are 50 percent people surviving, 50 percent aren't. And that was really, really frightening.[16]

David Courtney shared Lynn's concern. "My perception of it was that even with transplant, I'm definitely going to be putting a limit on my life." So he stalled for a while. But after he looked into things a bit more, "That's when I became aware that there was such a huge waiting list, and it came home to me, 'Wait a minute, there may not be lungs for me before I need them.' " Kathryn Flynn's disease was so rare that doctors could only guess at her life expectancy. As she researched transplant survival rates in the late 1980s, she found them too low to accept the risk. Flynn held back for eight years—on oxygen 24 hours a day during that time—until the odds were 90 percent that she'd survive a year after transplant, and 50 percent to survive three years.[17] Like others, she was trying to strategize so the timing of transplantation would be to her best advantage.

Although the life expectancy after transplant might be limited, to many people even the possibility of a couple more years looked good. Told to think about the transplant option, Shirley Stock declared, "What's to think about? I wanna live!!!!" For many people like Tiffany Vuncannon, the decision was barely a decision.

> I don't understand when people talk about the choice involved. I guess I do understand you can choose to sort of die with dignity and leave this earth very quietly. That's a valid choice, it is; but for me it just seemed like I wasn't ready to leave this earth yet. There was no resignation; there was no acceptance; I was not ready. To me it was like if the plane is going down, and you can grab a parachute and jump, well, I'm going to do it. Skydiving is not my idea of fun—I wouldn't do it on a weekend—but if the plane is going down, I'm going to grab the chute and jump. For me, lung transplant was my parachute.

Tim Choquette felt the same way. "To me it was a black-and-white situation. If I don't get it done, I'm just going to be dead. You don't even get a one in one hundred chance if you don't do it. So at least give me that one chance." Randall Benifield also felt compelled to take action. "[If] I've got the problem, I've got to do something about it. I can't just sit here and wither away to nothing."[18]

Patients weighed other factors as well. Laura Scott Ferris was concerned about donors. "The fact that someone else had to die for me to live troubled me more than I could put into words. Worse, because I was so tiny, it would have to be a child's lungs. I shuddered at the implications." The 27-year-old Ferris also worried about learning to cope with a whole new set of medical challenges. "As ridiculous as it might sound, I had grown 'comfortable' with my disease. Not happy about it. But it was part of me. It was me. I knew the rules of the C.F. game." Undergoing such a serious operation daunted Mary Peters.

> What really scared me was the surgery thing, because it was described as being very painful and something that took a year to recover from. What they were going to do was cut you from armpit to armpit and . . . pry apart your ribs and kind of shove one lung in and sew it up. I'm a baby when it comes to pain. Mom used to make us get flu shots and I cried every year . . . Now I was volunteering for someone to cut my chest open!

What worried Paula Huffman was not the pain, but the chance that she might not survive the surgery. "The more I read about it, the more scared I became . . . because if you do this and it doesn't work, you die."[19]

Most looked past the difficulties and risks of surgery to the potential benefits. Carol White was told by her coordinator that the transplant might not actually prolong her life, but if it worked well, it would definitely improve the quality of

her remaining time. "I would have grabbed any chance to live a normal life," she declared. Steve Bunsen, considering a transplant when they were still rare, was told by his family doctor that he could live a long time at his current 10 percent lung capacity. He resisted. "I basically told him, 'You try it.' I am not so much for quantity, I would much rather have the quality." Kathryn Flynn's father had died of emphysema, so she observed, "Dying of lung disease is a horrible thing. If you have the choice of getting your breathing back or just dying a long, slow death, get your breathing fixed! If it doesn't work, what's the worst thing that can happen? You die quickly, which to me is preferable."[20]

As they deliberated, many people sought out information from sources besides their doctors. Some headed to libraries, and the growth of the Internet opened a new arena from which many could learn. Shirley Stock's desire for information led her to use the Internet for the first time, and in doing so, she chose the user name "Needalung." New websites proved extremely helpful, as did online patient groups related to different diseases or to lung transplantation that used listservs and email to facilitate interaction. Dana Schmidt's experience was fairly common.

> When I found out I had to have a transplant, I was on the Internet every day looking at sites, seeing about the facts about rejection, the medicine, everything. So I researched very, very well and I actually went on a support site for transplant recipients and met a lot of people who actually told me a lot of good things.

Although Jimmy Carroll was pretty sure he would try for a transplant, he was very scared. One night at the hospital he talked with a nurse whose boyfriend had undergone a lung transplant and was doing very well. The conversation "totally changed the way I felt about it . . . just knowing that, it made me feel a lot better." Francisco Avila had a similar experience with a friend who also had CF. "When he got transplanted before I did, and to see all the stuff that he was able to do afterwards . . . to keep up with everybody else [made me feel], 'Okay, I need to do this.' "[21] Likewise Dare Reitz was motivated by a friend's experience, but the person she knew didn't survive the transplant surgery, and Reitz believed her friend had waited too long. "I was just so overwhelmed by [her death] and I thought, 'I am not going to let that happen to me. I've got to do something to survive.' " Daniel Ensign's doctors wanted him to consider a transplant, but Daniel's brother Jason had been listed and didn't survive the wait, leading Daniel to the opposite conclusion, that the whole transplant idea "was nothing more than false hope."[22]

They also considered healthy loved ones as they made their decision. Told that she only had a 50 percent chance of surviving a transplant, May Parker initially decided not to pursue one. "I am not going to do this to my kids. I'm not

going to die and then leave them to be raised by somebody else." When Carol White was deciding, survival rates had improved, and she made the opposite decision for the same reason as Parker. She half-joked, "I know he [my husband] wasn't ready to be a widower" and her two daughters weren't "quite ready to be without a mother." Happily, Charles McNeil's mother's position—"she said that she would stand by me in whatever decision I made"—freed the 17-year-old from worrying about her desires. However, Gladys Shepard almost wished her husband had not been so flexible. "I desperately wanted him to just tell me what to do, but this choice, he said, had to be mine alone."[23]

The Evaluation Process

The decision to pursue a transplant was a small first step toward actually getting one. One had to find, and then be accepted by, a lung transplant program. The programs put potential candidates through a rigorous evaluation. "The basic idea," observed Jimmy Carroll, "was to make sure that you were sick enough that you needed to be transplanted, but you were healthy enough that you could withstand it."[24] "Sick enough" meant being in the end stages of lung disease, but as Joel Cooper had discovered, having one's other systems in good enough working order to maximize the chances of surviving the surgery and thriving after it. Transplant centers wanted good candidates not only out of concern for their patients, but also because of the organ shortage; they did not want to waste lungs in a hopeless cause.[25]

Ideally, the evaluation process worked both ways, with transplant centers not only checking out patient suitability, but patients seeing whether they were comfortable with what the center offered. By 2003, there were over 65 hospitals in the United States performing lung transplants. UNOS recommended that patients learn as much as possible about transplant centers, ask a lot of questions of the transplant team, and choose the one that best met their needs. In a handbook she wrote to help people considering lung transplant, recipient Karen Couture suggested patients should ask the number of procedures performed each year, the surgeons' experience, the length of the waiting list for the relevant blood type, the center's survival rates, and whether there were requirements for relocation, rehabilitation, and support groups.[26] In the 1990s, UNOS began publishing information about numbers of transplants performed and some older information about survival rates, so patients could do comparison shopping.

In practice, though, patients often didn't have many choices. In the early years of the procedure, North Americans looking for a transplant center could only go to one of a handful of programs. Later it became possible for some people to find a more conveniently located one, but for many people, the nearest place wasn't close to home. "I lived in the state of Florida, and nobody in Florida [in 1994]

was doing lung transplants," explained Tim Choquette. "Suddenly I had to think about the logistics of getting myself to a place where this could be done and how was I going to manage it. That weighed pretty heavily on me." Some people learned they were not eligible at their nearest center—within some parameters each center could choose their patients—or that the center didn't meet their needs. Ed Pearlman discovered that he had to have stopped smoking for one year before being evaluated at the hospital he was considering, but because his doctor didn't think he'd live that long, he searched for one where he only had to be smoke-free for six months. Karen Couture started her evaluation process around her hometown of Boston, but when it seemed like the waiting list was too long, she sought other options farther away. While choices were good to have, the information could be confusing. A newer transplant center might have a shorter waiting list but not as much of a track record as a more experienced one; a smaller hospital might have fewer surgeons, but provided more personal attention. Many people felt they didn't have know enough or have much time to effectively evaluate good lung transplant programs, which, as Charles Tolchin noted, were "not exactly a category in the Yellow Pages." Therefore many simply followed the recommendation of their pulmonary doctor or an acquaintance.[27]

Health insurance was a major determinant of where, and even whether, a transplant would be done. Paula Huffman lived less than three blocks from Norfolk General Hospital. "It would be so much easier on me and on my family if I could have this [done] here," she observed. "But unfortunately for me . . . I'm on Medicare, and the only Medicare-approved facility in Virginia is in Charlottesville, three hours away. So that's where I must go." After enduring months of delays, another problem arose for Karen Couture. "The day before I was going to go, I got a call from their office, and they told me that the hospital was not covered by my insurance. It turned out that I had to start all over [at a hospital] in my HMO plan."[28] One's insurance coverage was often related to whether one had enough money to afford a good policy, whether one was healthy enough to work, where one worked, where one's parent or spouse worked, or even the state one lived in, all factors that were largely arbitrary, a matter of luck, related to one's past, and out of one's control. This fact could be extremely frustrating since insurance could mean the difference between life and death. At a time when they were already struggling with the enormity of transplantation, dealing with the complexities, ambiguity, and bureaucracy of insurance companies could push them to their wits' end. Ruth Donahue's doctors wanted her evaluation to begin on January 1, but on that date her husband's employer changed insurance companies, which created enormous confusion.

> First the insurance company said we weren't members, then we were, but HMO and not POS, then I couldn't have my primary care doctor, then I could, but we were still HMO and on and on and on! And during this fiasco, they wouldn't

> schedule the testing because it had to be pre-approved! I was getting extremely edgy and upset; I was literally seeing my time left being wasted day by day! And there wasn't anything I could do about it![29]

May Parker endured a similar problem when her spouse's company was sold. Although she was already near the top of the waiting list at Duke, the new insurance company wouldn't pay for a transplant there because it wasn't in their network. It insisted she be evaluated at a hospital in Alabama. Battling the company over a senseless second evaluation process and the prospect of moving again and perhaps losing the time she'd already put in almost proved too stressful for her family to endure. "My husband was freaking out," Parker recalled. She characterized the new insurance company's efforts as "econo-lung."[30]

In the late 1990s, the cost of a lung transplant could run into hundreds of thousands of dollars. Expenses included the pre-transplant evaluation; the recovery of the organ from the donor; the transplant surgery itself; medical personnel; medication; the hospital stay; and follow-up care and testing. Given the enormous expenses, hospitals had to carefully assess whether they could afford to transplant patients who could not cover most of those costs. Since few people had that amount of money in savings, insurance was essential. Each insurance company made its own determination of which procedures to cover, and often it took years of lobbying before they included lung transplants. It's impossible to know how many people could not even consider transplant prior to that. For those with the inclination and resources to fight, it took time—and they often had to appeal the initial decision, enlist the help of their doctors, or even hire attorneys. Even when Medicare or a private insurance company did cover many of the transplant costs, it usually didn't cover them all. Many companies only covered 80 percent, which left a lot for the recipient to pay. Others had annual or lifetime caps to worry about. Prescription drug coverage differed dramatically between policies, which was significant since immunosuppressant drugs, which would be needed for the rest of recipients' lives, could cost $1,000 per month.[31] The reality, as Mary Peters put it, was "you can't even get evaluated unless you have insurance coverage or a big chunk of money in the bank. It really is rationing of medicine, which is sort of disturbing. And yet they [hospitals] don't really have a choice." Despite the shared desire of the government, UNOS, medical personnel, and the public that transplants be available to all without discrimination based on nonmedical factors such as race, ethnicity, sex, or religion, bioethicists recognized that in practice, financial factors eliminated some patients from considering transplantation. Charles Tolchin wasn't yet sick enough for a transplant but knew he would be soon. When he asked his surgeon for advice, the surgeon offered, "Keep healthy and keep your insurance."[32]

The "financial ability" test was only one of a battery of tests patients had to pass in order to be accepted into a transplant program and be officially put on

the UNOS waiting list. "They do every test in the book, just about," commented Lori Hughes. The medical team analyzed the condition of the patient's lungs with x-rays, a ventilation-perfusion lung scan, pulmonary function breathing tests, a chest CT scan, and sometimes a six-minute walk. The transplant team looked for other life-threatening diseases (such as cancer, AIDS, or tuberculosis) that would render the transplant impractical, and wanted to uncover viruses or bacteria the candidate had been exposed to in order to plan their pre- and post-transplant care. To confirm that the patient's other organs were functioning well enough to withstand the transplant, they performed a heart catheterization, electrocardiogram, echocardiogram, and abdominal ultrasound and they analyzed blood, urine, stool, and skin samples. Women got a pap smear, and men a prostate exam, and everyone underwent a thorough exam of their sinuses, eyes, and teeth. If the evaluation was done while the patient was checked into the hospital, it could take anywhere from three to five packed days; to do everything outpatient, it could take anywhere from three weeks to a couple of months.[33] Many people were so overwhelmed by the array of things done to them that it all became a blur. "I remember the evaluation as being really bad, so I think I've blocked out some specifics," laughed Tiffany Vuncannon. But she did say the evaluation was "probably one of the worst things" about getting a transplant. Although Paula Huffman found the process interesting and "sort of fun," more typically patients described the evaluation as "tiring," "strenuous," "rigorous," "invasive," and "grueling."[34]

Sometimes a few things stood out during the process. Even veterans of medical treatment were surprised by the amount of blood taken. "Tons and tons of blood work," noted Lynn, and then "more blood tests . . . and more blood tests." For Pauline DeLuca, though, it was the heart catheterization that was memorable.

> It's when they go in your groin and they feed a tube up through your arteries into your heart, and they take pictures of your heart and they look around. You're laying on a table and you're afraid to move, because one flinch and it's all over. It actually feels like there is a bug in your heart when it gets there. It's painful, yet more than the pain was the fact that I was terrified, I think, and I was just so ill. It made me sick. They clamp your leg with this huge clamp; I was bruised so bad. It couldn't have been over 20 minutes, but to me it was two years lying on the table. I was absolutely terrified . . . If they ever try to do it to you, my only suggestion is to run.

Charles Tolchin didn't like the bone density scan, for which he had to lie perfectly still for an hour, trying not to cough.[35] For others, it was the psychological test that stood out. Transplant centers rarely rejected people solely on the basis of psychological factors, but they did want to make sure a candidate did not

have serious mental illness and did have sufficient psychological resources to handle the transplant. Laura Scott Ferris found her psychiatric evaluation, which involved memorization and computational tasks, to be "stupid" and "irrelevant." She had been expecting to be asked about the "real issue" of dying. Sharolyn Converse understood the point in being asked questions that got at whether she was going to have sufficient support to undergo a transplant, but "I can remember just sort of feeling that your whole life was picked clean. To me it was like you were imagining a social worker coming to visit your house to check out if it was a suitable environment."[36]

Understandably, candidate Frank Avila asserted the evaluation process was "physically and emotionally draining." Frequently it served as a confirmation of one's poor health. "It made me realize how sick I was," reported Bob Festle. "There were a lot of tests that I should be able to do and it was really difficult to do. So that was tough." For Kathleen Feeney, the pulmonary function tests "showed that my function was low enough, easily, to qualify for transplant. That was a shocker. Because I really didn't think that I was." Mary Peters's test results yielded especially bad news.

> The most disturbing was at the time my $FEV\text{-}_1$ was only 16 percent of predicted. $FEV\text{-}_1$ is how much air you can force out of your lungs in the first second that you start blowing out. Sixteen percent is a very low number and statistically what they said was that that put me in a category of people who were going to die before they got lungs.[37]

The evaluation also forced people to face exactly what a transplant would entail. Patients met with the transplant team and were told a great deal information about the length of the waiting period, the surgery, the recovery process, the post-transplant drug and testing regimen, the risks of living with one's immune system suppressed, and life expectancy. The medical team stressed the concept that undergoing a transplant meant trading an incurable disease for a whole different set of medical problems. While people couldn't always take in all the details of what they were told in these meetings, they usually remembered the big ideas and the tone of the conversation. Mary Peters remembered that they said she didn't have good odds for surviving the likely 12- to 18-month wait and they were "not painting a very good picture" about what life would be like after transplant.[38] Pauline DeLuca recalled that her transplant team emphasized, " 'This is a serious thing, and you got to really take it seriously.' [The surgeon] was very, almost negative, [stressing,] 'There's going to be hard work, blah, blah, blah.' And I thought, 'My expectations are realistic here; I don't think it's going to be a cake walk.' Everybody else was pretty much nice, but the surgeon was mean."[39] Kathleen Feeney's surgeon was quite blunt, but she didn't find him mean.

> He and I clicked big-time. I liked him particularly because he didn't pull any punches. He said, "Okay, here's the situation. This could happen and this could happen and you could die. This could happen, this could happen, and you could be really sick. This could happen, this could happen, and you could still be on oxygen. The best case is this, this, and this, and you're off leading a happy life." He said, "We like people to know it's not automatically a given that you'll come out of this fine. You could die on the table. You could die waiting for the transplant. You could die after the transplant. You could have four years then, boom! It's just a matter of giving you the best opportunity to live a longer life but with a quality of life."

Although she appreciated his honesty, it still was difficult for Feeney to hear.

> It wasn't really telling me anything that I didn't know, but it made it very real. I was crying. I broke down and cried and Kirk [my husband] got a little teary. It was very, very overwhelming, it really was. I tend to be the kind of person that when I go through a lot of stuff, I'll talk to people about it afterwards. I didn't talk to people about the transplant evaluation for about a month. It took me that long to process it enough to even be able to talk about it with my closest friends without breaking down into tears every time I did.[40]

The other frightening aspect to the evaluation process was, as Frank Avila put it, "You're not sure if you're going to get accepted." Many problems could result in someone being rejected by the transplant program. Not knowing exactly which things might get them blackballed caused anxiety. Charles Tolchin was afraid of "antagonizing the transplant team," and warned his parents to "do everything the team wanted." Sharolyn Converse worried about her osteoporosis. Dana Schmidt had heard rumors that her chances weren't good because she had been on a respirator and had an ulcer.[41] Such worries were understandable, especially given that so much was out of their control. If their bodies had developed debilitating lung disease, who knew what other problems might be uncovered? Then there was another possibility: that the center would say the time was not right. "I was so afraid I'd be too healthy to get on the list," reported Mary Peters, "and I was also afraid I'd be too sick to get on the list." After days of testing, some people got the news that more tests were necessary, which increased their anxiety. Although she had never smoked, Ruth Donahue learned that one of urine tests indicated the presence of nicotine, which meant she had to be tested twice more. Bad news meant Bill Macina's evaluation, which was supposed to be a three-day process, ended up taking six. His wife recalled, "I never felt so scared in my life."[42]

The results of the evaluation usually came after a few weeks. For some, it was the bad news they feared. Don Hawkins was told his disease had not yet progressed far enough for transplantation. Harold Blaise was turned down by

three separate transplant programs because of physical problems unrelated to his lungs. Randall Benifield, who had a history of serious heart problems, pursued transplant unsuccessfully for seven years. Laura Richards was bitter about the reasoning used by two places for rejecting her.

> They looked at my past and said, "We can't take a chance, giving you somebody's lung, [when] you may not take care of yourself." So they denied me. I had some emotional problems and . . . they looked at it as I wouldn't take care of myself. I felt as though they were playing God. You know, they were telling me that I wasn't worthy of living, because I had some problems in my past.[43]

Mary Peters, who got the good news that she'd been accepted, used the same phrase as Richards in describing the difficulty of transplant team's job. "The difficulty with transplants is there aren't enough [lungs] to go around. So the doctors and nurses are forced into the position of playing God. They have to decide who should get it, and what they do is they try to choose people who would most be likely to survive and to use the organ."[44] By the mid-1990s, transplant centers had come a long way from the earliest days of lung transplantation, when individual surgeons made the decisions about which few patients would receive organs and could use whatever criteria they wished. Although transplant centers still had autonomy and there were still judgment calls to be made about which people they were willing to accept (such as whether to transplant those on a ventilator or harboring certain infections), as the lung transplant field and UNOS evolved, more consensus developed about who were "good candidates." Still, some centers tolerated greater risks. This meant that although the news that they had been rejected was devastating, Hawkins, Blaise, Richards, and Benifield could apply elsewhere. Those four eventually were accepted somewhere, though not everyone was.

Some people got the news that they weren't rejected, but neither had they been accepted. Richard Throlson had to lose about 20 pounds, improve his liver functions, and be weaned from a blood thinner that made surgery too dangerous. After dealing with these issues for about nine months, he was officially accepted. Russ Adair had the opposite weight problem; he needed to gain at least 20 pounds before he could be listed, so he "ate milkshakes, ice cream, and four dozen chocolate chip cookies every week." Some people who were underweight had to take less enjoyable measures, such as ingesting nutrients through a tube surgically inserted directly into their stomachs. One test suggested Laura Scott Ferris had kidney damage that would make a lung transplant impossible. She hung up the phone feeling "completely and utterly defeated. I felt as if the last nail had been driven into my casket . . . " Ironically, this news ended any ambivalence Ferris had been feeling about transplantation. "I hadn't realized just how deeply I wanted to cling to life until I had my best chance denied." Fortunately, subsequent testing

showed the kidney problem to be minor, and her center put her on the waiting list for transplant. "Another reprieve," she noted.[45]

Not surprisingly, the news that they were accepted into a program pleased people who were now considered transplant "candidates." "I was LISTED!!!" exclaimed Ruth Donahue, who had found the entire process to be a long and grueling ordeal. "Thank God! I was so relieved that I finally KNEW what was going on. It was the indecision and not knowing that was slowly doing me in, mentally." Karen Couture had endured frustrating delays and other complications before finally finding a hospital with a waiting list short enough so that she might survive until an organ came available. After she finished the evaluation, she discussed the results with the program director. "At that point it wasn't official, but it was pretty close to official," she recalled. "I just remember the relief we felt when we left the office. Standing in front of the elevator, me and my dad both broke down and cried."[46]

* * *

Being considered for a lung transplant meant a person had end-stage lung disease and had to face the fact that death was imminent, which was usually quite difficult. At the same time, however, being evaluated meant the person was fortunate enough to live in a time when lung transplantation was an option for some people with end-stage lung diseases. Being accepted into a transplant program also meant they had some things in their favor, such as being sufficiently healthy in the rest of their body, having sufficient resources (such as insurance), and having the necessary psychological characteristics to make a transplant program decide they were good candidates to undergo the potentially life-saving procedure. Still, those who were accepted could not know whether they had good timing—whether they were being offered this option too early or too late. Much was out of their control. Some had found just making the decision to be stressful, while for others there barely seemed to be a choice. For most, the evaluation process proved grueling and eye-opening, but it marked the first stage in an opportunity for a second chance and thus provided a glimmer of hope. Such hope would prove necessary to surviving the difficult waiting period that lay ahead.

CHAPTER 4

Waiting and Coping

> I was scared, in all honesty. The unknown was scary and the waiting was not fun.[1]
>
> —Howell Graham

After being accepted into a lung transplant program for end-stage alpha-$_1$antitrypsin deficiency, May Parker struggled with shortness of breath, a near-death experience, and her lung capacity dropping to 11 percent. Her family was distressed, too—her husband afraid of losing his wife and her daughter shaken by seeing her father cry. They all felt anxious about the fact that life could change in an instant if she got called for a transplant. "Every time the phone rang, I jumped six feet," remembered May. More quickly than they expected, May got an exciting 3:00 a.m. phone call from a transplant coordinator telling her they had donor lungs available for her and she should get to the hospital (five hours away) as fast as possible. Before she arrived, however, she learned the transplant would not take place, which was very disappointing. After this "false alarm," May was told to move closer to the hospital so she could get there sooner when called and so she could attend a three-week pre-transplant exercise and preparation program. May's husband couldn't go with her because he needed to work to provide her with health insurance, and May's mother was too ill, so her daughter Charla volunteered to drop out of college and accompany her. Since the family was very close, the separation was hard. And even though mother and daughter were like "best friends," this arrangement was not always easy. "We're living in this *small* apartment, and we're going to get on each other's nerves quite a bit," admitted Charla. "In the end we still love each other and everything's fine, but we go through these situations where it's just like, "God, just go away."[2]

During the wait the Parkers had to deal with stress, uncertainty, anxiety, declining health, and battles with their insurance company; and they coped in part by relying on new friends they made through the lung transplant program. At first, May found her pre-transplant program daunting, she recalled. "I thought I was going to die the first week, I really did. I told my daughter, 'I can't do this.' " Soon, though, May came to appreciate the exercises, information, and most importantly, the other people in the program. Charla described the other participants as "our family over here, our home away from home. We tell them our problems and it's just real tight. That's our support, that's why we really really like it here." Besides providing her with support, meeting people with different and very severe lung diseases gave May new perspective. Before that, she said, "I felt really bad for myself, but now I don't anymore. I'm just happy I have this chance." Although May readily admitted that the waiting period was scary, she believed she and others could adapt to it.

> Everybody is going to feel sorry for themselves because that's only normal. Sometimes you have to vent by feeling sorry for yourself. But then you just have to pick yourself up and dust yourself off and start all over again. It's like being on a diet—you've got to have that cheesecake once in a while [laughs], but then you go back and you do it all over again. You just can't give up. I think that where there is life, there is hope.

Like May Parker, those accepted into a lung transplant program discovered that life on the waiting list could be hard. In terms of experiencing physical decline and emotional strains from facing death, their difficulties were similar to those faced by anyone with a life-threatening illness. In some key ways, however, lung transplant candidates were different. Typically when someone is diagnosed with a serious disease, their physicians begin administering available treatments (such as surgery, chemotherapy, or radiation) right away, but because almost all lung transplants required lungs from deceased donors and because there were not enough donor lungs, lung transplant candidates usually had to endure a long wait for the treatment itself—and not know when or if it might become available. The fact that lung transplantation could not be scheduled in advance impacted candidates in many significant ways. In addition, like Parker, they frequently endured "false alarms" and had to relocate and be separated from their usual support system. These conditions meant candidates experienced a host of feelings ranging from hope and excitement to fear and frustration over their powerlessness. For Frank Avila, this aspect of the wait was more difficult than the physical challenges. "There is a lot of emotions that are involved. Are you ready? What's going to happen afterwards? What's going to happen? Is it going to happen at all? There is all those questions of, 'What if…? When? What? Why?' I think that's the hardest part."[3] Although no two candidates had exactly the same experiences waiting,

they all faced uncertainty; not everyone had the same positive attitude as May Parker, but they typically adopted one or more of a predictable set of strategies to cope with their unusual and stressful circumstances.

The Experience of Waiting

When they were accepted into a lung transplant program, candidates came to understand that the remainder of their lives would be characterized by uncertainty. Continued survival would depend upon major surgery, which came with risks, and a transplant's success would depend partly on the quality of the donated lungs and how the recipient's body reacted to them, which were impossible to know in advance. Their lifespan after the surgery would be limited, but the length was unpredictable. In 1999, about 87 percent survived at least three months after the surgery, 76 percent at least one year, 59 percent three years, and 47 percent five years. Nor was there a guarantee that donor lungs would become available at all, and if they did, when. Often doctors told candidates that their wait could be a year or two, but the average waiting time varied from year to year and increased through the late 1990s and early 2000s. In 1998 it was 1,105 days (about three years).[4] Regardless, for a particular individual, the arrival of donor lungs would come with no warning. In the 1990s, UNOS determined priority on the waiting list by the length of time a person had been officially waiting; within the group of those who "matched" a donor lung, the longer a person had waited, the closer one was to the top. That meant an individual person's chance depended on a lung becoming available in a comparable size and blood type—and on how many patients in the same region were ahead on the list with those same characteristics.[5] Having a rare blood type or size could be a blessing or curse; there would not be many donor organs, but there also might not be many others ahead of them with the same needs. The opposite held true for patients with more common blood types. Thus most of the factors affecting one's chances were things entirely out of the control of candidates and their physicians. The worst part of the whole transplant process, according to Ruth Hall, was

> not knowing when it is going to happen. I used to refer to it like having a baby. [With] the baby, you do know when it's coming: nine months later. This you don't know if it's coming in two months, eighteen months, or two years later. The not knowing part is what gets you.[6]

People with any life-threatening disease worry about whether or not their treatment will work; the subtle difference for transplant candidates was wondering whether they would get the treatment at all. They recognized the grim reality that some transplant candidates did not survive long enough to receive an organ.

In the year 2000, 922 of the approximately 5,000 people on the waiting list received a lung transplant, but over 500 died.[7] "Patients waiting for a transplant are under so much stress and anxiety," acknowledged a member of one transplant team. "They worry about when the call will come or whether they'll survive the operation."[8] Karen Couture worried more about whether she would get the operation at all.

> My pulmonologist, what he had done is he waited until he thought I had a year and half left to live because that's what he thought the waiting list was like. The thing is, though, the waiting list is growing all the time, and it really was more like a three-year wait on average.

For Jimmy Carroll, the fear increased when he had to be hospitalized.

> I was worried. I was getting sicker and sicker, and getting sick more often, and so I was just coming to grips with the fact that this really is going to have to happen, and that it's a major thing, and that I might not survive, and that even if I do survive, it's going to be horrible. So I was having a lot of trouble sleeping.[9]

As Carroll suggested, the uncertainty of waiting could combine with lung disease to precipitate problems with anxiety. Physician James Blumenthal explained, "Often, when a lung patient is short of breath, he or she becomes anxious or agitated, which can then cause them to breathe faster and shallower. It can then quickly become a vicious cycle." Pauline DeLuca described the phenomenon. "I couldn't breathe, so I'd get anxiety attacks, which are horrible. Your heart's racing and your whole chest feels like it's numb. It's terrible." This did not happen to everyone. One study of lung transplant candidates showed that only about one-fifth had levels of anxiety higher than the average population, which the authors thought remarkable given their situation. The fear could come and go, according to Jimmy Carroll. "I remember telling people that probably 80 percent of the time I was actually really looking forward to [the transplant], 15 percent of the time I was kind of dreading it, and 5 percent of the time I was downright scared. I thought those percentages were pretty good."[10]

Hoping to be strategic about timing, some doctors encouraged their patients to go on the waiting list as soon as they met the minimum criteria for transplantation. These candidates accrued time that gradually moved them higher on the list, but their status was "inactive," meaning that if a donor lung came available, they would not take it. This status worked well for people who wanted to get as much "mileage" as they could out of their native lungs. Brett Pearce, who hoped to finish his senior year of college but had already once been on the brink of death, viewed inactive status as a sort of insurance policy. Things did not always work as hoped, however.[11] When Tiffany Vuncannon was originally put

on the list, her physicians thought she probably would not need the transplant for at least eighteen months. Surprisingly, Vuncannon was offered donor lungs shortly after being listed (because she had a rare blood type). She and her surgeon turned them down and the lungs went to someone else. But within six months, Vuncannon suddenly found herself hooked to a ventilator with about 48 hours to live.

> They finally took my parents aside and said, 'If she doesn't get a transplant, she will die.' The irony was that I had just a short time before been doing so well we had turned down lungs. Now, we got down to the point where it was just watching the clock, under the gun at deadline to see if another pair were going to come in in time.

Lori Holbert had also been inactive when her right lung collapsed, so her doctors changed her status to active. Hospitalized for three months, she prayed for "perfect lungs at the perfect time." Unfortunately, a whole host of problems meant she had to be taken off the active list because she had become too weak to survive transplant surgery.[12]

Physical deterioration inevitably occurred during the waiting period, which naturally caused stress. In particular, becoming dependent on others could cause frustration. "I never liked asking for help," admitted Frank Avila, "and all of a sudden it's like, 'Okay, now I need to ask for help. I need for somebody to be able to drive me around or be able to do the laundry or do the grocery and stuff like that.' "[13] Such assistance could undermine one's identity, as Tiffany Vuncannon observed.

> I had just established my independence and now I'm having to go back and live with my mother again. She's having to tie my shoes and help me dress and I'm 23 years old. This was having to make compromises in my adulthood when my adulthood was not that firmly established yet to begin with. It was a very trying time.[14]

Randy Sims was in his early thirties, but it was no easier for him. While waiting, he separated from his wife, quit work, sold his house, and had to move back with his parents. That, he said, "was never the plan." Mary Peters was still pushing herself to go to work every day, but that meant she had to spend almost every other waking hour trying to stay well with therapy.

> When I got on the list I was still working and I was still spending six to eight hours clearing my lungs and I was living by myself at the time. It was so difficult. I just felt starved to talk to people—you know, to get a hug, to see them. I thought I was losing my grip on reality whenever I was living alone then. Eventually, I couldn't . . . I needed assistance.

Until his illness, Joe Driskill had never considered himself weak.

> This macho retired military colonel of 29 years service, who had even played four years of college football . . . could not even stand up long enough to manly use the bathroom. Seriously, from a weight of 185 pounds, I was down to 124. My FEV1 was 9% of what was expected. Even though I was on three liters of oxygen, [my wife] had to physically help me in the bathtub and manhandle me out. My life was miserable, and worse, I knew I was making the life of my sweet wife of 40 years even more miserable. I was totally dependent on her.[15]

Though difficult, such misery and decline were normal for someone who was dying. What was different for people on the waiting list was that they feared their decline would rule out the possibility of receiving their treatment. Melodie Greene suffered a stroke after a heart procedure, and when she awoke, "My first thought was, 'They're going to take me off the list.' " Although studies showed that some patients, especially those with cystic fibrosis (CF), had weathered so many bad spells that they overestimated how long they could survive, most candidates realized when they were nearing the end.[16]

Deterioration could lead to depression. College-aged Laura Rothenberg found the waiting almost intolerable. "Life as I knew it has died, in that I have no control. Everything has become about the wait, it has taken me over." Describing herself as "quite depressed," she could not fathom waiting another month. Dana Schmidt had become horribly weak. "I can't say how depressing it was because six months previous to this I was planning a wedding, going to work full-time, and now I am literally bound to the bed. It was pretty bad." After 11 months waiting, Laura Scott Ferris said that she had "grown morbid," and cried, "I can't do it anymore." As a result of the despair in her voice, Ferris' physician moved her to a "hospice-like" facility. A declining Shirley Jewett wrote in her diary, "I'm depressed and scared. I have the feeling of impending doom all the time now and feel extremely weak."[17] One study showed that while the overall mental health of lung transplant candidates was comparable to a random sample of healthy people, the candidates waiting had much higher levels of depression. Another study found 39 percent of the candidates polled were mildly to moderately depressed, 7 percent moderately to severely depressed, and 2 percent extremely depressed. Still, the authors pointed out, the majority of candidates did not suffer from depression and some were able to get relief from counseling or medication.[18]

While the waiting period could be depressing, it also contained hope due to the possibility that their lives could take a dramatic turn with only a moment's notice. Since fragile donor lungs had to be inserted quickly and it was crucial that lung candidates near the top of the list could be contacted any time of the day or night and immediately go to the hospital, transplant programs issued a pager (or "beeper") to candidates. (In the 1990s, cell phones were rare so a pager

was the solution.) Usually if a donor lung came available, a center would first try to telephone the candidate's home, and then try the pager. Once he was put on the list, Randy Sims noted, "The telephone ringing had really taken on a whole new meaning for me… Every time it would ring, it gave me a unique feeling, a feeling of excitement combined with a 'knot in my stomach.' " Similarly, Laura Scott Ferris recalled, "I would often hold the pager in my hand and look at it. I found it exhilarating and frightening at the same time."[19] People with other types of end-stage disease could usually tell if their treatments were not working and realize that there was no more hope, but for those on a transplant waiting list, the pager represented the chance for a death-bed rescue.

False Alarms

"False alarms" were stressful experiences that while not familiar to people with other kinds of terminal diseases, were fairly common for people waiting for a lung transplant. In a false alarm, a candidate was told to hurry to the hospital, but then the surgery was called off, usually because the donor lungs were found to have problems. Invariably getting the first phone call evoked strong feelings. "I was just totally fired up," remembered Jimmy Carroll. Laura Richards recalled, "It was hard to get my breath because [I was] so excited and nervous."[20] But before she could even leave the house, Dare Reitz learned that her potential donor lungs were too damaged to be used. Others made it all the way to the hospital and like Pauline DeLuca, were admitted and prepped before the operation was called off. "They get you psyched up to come in; they do the blood work; they do the x-rays; they do all this pre-op stuff so you're getting ready to go to surgery," DeLuca reported, "and then they say, 'Never mind. It didn't work out.' "[21]

A few candidates found a silver lining in the experience. Richard Throlson said he had been feeling "reluctant" and was "still a little worried" about a possible transplant, and consequently he actually "*wanted* one dry run." Using language like "dry run" indicated an attitude encouraged by some transplant programs that the experience was more like a practice run than a failed attempt. Indeed, Carol White said that after she learned her call was a false alarm, she felt relieved "in a way" because it helped her understand what the real thing would be like. Although disappointed, Frank Avila admitted feeling some relief as well, "because you never know if you're going to come back out of the surgery… " After hearing the team's reasons for rejecting the donor lungs, Bob Festle concluded, "Well, I'll wait until I get the best set I can get." Carol White similarly looked on the bright side, thinking, at least "I know I'm at the top of the list if I have already had a dry run."[22]

For most people, though, false alarms were very disappointing and upsetting. When the coordinator told Charles McNeill that the donor lungs were no

good, he was "stunned" and "wanted to cry." It felt like wasted effort for people like M. L. Bryan, who had traveled 220 miles. Mary Peters was shaken by her experience. "I had gone through this whole adrenaline rush that day and nothing came out of it…And it really made me question the whole thing. Did I really want to do this?"[23] Pauline DeLuca said the false alarm was "really devastating," and that she found herself thinking, "God, I need them so bad. What are the odds that I'll have another chance? This was probably my one chance." While false alarms were difficult for almost everyone, they tended to be worse for those who went through the experience multiple times, like Laura Richards who had five and Frank Spears who had ten. Tom Fereday grew more distressed with each incident.

> I think the first one I really wasn't ready. The second one was kind of like the first one, an inconvenience: "Okay, I gotta go back." The third one was like, "Okay, let's do it. I don't have much time." [At that time] they only gave me a month [to live]. I just slept 18 hours a day, and most of the time I couldn't walk 20 feet. It was bad…I didn't think I'd get another call, realistically.[24]

The strain of waiting could be exacerbated because candidates frequently had moved away from home to be closer to their transplant center. Finding somewhere to live in a new place for an unpredictable amount of time could be stressful, and it could be difficult financially since the expenses were not covered by insurance. Laura Richards's transplant team had predicted she would need to move for about 6 months, so with the help of a fundraiser, she thought she had sufficient resources for the wait, but when it stretched to 13 months, her funds were running out. She had to haggle with Ohio Medicaid and Social Security, and her parents refinanced their house. After 18 months, Daniel Ensign's transplant center stopped accepting his insurance, and as a result he had to repeat a whole series of tests, play "phone tag" for four and a half months with the company and center, and appeal to his senator for help. Not surprisingly, one study confirmed that lung transplant candidates reported feeling a moderate sense of financial pressure.[25]

Being uprooted could be difficult in a social and emotional sense too. Teenager Kimberly Pearce recalled how she felt about being in a new place.

> We were just very scared. The only thing you ever saw was a hospital and the apartment complex. And then University Mall was the only mall, and there were just like two or three stores there you'd even want to go in. And we thought we couldn't even go into town or anything…We didn't know anyone.

At a time when they were weak and anxious, transplant candidates were separated from their usual support system. The separation from his loved ones bothered

Randall Benifield most around the holidays, including the first time he couldn't spend Christmas with his family. The unpredictability of the length of time posed issues, too. Teenager Charles McNeill recalled, "I expected to be there a few months, get transplanted, and come home. No problem, I could handle that." When the wait turned into nine months, McNeill realized, "Boy was I wrong!"[26] Making the move posed a special problem for Kathy Vanderford, whose transplant team required her to have a support person with her. "I had no one—my husband had to stay at work to keep our health insurance coverage, my son was too young, and there were no other family or friends who could come with me. I didn't know what to do." Eventually, a family took Vanderford in, and while she was very grateful for their kindness, she still missed home enormously. "The [host] children and friends entertained me by day, and I talked with [my husband and child] each night. Bedtime was the loneliest and most frightening part of my day. I just wanted to be home with my family!"[27]

Even those lucky enough to have a very capable support person with them felt the strain. Tim Choquette's wife moved along with him, but her job required 12-hour shifts. "So I was kind of alone, and of course I was struggling [physically], so it was pretty rough." Laura Richards noted another difficulty of being "transplanted" to a new place: "It's lonely." Waiting could tax both candidates and their caretakers. Laura Richards observed of her mother, who relocated with her, "She's the one who has to put up with my moods and my frustrations. She's the one that watches me get sicker. She's gotten grayer." Tiffany Vuncannon described another problem:

> I had a 550-square-foot, one-bedroom apartment and my mom was staying with me. Each of us didn't have our own space. It was difficult . . . We each are people who like our own little "me time," time to ourselves to go off and read or whatever. That wasn't real possible in such a tiny apartment.[28]

After her transplant, Cheryl Maxham's husband told her, "You know, Cheryl, you weren't exactly the nicest person in the world when you were sick and dying." Twenty-six-year old Laura Scott Ferris did not have to move and had the benefit of a loving fiancé and mother, but she found the waiting "unbearable." She recalled that she and her fiancé quarreled over silly things.

> I was quick to find fault and quick to anger. Kent always took the brunt of my anger. Inevitably, I would hate myself for treating him badly. I wasn't mad at him. I was mad at being short of breath all the time. I was angry that I could no longer walk a short distance. I was tired of oxygen tubing. I felt like a dog on a leash . . . I was getting so tired of hanging on. I was running out of time. Everything rested on waiting for that pager to beep. Just beep, dammit!"[29]

During the waiting period some lung transplant candidates also struggled with guilt. Many felt bad about their loved ones' sacrifices.[30] Laura Richards fretted about her 77-year-old father who had to live alone while her mother relocated to care for her, and Steven Bunsen worried about his children after his wife decided to accompany him for the wait. Judy Ryan felt pangs of conscience for a different reason. "The guilt that I felt, which most people with emphysema feel is: you did it to yourself."[31] While anyone seriously ill might feel guilt over the impact their disease had on their loved ones, lung transplant candidates felt guilty for an additional reason: the source of the organ required for their treatment. "You think about that it will be better for you if you make it through and [if] you get your lungs, [then] that it will be a better life," said Lori Hughes. "But then there is another part that says, 'Well gosh, if I pray for me to get my lungs, you sort of feel like you are praying for somebody else to die.' " Randy Sims felt the same way. "It was very hard for me to come to grips with the whole idea of what would be happening to someone else in order for my life to continue. During my wait on the transplant list, I had a lot of time on my hands, and spent a lot of time thinking about things like this. It was pretty overwhelming."[32]

Thus transplant candidates experienced many different feelings during the wait—anxiety, fear, loneliness, anger, hope, excitement, disappointment, depression, and guilt—and the feelings could vary over time. One study suggested they might feel more anxious and depressed the longer they waited.[33] Harold Blaise found this to be true, but also pointed out that his feelings varied from day to day.

> It's been a rough nine months now and it doesn't bother me too much during the week when I'm occupied, but it bothers me on the weekend. I kind of sit and think, "Well, the phone hasn't rung and we've just been through another week. Here's the weekend and we've got another week coming up and I haven't been called yet." I think the longer you wait, the more stressful it's going to get.[34]

Melody Masha Pierson saw no pattern in how she felt during the wait. "There is no linear or chronological order . . . I go through any combination of feelings and have all kinds of thoughts at any given time." Mary Peters also experienced peaks and valleys. "There were periods that were hard and then there were periods that had a little bit of sanity to them." Ups and downs were characteristic of the schizophrenic nature of the waiting period itself; it was equally possible that the candidates might die or might be given a new lease on life. Cheryl Maxham captured the way she felt about the contradictory dual alternatives. "As sick as I was, one part of me knew I was dying, but there was another part of me that knew I wasn't going to die. It was like two different people, one saying, 'Yeah, you're sick, you're going to die.' And the other side of me kept saying, 'Something is going to come up, you're not going to die.' "[35]

How Candidates Coped: Relying upon Loved Ones and Community

Lung transplant candidates coped with the challenges of the waiting period in a variety of ways. Like people dealing with any traumatic experience, their most common strategy was relying on loved ones, whether those were family members, spouses or life partners, or dear friends. Jack Snyder counted on his wife of 38 years, who quit her job when he relocated, and "stayed right at my side. She exercised with me on the floor, on the walk thing, everything, right through it." Rosalie Gallogly also cited her spouse.

> Every time I got down, he would be there to tell me if I was being foolish, tell me to get back in gear. He never would look at the bad points. I'm 5' 8" and I got down to 90 pounds [and] he still would tell me I was beautiful. He would still, the whole time, keep everything up and tell me that I would make it.[36]

Middle-aged Barbara Stepp noted that in dealing with her transplant, her mother was "the greatest support person I have," as was the case for Laura Richards. After a very long wait, Richards was ready to give up. "I was very close to dying and I just wanted to go home. If I was going to die, I wanted to be with my family . . . [But] my mom asked me to please just try to hold on a couple more weeks, and so I did. And within those two weeks I got called." Researchers observed that in the early part of the waiting period, transplant candidates depended on their loved ones primarily for emotional support, but over time, their needs shifted to more practical and physical ones. This happened for Kelly Helms, a married 27-year-old with a career and home, who became as dependent as an infant. "[My mom] was having to comb my hair, bathe me, feed me, wipe my butt, I mean everything! I couldn't do anything for myself. That's how weak I was . . . Thank God I had such a great mom that was like a rock."[37]

Some candidates realized how extraordinary this assistance was. Joanne Schum, who underwent a transplant and later had a sister on the waiting list, reflected that it was almost harder to be a support person than a patient. "Dealing with my own death was much easier. It's like, 'Okay, I'll be dead. What do I have to worry about?' It's not fun being [a] support person." Many candidates were not surprised when members of their family of origin came through for them, but the actions of a spouse, boyfriend, or girlfriend might be more unexpected. "Throughout my entire life every woman that I was ever involved with (with the exception of two) had left me when I got sick," wrote Scott Jemison. Supplementing the super-dedicated loved ones who assumed the daily caretaking were others who offered more intermittent but still crucial assistance in the form of a supportive presence. Tiffany Christensen noted, "Anyone who sits with a person in a time like this one, a time of incredible discomfort, is a hero in my eyes."[38]

In a noteworthy coping strategy, candidates frequently sought the support of other transplant candidates and recipients who formed a lung transplant community. This community stretched across the nation, aided by the energetic efforts of its participants and the timely growth of the Internet. Volunteers formed the Second Wind Lung Transplant Association in 1995 with the mission "To improve the quality of life for lung transplant recipients, lung surgery candidates, people with related pulmonary concerns and their families, by providing support, love, advocacy, education, information and guidance through a spirit of service, adding years to their lives and life to their years."[39] The organization's website posted stories of people who had undergone transplantation and facilitated communication through listservs, message boards, chat rooms, and a directory of members. Many of the founders were recipients who remembered their own struggles while waiting and were happy to email or talk with others who were waiting. Dare Reitz said the organization helped her considerably.

> You need that kind of support. It's a different kind of support than with family. Family's always there to support me, but when you have the support of somebody else that is going through the same thing that you are, someone who can relate to you, that makes it a lot easier. You are dealing [with] and complaining about the same things all the time.

Sharolyn Converse agreed that the ability to empathize made for a distinctive and "wonderful" kind of assistance. "People who are on the transplant list really need to get the support of the other people who are on the transplant list, or at least other people with lung disease," she asserted, "because it's very hard to understand what it feels like when even the smallest incline becomes a nightmare." Besides experiences and feelings, lung transplant community members shared common language. "We talk PFT-talk a lot," said one member, referring to pulmonary function tests.[40] For people who were weak and homebound, Internet support groups, whether for transplant or a specific lung disease, could be especially helpful. Carol White recalled, "I sat right here all day, every day on that computer . . . because I had nothing else to do, I guess. But I was on it from morning until night, until bedtime." Karen Couture agreed that it was "really helpful" to find an Internet support group since her life changes, such as using a wheelchair and oxygen, were so different from her local friends, who were getting married and having children. "It seemed like the only people that understood were people who had been through something like this."[41] Cheryl Keeler took the organization up on its offer of a mentor to whom she could ask questions she felt silly asking her doctor. "She was a God's send to me because I was able to ask all of my questions in the privacy of our emails. I didn't feel stupid, ungrateful, foolish or uncomfortable. I simply felt accepted, encouraged, and not alone facing the challenges that were ahead of me" M. L. Bryan felt grateful that he didn't

need physical proximity to learn about lung transplantation. He explained, "I have names of people I'd never met that I called and talked to them about it." Dana Schmidt concluded, "I just found a lot of comfort in that website."[42]

In addition to the national online community, there were local lung transplant communities that formed through patients' connections to particular transplant centers. Physical proximity was not sufficient to create community, however; those individuals could just as easily remained separate from one another, strangers who never interacted. Instead, building upon the lessons Toronto General learned with Tom Hall and the early lung transplant recipients, many lung transplant centers hosted support groups for their candidates.

Support groups could be formal or informal. Some transplant centers sponsored groups that met regularly and were run by a social worker or psychologist to provide an opportunity for candidates to share their feelings. Harold Blaise said the facilitator of his group had "a way of opening people up and getting them to talk and it brings out a lot of things that people wouldn't normally discuss." Some groups were more informational in nature, featuring speakers such as a surgeon, coordinator, or a pharmacist who clarified different aspects of the process. Lung recipients frequently served as the featured speakers, answering questions from the waiting candidates, which Pauline DeLuca appreciated.

> That support group was very beneficial because you actually talk with people who have been through it. You could ask them questions, "Was there pain? What about this? What about that? How are you doing on recovery? Did the incision hurt you?" Everybody was very forthcoming with information. Everybody wanted to talk about it, wanted to share, it was great. Support groups are awesome.[43]

For Joanne Schum, the main benefit of the support group was hearing from the recipients who were doing well. "At that point, I was very scared to do [the transplant] still. It was really helpful." The move to the center was also helpful for Steven Bunsen, who had only recently learned of his disease, alpha-$_1$ antitrypsin disorder, and had never met anyone with it. "When we got to St. Louis, I found out then that I wasn't the only one in the same situation, and that helped a bunch. It still wasn't good, but it made it a lot easier." At his hospital, Bunsen reported, many of the waiting candidates lived in the same apartment complex and relationship extended beyond the hospital-sponsored activities. "Every Monday night we would all get together and have kind of a good old bull session." Bunsen said this gathering "was great," except when it conflicted with Monday Night Football when he'd "leave a little early once in a while."[44]

Support groups were not universally enjoyed, however. Although Joanne Schum liked hearing good news about transplant recipients, "when they talk[ed] about their surgery or complications, it was scary to hear, and I think I plugged

my ears a lot . . . At that point, it was not what I wanted to hear about." She was not alone. One study showed that lung candidates differed significantly in the type of information they wanted before transplant. Some welcomed all types of recipient stories and details about every aspect of transplantation, while others feared learning about negative aspects that might undermine their ability to stay positive.[45] For others, formal support groups did not meet their needs. "I kind of went looking . . . for [recipients] to say, 'Yeah, you can do transplant and it's going to turn out fine,' " Bob Festle admitted. "And I didn't hear that. What I heard was that everybody had different experiences." Festle also stayed away because he felt different from the other participants, who in his opinion focused too much of their energy and identity on their transplant. "It's just that they are consumed by what happened to them almost, and that's all that's ever happened to them, whereas I have interests outside of my health . . . I didn't want to *become* my surgery." Another young man with CF had a similar experience. "I don't need this," Brett Pearce told his social worker. He felt the group could be useful for people who did not know much about transplantation or were uprooted from their homes, but not for him as a local college student with a sister who had already been transplanted. "I had my own things to do. I had classes, I had my own friends outside of the transplant group . . . You know, I didn't really need somewhere to go and talk to people." Yet while Pearce rejected the organized support group, he had formed a more casual alliance with some transplant candidates on his own that served the same purpose.

> We exercise together at the same time every day, and we've gotten to know each other. Those of us who are friends, and the therapists that we're friends with, we usually get together every couple weeks, every month, and we'll go out to dinner and a movie all together . . . That's more of a support group; that's more fun. You know, we don't need to get together and discuss what it's going to be like after a transplant, because we've all seen it through some other people. And so, we'll just go and hang out, and just have fun.[46]

As Pearce suggested, pulmonary rehabilitation was another place candidates and recipients formed bonds. Although it came as a surprise to some candidates who were barely capable of daily activities, many centers prescribed exercises intended to help them maintain their lung capacity and strengthen their bodies before surgery, and this became an additional venue for community building. Some centers required a highly structured candidate orientation, such as Duke's four-week program that involved exercises, support groups, and information sessions. "That's 28 days daily from 12:30 to 4:30," explained Barbara Stepp. "Seriously, it was 'boot camp,' and it really and truly helps you." Don Hawkins had the same ambivalence about the program at his center. "I began what I could only describe, and not maliciously, as controlled physical abuse of my body by

cardio-pulmonary rehabilitation therapists. This took place two to three times per week and sometimes it was painful, sometimes it wasn't." Wayne Foster found it exhausting just to be driven an hour each way to get there, to say nothing of doing the exercises. "It was just so hard," he said, "but you know, I enjoyed it too; I enjoyed meeting the people down there."[47]

Candidates appreciated rehab's social and psychological benefits as much as its physical ones. Although he was not required to attend so frequently, Charles McNeil did rehab five days a week because he had met a couple of guys around his age who were also waiting. "We had a lot in common. We became good friends and that made the wait easier." In his program, waiting candidate Frank Spears was assigned to an exercise group that included 12 people post-transplant.

> I got put with them and I call them my "road warriors." I was able to listen to them joke, talk, and laugh, and talk about what had happened to them and what their transplants have meant to them. These were folks who were only two or three weeks out [from their surgeries]. And that alleviated all that terror and all that anxiety, all the fear; it just all went away because I saw that there was life after transplant.

Some, like May Parker's daughter Charla, speculated that community formed quickly in part because many candidates had been uprooted from their usual support system. "Everybody's real close because everybody's away from home and everybody is in need of touch and love." Many characterized the strong attachments as being like family. Of rehab, Barbara Stepp said,

> It's a family kind of situation. You're so close to people that if you're not there or being there on time, somebody is gonna be on that phone, "Well, where are you and what's wrong with you?" And it just makes you feel good…You get to know people and really become close. Some of the relationships I have now with people that are from the center, I am closer to them than I am to some family members.

Recipient Judy Ryan told those on the waiting list that they could count on the continuation of that community: "We are soul mates and we will be forever linked."[48]

Being part of a lung transplant community empowered transplant candidates. Besides social interaction and friendship, it provided education. "I've met a lot of people, but I never realized how many different illnesses there were and how it affects you. It's an eye opener," said Harold Blaise. Dana Schmidt also appreciated the information she got from Second Wind's online community. "You just have to put, 'I have a question,' " she explained, "and you'll have 35-40 people answer you." While some medical professionals worried about

patients getting unreliable information from the Internet, the Second Wind community emphasized that individual situations differed and that nothing substituted for professional advice.[49] Still, candidates appreciated being able to get some information at the moment when a question felt urgent, rather than waiting until their next doctor's appointment, which might be weeks away. Armed with at least some information from an acquaintance, candidates could form better questions to ask their physicians and more fully understand the answers they were given. In fact, community members frequently reinforced the messages from a candidate's medical team. Another thing community members learned was the variety of outcomes that were possible with transplant. Their doctors could say, "Your lung could come tomorrow and it could come a year from now," or "Some people do extremely well and others don't," but knowing real people, one of whom felt great and was back to rehab just days after transplant while the other spent months fighting complications in the intensive care unit, brought home the facts in a personal and powerful way. After a false alarm, a transplant physician could tell a candidate that she still had a chance for a transplant, but it was quite reassuring to talk with a person who remembered just how trying a false alarm was and who actually did get another chance. It was very encouraging to actually know people with the same disease who were still alive seven years after transplant. Thus the very existence of a diverse lung transplant community gave candidates access to more information. "I've looked personally at the full spectrum, the good and the bad," stated David Courtney. "Acknowledging those things, and then also having that camaraderie with my fellow Alpha-$_1$ patients and with transplant recipients, it helps me to not feel quite so overwhelmed with the whole thing."[50] Shirley Jewett expressed appreciation for those who developed websites, writing, "Through those pages, I discovered hope."

Yet belonging to the community was not always easy. Not everyone waiting received a transplant. "The waiting time is very hard," Rosalie Gallogly explained. "You become almost family with the group. A lot of your friends die." Others got transplants and did not do well. Brett Pearce recalled how stunned he felt after a community member who seemed to be doing exceptionally well post-transplant died unexpectedly. Knowing these negative outcomes could exacerbate their own fears and generate additional difficult feelings to cope with. Tracy Raub said that at one point she stopped going to her Second Wind support group, partly because "we were losing a lot of friends. I just felt like . . . I need to separate myself from this because mentally that'll affect you." While it could be depressing to be surrounded by people suffering, it could also lend perspective, as May Parker reported.

> You go in there, and you do see other people, and you think you have it bad. But if you threw all your troubles in a bucket with theirs, you would want to go

> back and take your own because there are some sick people in this world. They can't do what I can do; they envy me. I'm lucky.[51]

The fact that lung transplant candidates and recipients formed a community is remarkable considering the many possible obstacles. Each candidate had his or her own intense struggle, and staying focused on one's own survival certainly would have been understandable. The diversity of the group also could have proven to be an obstacle. Candidates had different diseases which posed distinctive problems and could contribute to different identities.[52] In addition, the group's varying ages easily could have posed a significant barrier. Cystic fibrosis patients tended to be teens or young adults, and emphysema patients tended to be closer to their sixties, and people with pulmonary hypertension and pulmonary fibrosis frequently were in between. Despite these variances, Karen Couture said the Internet support group for lung transplant she found "was really for everybody," and there was clear evidence of sympathy and attachments across generations. Ruth Hall had a significantly younger friend who had a transplant. "She was 20 when she died," she stated, "and it was like a part of me died."[53] Transplant centers attracted people from all over. At Barnes-Jewish hospital in Missouri, for example, there could be farmers from Nebraska and urbanites from St. Louis. These differences, as well as those of religion, race, ethnicity, sex, and ideology were less visible and more easily transcended in the online world.

The greatest potential obstacle to community, however, may have been the fact that lung transplant candidates could have viewed one another as rivals for scarce organs instead of as allies. When she was second on the waiting list in her region, Laura Rothenberg composed a humorous letter (which she never sent) to the person ahead of her on the list, who she called "Number One," saying, "I don't hate you. I'm just envious. I want the next pair and you're in the way. Good luck to you, though. When you get those lungs I'll be Number One, in that glorious position that hundreds wish to fill, and there'll be some Number Two, like me, who is not sure what to do."[54] One interviewee described being called to the hospital as the "backup" in case the person ahead of her on the list had a problem and could not accept the donor lungs. She admitted feeling disappointed when she found out she would not be transplanted that day, especially when she heard "the surgeon said it was the best set of lungs he had ever seen." Still, when she saw the actual recipient being wheeled into surgery, she graciously wished him luck. She recognized that he had been waiting longer than she had and said she was just happy the lungs were able to help someone. This response was consistent with the community's strong emphasis on empathy and mutual support rather than competition. Indeed, Jack Snyder said after his false alarm, "At that time I was almost pleased not to have gotten the lungs because the young lady that got the lungs that night, she needed two of them and they were both good, and she was pretty close to the end." Barbara Stepp said there were times when she wanted to say,

" 'I'll wait and let somebody else go . . . ' There was one particular friend of mine, she was having such a hard time, I wanted to say if I got a call, 'Can you give it to Laura?' " Indeed, when others in their community got the call, candidates spread the word, celebrated, and eagerly awaited news about the outcome.[55]

Spirituality and Taking Action

In addition to relying on loved ones and the lung transplant community, transplant candidates coped by coming to peace with their situation. One of the most common ways many people did this was by relying upon their religious beliefs and practices. Melodie Greene explained,

> There were days that I was afraid, but for the most part I knew that I would be taken care of. My faith was an incredible gift and that made a big difference. [My husband] and I based all of our hope and faith on Jesus Christ. A favorite verse of ours was Romans 12: 12, "Be joyful in hope, patient in affliction, and faithful in prayer." That's a very short, simple verse, but very strong, and it carried us through.[56]

When people told Melody Masha Pierson that she looked well while waiting, she partially credited her Judaism. "I have the Torah. I have Tehillim, the book of Psalms. I have so many tools for life from beginning to end. Everything happens for a reason and everyone has a purpose." Religion helped many people cope with the uncertainty about transplantation by assuring them that there was a plan for their future, even if they did not know what it was. "During my wait, I cried and prayed," said Susan Burroughs, who found peace in a Bible verse that read: "For I know the plans I have for you, declares the Lord, plans to prosper you and not to harm you, plans to give you hope and a future." While some people were quite distressed by the lack of control they had over their situation, many believed in an afterlife, which meant they would be okay with or without the transplant. Pauline DeLuca reasoned, "I'm either going to come out with better lungs and be healthier or if I die I'll be in heaven. So it was a win-win for me."[57]

Not everyone had the same unwavering faith. Tiffany Vuncannon felt "just a lot of anger and doubting whether or not God existed." Sometimes Katey Ballard had faith and other times she questioned God. Although Shirley Jewett asked a Christian televangelist and faith healer to heal her, she also went to a Reiki practitioner for the Japanese (nonreligious) method of laying on hands to make use of universal life energy. Others combined a similar blend of traditional and nontraditional beliefs, occasionally bargaining with whatever higher powers existed or subscribing to superstitions. Isa Stenzel Byrnes admitted, "While I waited for new lungs, I bargained with God: *If I get new lungs, I won't ever complain. I'll be*

the best person I can. I'll give back. I'll never take anything for granted." Another candidate considered a particular nurse a good luck charm.[58]

Each person had to find his or her own method of psychological coping. Cathy Cuenin faced her fears and "became more and more at peace with living from moment to moment. As I settled into my life as it was, I stopped longing for a different one, and found that it was possible to live richly and fully in my dwindling sphere of possibilities." When she was waiting, Tiffany Christensen found that she "could barely stand it" until she decided to turn inward and focus on learning more about compassion. As a result, she declared, "my inner life began to open up in ways I never knew possible. I created a world within myself that was stimulating, satisfying, and gave me a clear sense of purpose."[59] Like some other older candidates, Judy Ryan felt she was well-equipped to handle the stress of the waiting period because of her stage in life. "I had to come to terms with my life and I was ready to die. A younger person might not come to terms with that, but when you're older and you're more mature, when you've lived your life, you've had your children, you've been married, you've worked, I think your outlook changes." Some psychologists theorized that CF patients also had more resilience and better coping skills because they had been managing their physical symptoms and adapting to changes since childhood. This point was illustrated by 30-year-old Isa Stenzel Byrnes when she reflected while waiting, "My life had been full of quality and meaning, and I had no regrets. CF had been my teacher . . . As my body had slowly succumbed to disease over the years, my spirit had grown stronger, wiser, and more capable of higher forms of strength."[60]

Candidates also viewed their previous life experiences as providing resilience. Besides mentioning his faith and supporters, Bill Poplett credited his ability to cope to "things that I've had occur to me over life. After 20 years in the service and different countries and . . . bad situations, I figure if I wasn't dead from some of those, then this wasn't going to get me either." Tracy Raub felt the same way about having weathered the recent deaths of her husband, brother, and father. Karen Fitchett also cited her background. "Since I didn't have a father all my life, I've always been a doer. I've always been independent . . . I've always been a strong person." In describing her own coping strategy, Tiffany Vuncannon said,

> The only way I can think of saying it is, "Don't be a whiner." I think there's a sense of you are responsible for your own happiness and regardless of the circumstances you can still feel like you have a blessed life . . . You have to sort of just look for the things that did [go your way] and look for the things that you can control. It's just sort of this "suck it up" attitude, you know, put your head down and keep running. My family doesn't shy away from hardships; they just get through it and I think that has been built into who I am.[61]

Specialists say there are many effective ways to cope, and that neither religious nor nonreligious coping is better. They also point out that there are different styles of religious coping.[62] Some believers adopted a rather passive approach to their situation by emphasizing their powerlessness in the face of God's will. Others, though, viewed their relationship with a higher power as more of a partnership, and thus continued to take initiative in the fight for life. For example, Paula Huffman declared, "I trust God. I think that my life . . . is in His hands," but her faith did not make her passive.

> Lung disease is the type of situation that if you give in to it, you will not live very long. You have to really be very determined. You have to be someone that is willing to push themselves. I am very committed to being in the very best shape I can possibly be in so that when I get those new lungs, boy, I'm going to hit the ground running . . . I refuse to allow [my disease] to dictate. I've tried to incorporate it into my life but not allow it to define my life.[63]

Like Huffman, Barbara Borowski tried to balance powerlessness and action. "I wasn't going to let something I could control take me over and control me. I turned everything over to God, so I could focus on my responsibility" to prepare for transplant. Scholars believe that the only "maladaptive" religious coping style is "punishing reappraisal," when people interpret their disease to be punishment from God. This mode of thinking was a strong predictor of distress and disability among candidates.[64]

Psychologists considered denial and mental disengagement to be dysfunctional coping mechanisms, but lung transplant candidates rarely utilized them. Instead, they tended to use active coping strategies, accept their situation, and seek support rather than denying or disengaging through alcohol or drug use.[65] That does not mean that some people did not "disengage" on occasion. Tommy Bullard explained, "I just sort of put [the possibility of transplant] out of my mind and went on with my life." Not constantly thinking about the disease and the need for transplant could be a helpful strategy; problems arose only if someone did it so frequently that he stopped taking care of himself. Bullard did not do that, and indeed, many would have found forgetting about their health problems impossible. As Lon put it, "Every day centers around lung disease whether you like it or not."[66] It is possible, of course, that transplant candidates did not admit to researchers that they coped by using alcohol or illegal drugs, but most appeared to be very aware of the health risks of doing so. One candidate was an exception. Matt Byrd's philosophy during the wait was to continue living life to the fullest, which included having a couple of beers every day at a local bar. He acknowledged that his transplant doctors were not thrilled, but reported his CF doctor told him that "just drinking a couple beers was better than laying on the

couch and feeling sorry for myself." When asked why he still drank while on the transplant list, Byrd answered,

> Because it was the only thing I can still do like I was a normal person, and do it well. Everything else . . . I used to be able to play soccer and do it well, and then all of a sudden that went; I was able to do the work and do it well, and then all of a sudden I couldn't even do that . . . But I can sit up at the bar and drink with the best of them, and still feel normal.[67]

Although he may have exhibited it in an atypical fashion, Byrd's desire to take action was a feeling shared by many others. Laura Richards clung to the fact that she could still drive even when she could do little else; Mary Peters even found a little solace in patient-administrated pain medication, explaining it gave her "a measure of control over the situation." For many, rehab provided that same sense. As she weakened, it took longer and became harder for Kathryn Foss to complete her exercises, yet she remembered, "I kept hoisting the weights, hoping for a little bit of control over at least one thing in my life." Actions did not have to be physical to be helpful. "I gathered every bit of information I could during this time on all of it," said M. L. Bryan. So did Shari Converse, who said information gathering was "my way of handling everything." Karen Fitchett said she advised others to cope the same way she had: "Take control of your disease—don't let it control you."[68] A person could take control of the disease, Fitchett felt, by learning about it and exercising, but there was another key to success: being positive.

Positive Thinking

Like Fitchett, members of the lung transplant community tended to emphasize the importance of maintaining a hopeful attitude during the wait. Insisting that it could help one survive, Scott Jemison asserted, "You just HAVE to have a positive attitude." Randy Sims suggested adopting a philosophy of "turning your obstacles into opportunities." Barbara Borowski acknowledged that at times she had felt hopeless, distraught, sad, and afraid, but she referred to those feelings as "useless emotions" she did not want to waste time on. Recipients and candidates alike encouraged one another to keep fighting for their lives, and bolstered their arguments with examples of people whose lives were saved at the last minute. "It works," asserted Fitchett. "You should never give up." Judy Ryan exhorted those who were waiting, "EACH DAY IS A GIFT—Take one day at a time, and NEVER GIVE UP THE FIGHT, NO MATTER HOW HARD IT GETS."[69]

Staying upbeat was a lot to expect of people who were suffering, of course. Fortunately, the community also encouraged its members to express their fears and sadness and then move on, as when May Parker likened occasional self-pity to eating cheesecake while on a diet. Mary Peters admitted, "I cried almost every day. That was one of my ways of coping." Paula Huffman simply experienced the feelings as they came.

> I have periods of time where I just get overwhelmed by things and I have periods of time when I get very sad about things, and when those times come, I just know better times are coming and I don't worry about them. If I feel like crying, I cry. If I want to lay in bed and I don't want you to mess with me, then I do that.[70]

Some intentionally cultivated their sense of humor while waiting. "I didn't think laughter would cure me," said Shirley Jewett, "but I knew that the more I laughed the better I felt. Part of our morning routine became watching the old version of *Family Feud* starring Richard Dawson." Melody Masha Pierson entertained herself by revising lyrics to an old song, "Matchmaker, matchmaker, make me a match, find me a find, catch me a catch. I need two lungs much better than mine so make me a perfect match." She also quipped that her husband had "morphed into a cook, chauffeur and cleaning lady. There are some upsides to all of this."[71]

Psychologists said that "positive reinterpretation" like that of Pierson was a common and effective method of coping in which people with lung disease reinterpreted a stressful event in a more optimistic manner. For example, instead of bemoaning the fate of living five hours away from her husband, May Parker found the silver lining in the move, declaring, "I've learned to fight again for my independence, and it's done me a world of good." Tiffany Christensen claimed that there were some unexpected benefits from living in "The Sick World": "There's a depth to this community, a vibrating knowledge of the fragility and value of life…There's something to be said for a world where That Which Is Important remains clear." On her application for a graduate social work program, 22-year-old Isa Stenzel Byrnes wrote that having CF had enabled her to openly discuss delicate issues such as mortality, self-esteem, and quality of life. In a perfect illustration of positive reinterpretation, she wrote, "I've learned how a negative aspect of one's life, namely, illness, can be channeled into a positive attribute."[72] Although there has been little scholarship examining whether people with different diseases cope in different ways, one study concluded that CF patients used positive reinterpretation, acceptance, and humor to cope with their lung condition more than patients with other types of end-stage lung disease. In general, though, the study found that patients with all types of end-stage lung disease showed surprisingly good psychological adaptation.[73]

Planning for Future Possibilities

One final way that lung transplant candidates coped was by making plans for the future. Many dared to set goals for a post-transplant future, and the goals almost always included getting off of oxygen, performing daily and favorite activities, taking on physical challenges, enhancing relationships, and having more freedom. For one candidate, creating a list of aspirations was a conscious strategy.

> When I start to get apprehensive, I focus on my wish list to put my mind back into a positive zone. Another time I use my wish list is when I wake up at 1 AM and can't get right back to sleep. Then I start with the letter "A" and go throughout the alphabet thinking of places to go, things to do, and people to see. My A activity is visiting the beautiful and historical Ahwahnee hotel in Yosemite for the Sunday brunch . . . My Z activity is going to the zoo with the grandkids. By the way, I rarely get to Z before I fall asleep again with a smile on my face.

Their goals were highly individual, as seen in the responses sent in by readers of Second Wind's newsletter to the question, "What would you most like to do after transplant?" Answers included learning the saxophone, dancing, playing with my grandsons, riding roller coasters, rejoining aerobics class, taking the kids to Disneyworld, flying, swimming, having sex, going out of the house at a moment's whim, traveling, and starting a band.[74] While Kimberly Pearce hoped to return to her spot on the cheerleading squad and graduate from high school, her 22-year-old brother Brett aimed to go to medical school. He took actions toward his goal, such as enrolling in biochemistry.

> I always studied as if I was going [to medical school] . . . I treat it as if I'm going to be here till I'm 100, and I continue to plan for that eventuality. I'm not going to *not* set up a retirement fund when I start working [laughs]; I'll still set one up. I know I probably won't use it, but I'll continue to plan as if I'm always going to be here. Because if you don't, there's no point in doing anything.[75]

One of the biggest challenges lung transplant candidates faced was how to cope with the two very different future possibilities: dying or undergoing a lifesaving transplant. The way a person might prepare for each possibility could be rather distinct, even opposite. Someone preparing for the inevitability of death might want to travel somewhere exotic or spend her last months in her own home, while someone pinning his hopes on a transplant would stay close to the hospital. Someone planning for a transplant would push herself to exercise and pay close attention to her diet while someone certain he soon would die might well rest and enjoy what pleasures he could.[76] Someone expecting to die might make end-of-life arrangements and say goodbyes while someone expecting transplant

might eschew such actions as pessimistic. It was difficult to contemplate and give equal energy to both possibilities, and people were often forced to make practical choices that tended to lean toward one more than the other.

Betting on either possibility had risks. Someone who was not fiercely dedicated to preparing for transplant might well die before one came available or be too weak to thrive when it came. On the other hand, there were risks to putting all one's eggs in the transplant basket. Kathy Vanderford, for example, had relocated to be near her transplant center, but then as she neared death, she wished she could go home to be in her own familiar space and with more of her family and friends. Unfortunately, at that point she was too sick to travel.[77] Another risk was that someone who was extremely focused on getting a transplant might not be ready for death. Elisabeth Kubler-Ross observed that people with terminal illness tend to go through a number of stages before finally coming to acceptance, but if a transplant was considered a possibility, people might not progress through all those stages. In fact, one study showed that many CF patients who were listed for transplant had not had discussions with their medical team about end-of-life care and by the time their death was imminent, they were incapable of talking about and making their decisions independently.[78] Although those patients waiting for transplant may well have desired the most aggressive end-of-life treatment, it probably would have been better for all involved for them to have considered and communicated their preferences in advance.

A final risk to betting on the transplant option was putting off life (in the hopes of a more ideal one in the future) instead of living it. Harold Blaise described the phenomenon:

> You can imagine what this [waiting] does to you day after day and week after week and each month. Your life goes in limbo. I mean you freeze for a long time in your life . . . waiting to get in there and get that transplant . . . That's where I stand now and I'm just waiting for the phone to ring. People are just trying to hold their lives together while they're waiting for new body parts, so to speak, and it sure does put your life in limbo. Once you're here and waiting there's nothing else you can do.[79]

A Scottish study found that this feeling of "having one's life on hold" was common during the waiting period. It quoted one candidate as saying, "If I was a video recorder, I'd be on pause at the moment. I'm not really living, I'm just getting by." Recipient Karen Fitchett reported that she had seen an alarming number of candidates fall into the same trap. "A lot of patients put too much into waiting for that call when they need to do other things. They sit there saying, 'I'm waiting for the call,' and I keep telling them, '*Don't do that*. Do stuff. Keep yourself busy.' " To combat this temptation, members of the lung transplant community adopted a maxim that they should try to take advantage of each day and really

live in the present. Ana Stenzel wrote to friends asking their encouragement for living "One day at a time . . . one breath at a time." That was, she noted, "Easier said than done."[80]

Some people rather successfully negotiated the challenge of coping with the dual possibilities of dying and being transplanted. Doing so required reflection, flexibility, and realizing that it was possible to live even if one's life was more circumscribed than it used to be. "It is possible, even with home IV regimens, to live a full life," insisted Scott Jemison.[81] To plan for life and death simultaneously, Tiffany Christensen imagined that she was going on a trip to an unknown destination that might be in a cold climate or a warm one, requiring her to pack accordingly for either option. Eventually she felt content with both options and learned "the greatest lesson in balance I could have ever received." Susan Burroughs undertook the same sort of process. Her biggest fear about dying was missing out on conversations with her family, so she wrote down many thoughts for her husband and daughter and also set down her desires about funeral arrangements. Once she made these preparations for the worst case scenario, she felt she could "concentrate on living" and prepare for a transplant. She signed up at a fitness center and worked out intensely, concluding, "We have two options, medically and emotionally: give up or fight like heck. I would never, never give up." Michael Pollack wrote to a friend that he managed to handle contradictory feelings. "I have been resigned—and hopeful—from the beginning of this destiny, and I pray to stay so to the end."[82]

* * *

Anyone who suffers a life-threatening illness has to deal with uncertainty about whether or how long they will survive. Lung transplant candidates had to cope with this uncertainty and also the fact that they had to wait an indefinite amount of time to get the potentially lifesaving treatment, if indeed they got it at all. They felt (and indeed were) powerless to do anything that might cause the transplant to happen. Not surprisingly, then, this waiting period provoked strong emotions, including fear, anxiety, frustration, guilt, and depression, and the stress was all the more difficult for people who were separated from their usual support systems. False alarms—another unusual phenomenon—were unpredictable moments that only heightened the tension. In spite of what Randy Sims called the "emotional roller coaster" of the waiting list, lung transplant candidates appreciated the opportunity to wait for a second chance, and found ways to deal with their unique challenges. Many of their coping mechanisms were useful to people with any end-stage disease, including relying on loved ones, calling upon their spirituality, taking action, staying positive, and planning for the future. The more unusual—and notable—one was relying on the lung transplant community, which while having difficult aspects, tended to be empowering. In general,

though, individual candidates used whatever combination of coping mechanisms they could. "You pray yourself energy, you cuss yourself into it or whatever," noted Jasper Martin. "Whatever you do, you just have to keep going." They did not necessarily think the ways they coped were admirable. "So many people tell me, 'I don't know how you got through all that. There's no way I could have done that myself,' " said Jan Travioli. She disagreed, averring, "The fact of the matter is, if you've got to do it, you've got to do it. If you're in that situation, you play with the cards you're dealt with. I think anybody could go through it if they had to, if they want to stay alive."[83]

CHAPTER 5

Getting "The Call"

They told my husband—they didn't tell me—that they were only giving me a week, and if I didn't have a lung by Friday, then they were going to take me off the list because I was too sick to have one. The next day I just laid around in bed all day; there was just nothing I could do. That night around nine o'clock the phone rang and they said they had a lung for me, get in right off. I was trying to get dressed to go and of course you'd get excited. I was really nervous and I couldn't breathe and my husband is like, "Come on, come on, we've got to go." It didn't even dawn on me that I could have died through the surgery or anything like that. I was just excited.[1]

—Cheryl Maxham

On Monday, May 6, 1996, the phone rang and it was the transplant coordinator. I was dead silent as she spoke, "Nancy, this is Joan at Sharp and this is your call." (I am tearing up just writing this to you I can hear her so vividly.) When I hung up the phone I experienced for the very first time, total panic and fear. It lasted less than a minute and then I became totally calm and absolutely ready. Then my husband Mark and I raced around the bedroom trying to figure out what to take. It looked like a Keystone Cops routine. I finally said, "Stop. All I need is a book to read, house shoes, and a robe."[2]

—Nancy Hulet

I started to laugh. I could die on the operating table but that didn't stop my laughter as I looked at myself, knowing it might be the last time I saw my physical form. I stopped laughing and stepped closer to the mirror. I examined my reflection. As I did, I whispered to God, "It's just You and me now. Thank you for this chance. And please, please bless that child that died and his or

> her family. Comfort them. Give me the strength, courage, and guidance to do what's ahead of me. And, if it's possible, don't take me yet."[3]
>
> —Laura Scott Ferris

After years of suffering with debilitating lung disease, facing death, undergoing a strenuous evaluation, and surviving the ordeal of waiting, the moment when someone got word it was time for transplant was bound to be dramatic and memorable. "Let's face it," said Scott Collien, "It's not every day someone rings up and says they've got a set of lungs for you." Years later Lori Hughes still pictured the exact setting when she got the call. "My husband and I were sitting, and we had just finished dinner. Dinner of pork chops and hash browns. I'll remember that forever." As Karen Couture put it, "The call is always in capital letters: THE CALL." It was met by an adrenalin rush. Frank Avila was in physical therapy when his coordinator walked in with a "look on her face that said it all." His excitement was recorded by the pulse oximeter he was hooked up to, which showed an increase in his heart rate. When he called his family, they got excited, too, and Avila "heard screaming and crying from my mom and sisters."[4] While excitement was typical, as the quotes at the start of this chapter suggest, there could be a host of other feelings and they might vary dramatically during the few hours before the much-anticipated transplant.

The opportunity represented by "the call" was an exceptional one. The call did not guarantee the transplant would occur, as the large number of false alarms illustrated. Many things had to happen for the transplant to proceed, and virtually all were out of the control of the transplant candidates. Their second chance would come about thanks to medical knowledge accrued earlier by transplant specialists, policies enacted by the government and the United Network for Organ Sharing, and the swift actions of scores of local and distant medical personnel. None of that mattered without donor lungs. The decision to donate was frequently made by the loved ones of people who died—who made the decision while feeling grief and dismay. The decision caused excitement and hope for an unknown person with end-stage lung disease. The partnering of these opposite circumstances and feelings was no coincidence; that one led directly to the other was the bittersweet reality undergirding organ transplantation.

Organ Donation

A transplant candidate got the call at a particular moment due to events that happened outside his or her personal and local circumstances. Although occasionally two living donors might contribute a lobe of their lungs to a younger and smaller recipient, such lung transplants happened in only 2 percent of lung transplants between 1988 and 2003.[5] Donor lungs tended to come from

a brain-dead person. The most common causes of brain death were cerebrovascular injury from an aneurysm or stroke; trauma to the head caused by a motor vehicle crash, fall, blow to the head, or gunshot; or, more rarely, loss of oxygen to the brain resulting from drowning, suffocation, some circumstances of heart attack, or drug overdose. Brain injury was an unusual way to die, accounting for only about 1 percent of all deaths.[6] It was often the result of a sudden tragedy, such as nine-year-old Aaron Steenland getting hit by a car while crossing the street, actress and waitress Lyric Benson being shot by her ex-boyfriend while on her way to visit her mother, or Air Force First Lieutenant Lamara Wynn suffering an aneurysm while shopping with her daughter.[7] Family members described their losses as "bleak," "retching," "incomprehensible," "senseless," "unbearable," "overwhelming," "nightmarish," and "torturous." If there could be anything positive resulting from brain death, it was that it was the main circumstance of death from which organ donation was possible.[8] Mechanical ventilation could temporarily maintain heartbeat and respiration in a way that slowed the deterioration of some of the solid organs, making them viable for transplantation. This preservation often proved insufficient for lungs, however, since events such as car accidents often damaged the fragile organ and because in many cases, donor lungs harbored infections. Lung transplants were less common than other types of organ transplants, not just because death from traumatic brain injury was rare, but because even among people whose organs were donated, so few had usable lungs.[9]

Transplants could not happen unless family members agreed to donate the brain-dead person's organs. That required a doctor, nurse, chaplain, or organ procurement coordinator to have approached the family in what one commentator called "one of the most stressful, emotional, and delicate" possible conversations. No one wanted to give the impression "that we're standing out here tapping our toes," but time was of the essence because organs deteriorated quickly. Joan Littel-Conrad, an organ procurement coordinator, performed her emotional job not because it was a legal obligation, but because it was worthwhile. "The tragedies are going to happen whether I'm there or not. But because of my job, I can make something positive come out of it."[10] She informed families of the option of organ and tissue donation and the number of people who might be helped by it, answered their questions, and listened to their concerns and grief without exerting any pressure. The time following news of a shocking death was a difficult time to make an important decision. Grief made even basic functioning difficult, much less a serious conversation. "It was all so sudden and unexpected," recalled Elizabeth Gallimore. "Your mind is just going in circles." After being with her husband in a motorcycle accident and then being told he wasn't going to make it, Adrienne Voegerl said the rest of the day was "a blur."[11] Decisions could also be complicated when not all family members were present. In addition, sometimes people declined to donate because they had misconceptions about the

process, didn't know what the dead person would have wanted, mistrusted medical authorities, or simply could not think of others at that moment.

For some people, though, the decision to donate a loved one's organs was easy. A driver's license notation could help clarify matters, but it was even better if a conversation had taken place. Pat Ledbetter had initiated such a conversation with her children, assuming they would someday have to deal with her death. She never imagined that instead she would be facing her 22-year-old daughter's sudden death. "[Al]though it was hard to make the simplest thought processes work in the midst of such grief," Ledbetter said, "since we knew her wishes, it was not a difficult decision." Sometimes families reported that discussions about organ donation felt eerily prescient. When she was 17, Lisa Smith talked with her father about wanting to be an organ donor, and he told her she was too young to sign a legal document. "Well if anything happens to me, that is what I want to do," she asserted, less than a month before she suffered an aneurysm.[12] Sometimes a family did not know the wishes of the person who died, but felt confident nonetheless because donation seemed consistent with their loved one's values or characteristics. Lisa Davis had just finished training as a respiratory therapist when she died, and her loved ones said she "was always the first one to jump in and help others." Mary Steenland had "the intuitive certainty that this is something that [son] Aaron himself would have been comfortable with." Transplant coordinators frequently heard the refrain, "Although we never talked about it, I think she would want to do this to help other people." Many donated for religious reasons, seeing it as "the ultimate manifestation of Christianity—giving to your fellow man." Will Freeman, 18, put it more bluntly: "What a waste if you have a chance to save people but don't. Mama understood that."[13]

Those who made the decision to donate often benefitted from having done so. Pat Ledbetter recalled that one of the worst things about her daughter's death was "the awful sense of powerlessness" to reverse what had happened. With organ donation, however,

> we could choose to offer the precious gift of life to others. I could perhaps save some other mother this enormous, unbearable pain. Having a decision that I could make, a choice that I did have some control over, even as my world careened out of control, seemed to restore some sense of empowerment and balance that awful night.[14]

This sense of powerlessness was a feeling donor families shared, of course, with people on the waiting list. For Donna-Marie Bowers, the experience was paradoxical.

> Being the parent of a child who died was the most difficult thing I have had to endure in my life. In contrast the act of donating her organs was one of the most

> profoundly moving and strangely wonderful experiences I have had. Nothing could change the outcome of our accident. Fortunately for my family we had the opportunity to make Jenna-Marie's outcome help others.

Hopelessness was somewhat tempered by the possibility that some part of their loved one would live on. As Michael Tucker put it, "Usually with death, it's so final. And this made it possible for it not to be final."[15] The consolation from donating only went so far. Counselors who worked with donor kin confirmed that the circumstances of their losses, especially the suddenness, meant that their grief was ongoing, lingering for years. Still, most people who chose to donate a loved one's organs never had any second thoughts about having done so.[16]

In a small number of situations, there was an alternate way to supply organs for lung transplantation: living donors could give up part of their lungs. The rare operation known as living lobar lung transplant involved surgeons taking one lobe of a lung from two separate donors (the lungs of a healthy person have five lobes) and transplanting the two lobes into the recipient's chest. There they filled the available space and served as the recipient's new lungs. Because each lobe had to fit into the recipient and serve as his/her whole lung, this surgery was usually only performed on children or very small adults for whom the odds of getting an organ from a cadaver in time were slim. While this type of organ donation did not involve a tragic accident, it certainly involved sacrifice, and for that reason, it was controversial. One of the first principles of medical ethics is to "do no harm." Performing risky surgery on a person dying from lung disease could be acceptable because it might save that person's life, but doing it on perfectly healthy donors offered them no medical benefit and also endangered them. While death was extremely unlikely for the donors—the chances were about 1 in 10,000, according to one estimate—each donor lost about 18 percent of his or her lung capacity, and complications could occur. Donation involved undergoing an extensive evaluation and being hospitalized for around ten days. After the surgery, donors were unable to work, cook, drive, or otherwise care for themselves or others for four–six weeks.[17] Opponents of the procedure also worried that guilt and emotional involvement made it difficult for related donors to give truly free and informed consent. While they acknowledged the risks and ethical concerns, a few surgeons fulfilled the desires of relatives who desperately wanted to donate. Barbara Sewell, a donor and the mother of a recipient, appreciated that. "I don't understand why anyone would say a parent doesn't have a right to try to save her child's life."[18]

In the rare instances of living lobar transplants, the donors tended to be happy and looked forward to witnessing the benefits of their gift, while in the vast majority of lung donations, the gift was made by the family of the donor, and done with a heavy heart. Whether made by grieving loved ones in the aftermath of brain death, farsighted people who made known their decision to share part

of themselves while still alive, or living loved ones who were willing to risk giving up a lobe, the decision involved an element of sacrifice. Organ donation was a thoughtful, intentional, and meaningful gift.

Getting "The Call"

Transplant candidates who got the call had no control over the circumstances that made donor lungs available. The nation's organ system also shielded recipients from obtaining much specific knowledge about donors—whose situations they did not cause and could not change. At the moment lucky candidates got the call, they were caught up in their own unique personal drama of trying to survive. Most were in such dire straits that getting the call was very exciting.

Occasionally, an individual's circumstances tempered the excitement. Fear froze Scott Collien for just a second. "My first thought was could I go through with it? The thought that I might die during surgery weighed heavily on me." When the hospital called Kelly Helms, who was on the brink of death, she remembered, "I was amazingly calm, and I think that's because I was so weak at that point, and so tired. I remember getting up, and going in my parents' room, and going, 'They just called; they think they have a lung.' I mean, I was excited, but I was so weak, it was like I couldn't move fast or anything."[19] Charles McNeill, who had already experienced a discouraging false alarm, responded to a new call with skepticism that this was really "the one." "I wasn't getting excited because I had been this far before. I was trying to be calm." Even as the preparations progressed, McNeill refused to get his hopes up. "I was ready to go to the operating room, but I still wasn't buying it. I kept asking, 'Is it for real this time?' " Daniel Martini's son did not think his father was near the top of the list, so he didn't expect a call about transplant. When the phone rang, he had a puzzled look on his face, and said, "We don't know anybody in Madison, do we? I think this is another telemarketing call." Fortunately, he picked up the phone.[20]

Others were less surprised. "It was really kind of weird, a week before I did get my call, I started having a strong feeling it was going to happen soon," said Karen Couture. "I sort of subconsciously started doing these to-do lists, and started taking care of bills, and mentally getting things in order. I already had my bags all packed and ready to go." When the phone rang, Lori Hughes felt she knew what it was, telling her husband, "Get the phone, they're calling about my lungs." Dare Reitz had a similar experience. When her coordinator called and remarked that she didn't sound too excited, Reitz replied, "I knew you were going to call."[21]

Because lungs can't survive long without a blood supply, candidates needed to get to the hospital quickly. The urgency and excitement made some people

confused. When the phone rang and it was her coordinator, Charity Fennell recalled, "I began to shake like a leaf. Nothing went right and nothing went fast enough. I wanted to call my best friend Charlene and I know that phone number as good as I know my own, but I couldn't remember it to save my life." After he got called, Matt Byrd watched the people around him panic, his friend "act[ing] like I was about to have a baby," his grandmother "hysterical" as she tried to track down his parents, and his father "a nervous wreck." Steve Bunsen remembered both the urgency and the humor surrounding his call.

> It was about two o'clock in the morning. I had been up to the bathroom and the phone rang and the coordinator that called said, "You sound wide awake," and I explained the situation. She said, "Well, just get yourself down here, we've got a pair of lungs." We discussed what I needed to bring, the inhalers and what have you. I do recall she said, "Just come in your pajamas," and I said, "I'm sorry, I don't wear pajamas. I'm going to throw on a pair of jeans if that's all right with you." We did do that, and it was a rather hasty trip.[22]

Candidates who had relocated to live near the hospital and those who were already in the hospital didn't have far to travel. "I just woke up at 1:30 in the morning with two nurses' aides rolling me out of the sack," laughed Jasper Martin. Most people, though, traveled by car following a prearranged strategy. M. L. Bryan planned to drive if he had time, but had made arrangements for a charter airline flight to be ready at any moment if he had to rush, which he did.[23]

Usually these arrangements worked as planned, but not always. The timing was disconcerting for Mary Ellen Smith when she received the call in North Carolina: "My husband was in Georgia, all my family was everywhere else, and it was just me and a seven-year-old child." After coolly telling the coordinator she'd be right there, Smith frantically tried to find someone to take care of her son and reach her husband. Daniel Ensign's plan of traveling via helicopter was foiled by thunderstorms, and he and his wife ended up hurriedly driving to the hospital. Because Judy Ryan lived at the outer limits of what her transplant center permitted, three hours away, she had made arrangements with a local ambulance service for when it was time to go.

> Unfortunately, when I called, there were no ambulances available and I kind of got upset. How am I going to get to Chapel Hill? Fortunately, I called an older couple that I was friendly with and they brought me up to Chapel Hill. But that was a little upsetting. On the way up there, my friend's husband Ed, he was driving 80 miles an hour—a wonder we weren't stopped. I kept talking [on the phone] to the nurse, [who said,] "Hurry up, hurry up. You've got to hurry up." So it was push, push, push.[24]

Once candidates arrived at the hospital, many tasks remained. They needed to be admitted to the hospital and sign documents. There were blood draws, chest x-rays, an EKG, and other tests to make sure everything could proceed safely. They got weighed, shaved, and cleansed with a betadine scrub. Intravenous lines and catheters were inserted, and the first dose of anti-rejection administered. They also had to drink a bad-tasting laxative, called Golytely, to clean out their bowels. One person noted, "There's nothing 'lightly' about it." Often these preparations were done very quickly, and the candidates just did what they were told. "It all happened so fast that I didn't have much time to think or worry," remarked one person. In language similar to that used by many donor families, another candidate said that it was all "a blur."[25] The spontaneous and hurried nature of the call meant many patients were preoccupied with getting in touch with loved ones or thinking about other arrangements. Many felt sad about the absence of family or friends and hoped they could contact them before the surgery began. "It all happened within, I'd say, an hour and a half," remembered Dana Schmidt. "They came and got me, they put me in a gown, they shipped me down to this surgery operating room. And my husband wasn't there, my father wasn't there, it was just me and my mom." A "very nervous" Frank Avila became "very relieved" when he saw his father walk into the holding area.[26]

Ironically, after all the rushing, some people then had to wait for the lungs to arrive or for some problem to be dealt with. As they administered vitamin D to Lori Hughes to counteract a blood thinner she'd been on, they did so too quickly, and her heart stopped. She turned blue and passed out. When she regained consciousness, the first thing she asked was, "What about the transplant?" Fortunately, it could proceed. If they were forced to wait, candidates passed the time in different ways. Charles McNeil, whose lung disease was cystic fibrosis (CF), read *Sports Illustrated*, amazed by the coincidence that Boomer Esaison was on the cover, posing with his son who had CF. Many prayed with their families, friends, and clergy. Kathleen Feeney and her husband made animals out of balloons, and she read a mystery novel she'd chosen for good luck, entitled *Second Wind*. Kelly Helms found the waiting so difficult that she eagerly accepted the doctors' offer to put her out with a sedative even before they knew the donor lungs were all right. Lee Starr napped without any help.[27]

If the wait got very long, patients usually assumed the worst, sometimes with good reason. The lungs for Richard Mannheimer were delayed because police had pulled over the vehicle transporting them for erratic driving. A skeptical officer called the hospital before believing the driver's story.[28] Pauline DeLuca had good reason to worry, too. After waiting six hours at the hospital, her surgeon told her he thought the lungs looked good, but the donor had died of an unknown infection, and some of the transplant team thought they shouldn't use them. "It's up to me?" DeLuca exclaimed. "Don't make *me* make this decision. My God!" After talking with her family, she decided to take the chance, and the

surgery went well.[29] Carol White and her husband waited so many hours they assumed the operation would be cancelled. After a while, all they could think of was how hungry they were and began to make dinner plans. Her husband kept saying, "If we get out of here before 8:00 [when the restaurant closed], we'll go to Bullock's [Barbeque]." Disappointed when 8:00 passed, they were surprised when a doctor came in, announcing the transplant was on. "Lord have mercy, the next thing I knew I'm going down the hall to the operating room and they're sticking that thing in the vein in my neck. I looked up at the guy who was taking me, and I said, 'I guess it's too late now for me to change my mind.' He said, 'Yes ma'am, lie down and shut up!' "[30]

Candidates approached their last pre-surgery conversations differently. Tom Fereday took the time very seriously. "I got a couple of minutes to make phone calls to people and to thank them for what they had done," he recalled. He told them "that I loved them and I didn't know if I would see them again, but I appreciated them." Exhausted by a long drive and all the preparations, Karen Couture was incapable of such meaningful conversation. "I heard stories of other patients when they get wheeled into the operating room, telling their family how much they love them regardless of what happens. I didn't do anything, no big goodbyes or anything. I was just like, 'Let's get this thing over with.' " Bob Festle was also aware that it was a significant moment.

> As they were leading me into the surgery my mom and my brother were there, and it was kind of one of these dramatic moments where everyone is supposed to be crying, everyone is supposed to be nervous because you might not survive the surgery. I think I just said something like, "Oh well, I'll see you later," confident that it would work. That did not seem like enough to reassure them, so I said, "Will someone tape [the television program] 'Melrose Place' for me?" because I was going to miss it that night because I was in surgery. I think everybody got a laugh out of it. I think it kind of put people at ease a little bit . . . It was something that showed that I was sure it was going to work.[31]

Ruth Hall also used humor to break the serious pre-surgery mood, saying she "cut up the whole time she was in the prep room." Thinking of others in her final moments before transplant, Linda Jozefowicz asked the chief resident whether her heart would be in good enough shape to donate to someone else if her surgery failed. Kathleen Feeney blended practicality, humor, and confidence as they wheeled her toward the operating room. "Bye Kirk, I love you, see you later," she said to her husband as she interlocked pinkie fingers with him. Asked, "Aren't you going to kiss him?" she replied, "Look, he's got a cold. I'm not going into surgery with a mouth full of germs. He knows I love him; I know he loves me. I'll see him later."[32]

Once they'd said their goodbyes, candidates were alone with their feelings. "I really think you're in a little bit of shock," said one person. "It's a little bit surreal." Fear was common. "I got a little scared, to tell you the truth," remembered Jasper Martin. "Probably the last thing I thought of when they put me under with the sedative was 'What in the hell have I gotten myself into?' " Mary Peters was already worrying about her immune system, describing herself as "a little paranoid. I was watching the O.R. nurses to make sure they used sterile technique and didn't introduce any germs. I really wasn't afraid of not surviving the surgery. I was more worried about what would happen afterward." Kathy Vanderford had enjoyed her pre-op time with friends and the chaplain, and had felt positive and excited. But she recalled, "When they wheeled me into the operating room, my mood changed to momentary terror as I saw three tiers in a semicircle surrounding the operating table, each one lined with tray after tray of instruments." Bill Poplett said a prayer for the donor family right before being operated on. Laura Scott Ferris's last thoughts alternated between the spiritual (which had her anxiously reciting the Lord's Prayer) and the practical (worrying about the icy cold of the operating table on her backside). As staff were busy attaching things to him, Scott Collien said that both mentally and physically, he felt "about as uncomfortable as you could get."[33]

Others were more confident going into surgery. As Dare Reitz was waiting, a nurse conveyed to her a phone message from her pulmonologist, who said that he wouldn't be able to see her before her transplant, but that he would see her afterward. "That's all I needed to hear. He was so sure that he would see me after surgery that I felt so relieved…All of a sudden I just totally relaxed." Naked, covered with blankets, and ensconced in the chair-like table on which she'd be operated, Mary Ellen Smith watched the medical team do its preparations.

> I was so amazed because everywhere everybody was working around me, very quietly, very quickly. They were opening up all these paper packages. I said, "This is amazing," and they said, "You're still awake?" I said, "Yeah. Tell me what all y'all are doing." They were telling me what they were doing and all and one of the nurses said, "Aren't you afraid?" and I said, "No, I think everything is going to be fine, don't you?" She said, "Well, of course." That's the last I remember.

David Lee was reassured as well, because right before he lost consciousness, he overheard someone ask how the lungs were, and the response was, "They're beautiful." Jimmy Carroll's confidence came from looking at his transplant "like it is an astronaut going into space. It's kind of a scary thing to think about, that you're sitting on top of this rocket that's going to take you to the moon or wherever. But you know that so many people have worked and planned toward that, and those people know what they're doing."[34]

Some weren't exactly confident but had reached a place of acceptance. Dana Schmidt worked through her fears, thinking,

> I don't know if I can do this. I don't know if I can go into an eight-hour surgery. But as I went down to the operating room I thought, "You know, I am going to die if I don't have this," so the fear went away and I was just ready to get it over with. I would say when I got in the operating room I wasn't that scared anymore.

As it did for many people, Frank Avila's peace of mind came directly from his religious faith. "I felt peace because I knew that God was with me," recalled Avila. "He was going to be there to make sure that everything went right." Cheryl Maxham's reasoning was based on a more down-to-earth assessment of the situation. "I figured if I die on the table, I'm not going to know it. You know, when they put me out, that's going to be it. If I wake up, yea; if I don't, I'm not going to know."[35]

Regardless of whether they felt afraid, confident, or at peace, all feelings soon disappeared as the drugs took effect and the candidates lost consciousness. "My thoughts were interrupted when the doctor told me to breathe deeply and relax as he covered my eyes with a gauze bandage," recalled Don Hawkins. "A minor pain at the vein in my neck indicated that a needle had been inserted and I began to drift off. IT HAD BEGUN."[36] For the next few hours there was nothing they could do. There would be no fighting for breath or fighting against death; their lives were in the hands of the medical team, about to perform an operation once considered impossible. Amid a donor family's sorrow, there was the possibility of renewed life as some lung candidates finally received the long-anticipated and hoped-for second chance that many others would never enjoy. They had embarked upon a life-changing experience.

CHAPTER 6

Second Wind: Life after Transplant with a Donor Lung

> I refuse to live in a bubble! As my surgeon says, "We gave you these lungs to go out and live."
>
> —Joanne Schum

> I am thankful for the past 5 ½ years I've been able to live and for this reason I don't take anything for granted. But, most of all, I will never forget how I got the [lungs], where they came from, and how I fought for my life.
>
> —Carolyn Boyd[1]

After months on the waiting list feeling scared and "miserable" and knowing he was near death, Howell Graham felt very relieved to undergo a lifesaving double lung transplant in October 1990, but the period after his transplant was no cakewalk. Early on, he was in so much pain he was "practically jumping off the stretcher." Terrified, he clutched the hand of an intensive care nurse for much of her shift. Within days, Graham's new lungs were functioning well, but he was so accustomed to being on supplemental oxygen that he was afraid to give it up. "I just didn't think I could make it without it," he recalled, and his surgeon had to physically take it away from him. Soon Graham was being taken to an exercise room to walk on a treadmill and ride a bike. "You're just so tired and you just don't want to do it," he recalled, but he appreciated the physical therapist he alternately called a "great person" and a "slave driver." Graham also had to learn about an extensive new regimen of drugs he would take every day to combat rejection, but he downplayed the adjustment, saying "It's nothing," and that "28 years of training" with cystic fibrosis (CF) had accustomed him to ingesting lots of medications and taking care of himself.

Graham recovered well enough to be released from the hospital about a month after his transplant, and then his problems shifted from short-term physical ones to more basic ones related to identity. Who would he be now that he could breathe easily? He felt and looked different from before because he was finally able to gain weight and one of his drugs made his hair "ungodly thick." He was suddenly famous in his hometown, interviewed by a television station and featured on the front page of the newspaper as one of the first people with CF in the southeast to get a double lung transplant. Yet once out of the spotlight, it was less clear how he should spend his time. He had difficulty finding employment due to having been out of work for almost a year and his daunting health history. He was a new person socially, too, since he was energetic and excited about having cheated death. "I was partying every night and dating a lot. I had been sick for a while, and I was going to have a big time. I was a complete maniac." Eventually Graham found himself. He got a good job, met a woman who helped him settle down, and stopped believing people who treated him like a hero. "I'm not anything special," he commented. "If your back's up against the wall and it's life or death, you would do the same thing." Graham can certainly be seen as having successfully built a new life after transplant. A lucky man, he was still living well over 20 years after the operation (figures 6.1 and 6.2). Yet he never forgot his good fortune and the fact that it came thanks to an anonymous donor. Although

Figure 6.1 Howell Graham works full time and continues to sail 21 years after his double lung transplant. Courtesy of Howell Graham.

Figure 6.2 Recipient Howell Graham with his dogs on the beach. Courtesy of Howell Graham.

he had trouble expressing his gratitude to his donor's family, he said, "I feel I've been given so much that I want to give something back."[2]

Did Howell Graham have a "typical" post-transplant experience? In some ways, he did not. Twenty years was much longer than most recipients lived, and most did not go through a wild stage in the aftermath. In other ways, however, Graham's story reveals some shared challenges and experiences. First, he found the recovery period hard. Graham was relatively lucky, since his obstacles were short-lived, but difficulty in the first weeks was common. Recipient experiences varied enormously during the months after surgery, ranging from disastrous for a few to almost miraculous, but full recovery often required six months or more. Second, like Graham, recipients learned that physical recovery did not mark the end of the journey. Once they achieved better health, they faced more metaphysical questions, such as, "Who am I now?" and "How should I live?" These questions arose in part from the unique nature of organ transplantation. Unlike those who benefitted from other types of lifesaving treatments, lung transplant recipients' survival resulted from an organ that originated in someone else's body. In order to prevent rejection of the foreign organ, recipients faced a new medical regimen, which would have to be maintained for as long as they lived and would suppress their immune systems. Now quite vulnerable to other problems, they would have to decide how to approach life with new risks and uncertainty. In addition, like Howell Graham, grateful recipients often needed to come to terms with the fact that the person who donated their organ had died.

Experiences after the Surgery

Around the turn of the twenty-first century, a person's lung transplant surgery might have lasted anywhere from four to nine hours, depending on the type of procedure and how easily their native lung(s) could be removed. The operation would not have begun until the surgeon received word from the retrieval team that the donor lung(s) looked good. In a single lung transplant, the surgeon made an incision on the patient's side—the side of the lung to be replaced—about six inches below the armpit. Once the donor lung arrived in the operating room, the surgeon collapsed and removed the diseased lung, cutting its main airway and tying off its blood vessels. After inserting the new lung, the surgeon attached three main connections—the main airway (bronchus), the pulmonary artery, and the pulmonary vein. In a bilateral ("double") lung transplant, the incision was made across the front of the chest at the base of the breasts so that the chest opened like a "clamshell" or the hood of a car so the surgeon could first remove and replace the more diseased lung and then do the same with the other. In some cases, the recipient needed to be connected temporarily to a heart-lung bypass machine that pumped blood and supplied fresh oxygen. Last, the surgeon checked the functioning of the new lung or lungs, removed excess blood or mucus from the airway, inserted tubes to drain air, fluid, and blood, and then closed the chest incision.

The vast majority of lung transplant recipients survived the operation, but their postoperative courses differed dramatically. By the mid-1990s, lung transplant surgery had a one-year survival rate of about 78 percent, and 87 percent of recipients made it through the first three months.[3] Recovering from major surgery takes time and for some, the process went smoothly; regaining consciousness brought relief as they realized they had survived the operation and breathed more easily. Upon first waking, many were alert but still connected to a ventilator, which controlled breathing through a tube through the mouth and into the trachea. Pauline DeLuca had dreaded being on the ventilator because it was reputed to be very uncomfortable, but when she awoke, she observed, "Maybe this doesn't hurt at all. It just breathes for you." Tim Choquette took immediate comfort in seeing the monitor for his oxygen saturation rate. Before his transplant, his rate had hovered in the low 80s. "One of the first things I saw was the number 100 percent on the screen and was like, 'Wow. Is that thing connected to me or is somebody else here?' It was pretty darn exciting."[4] If things were going well, doctors would remove the ventilator fairly quickly, a moment many patients recalled with great pleasure. "As soon as I was pulled off the vent, I couldn't believe how well I could breathe," said Rosalie Gallogly. Carol Stimmel's ventilator had already been removed when she regained consciousness. "Oh my God, the difference was amazing," exclaimed Stimmel. "I could breathe. The first time I woke up, I could breathe. It was wonderful."[5]

After being removed from the ventilator, the next step was being weaned from supplemental oxygen. This also occurred quickly for fortunate recipients such as Rosalie Gallogly, who was on oxygen just a day and a half. "I felt better a lot faster than I had expected," she reported, "a lot faster." Frank Spears had his single lung transplant on a Sunday morning, was out of intensive care in less than 24 hours, and was taken off oxygen by Tuesday morning, when his surgeon matter-of-factly pulled the tube out, saying, "That's that." Before the surgery, Spears had been dependent upon four liters of oxygen and had 12 percent lung capacity. Two days after surgery, with only one good lung, he had 76 percent capacity and could "feel the difference right away. Going from 12 percent capacity, which was on oxygen, to the capacity I have now, it's a born-again experience."[6]

The luckiest recipients had relatively low levels of pain and were able to start moving quickly. While some discomfort after a long operation was inevitable, physicians hoped to limit the pain so that they could get recipients sitting, standing, and using the new lungs. "I don't remember being in pain," Frank Spears claimed. Similarly, Daniel Ensign said the recovery was "really no big deal" and a hernia operation had been "10 times worse." Laura Scott Ferris described feeling stiffness and discomfort rather than pain, as if she were wearing a tight underwire bra.[7] The combination of smooth surgery, good donor lungs, and overall physical well-being could lead to great results. Bill Poplett was released from the hospital just six days after his operation; that morning he had ridden ten miles on the exercise bike and walked thirteen flights of stairs. When Charles Tolchin did his first six-minute walk test, he set a local record as "the first person to run four weeks after his operation." Don Hawkins was released ten days after his surgery and was working full-time after two months. "They had told me that it was going to take probably anywhere from four to six months and I said, 'I don't think so. I don't have time to waste; I've got to get back to work.'"[8]

For others, however, the postoperative period was far from smooth. Even regaining consciousness was difficult for some people. Cheryl Maxham recalled,

> I woke up and there is absolutely nobody there in the room. Oh, I'll never forget that. I had this tube shoved down my throat and my hands are tied down to the bed. I couldn't reach the bell cord to call. I couldn't call anybody, because you can't talk, and I remember laying there and I was so scared. That was the worst part.

When Mary Ellen Smith awoke, she was irritated by the ventilator tube sitting at an odd angle in her throat and became agitated because she couldn't explain the problem to the nurse. "When you can't talk," she explained, "you're afraid."[9] Confusion could also be a problem. Laura Scott Ferris recalled going in and out of consciousness and having heavy eyes; though her family was in the room with her, she found it hard to recognize them because they wore surgical masks.

Delirium or "postoperative organic mental syndromes" were fairly common during the first 14 days. For Laura Scott Ferris, hallucinations included green slime on the nurses' heads; Ana Stenzel thought she was in post–Civil War Savannah; Jan Travioli believed the patient next to her was having sex with all the doctors; Tiffany Vuncannon thought a nurse was trying to kill her.[10]

Breathing on one's own was not always easy, either. Some experienced complications that made getting off the ventilator or supplemental oxygen problematic. For others, the problem was different. Although they had dreamed of life free from an oxygen tube, when the time came, many were afraid to give up what had been their lifeline. Jack Snyder resisted, and his transplant coordinator "finally walked up to me and said, 'Jack, you trust me, don't you?' " When Jack answered yes, "She just reached over and plucked it off me." Nor did Kathryn Flynn want to let go.

> You're always reaching to make sure the hose is there in your nose. So they have to trick you. So what they do is they come in when they think you're really ready and they turn it off but they don't tell you. Then they'll come in a couple of hours later and say, "Do you know you've been off oxygen for two hours?" They had to do that to me.[11]

In contrast to those whose first breath was a glorious moment, Laura Scott Ferris reported hers was "a moment of sheer panic. I didn't know what to do. I didn't know how to breathe!" It had been so many years since she'd breathed normally that she had automatically reverted to very shallow breathing. She had to will herself to relax and mimic her mother's breathing. Ana Stenzel's new lungs expanded slowly, and she worried about whether they were working, felt she couldn't breathe, and hyperventilated. After this panic attack, a psychiatrist consulted with her. For a day or so, Pauline DeLuca tried to stay awake, thinking, "I better not sleep because I might forget to breathe.'"[12]

Not everyone experienced the relatively painless recovery that others raved about. "I felt awful!" exclaimed Tiffany Vuncannon. "I thought I was going to have this moment of waking up being able to breathe and everything was going to be great, but I was in pain. Most of the time I just felt like I was just a big sack of tubes and needles." Dare Reitz explained, "I had 85 staples. It hurt like the devil." For at least a couple of days, recipients had two or four uncomfortable chest tubes, which originated near the lungs and passed out through the skin to a machine that created suction to drain fluids (figure 6.3). Despite pain and chest tubes, recipients needed to sit up and cough as soon as possible since the surgery cut the nerves that prompted coughing and interfered with the process by which cilia normally moved mucus out of the lungs. Coughing and moving helped the lungs function and kept fluids and infections out. Still, the instructions surprised Matt Byrd. "That was probably the worst pain because I just had my chest ripped

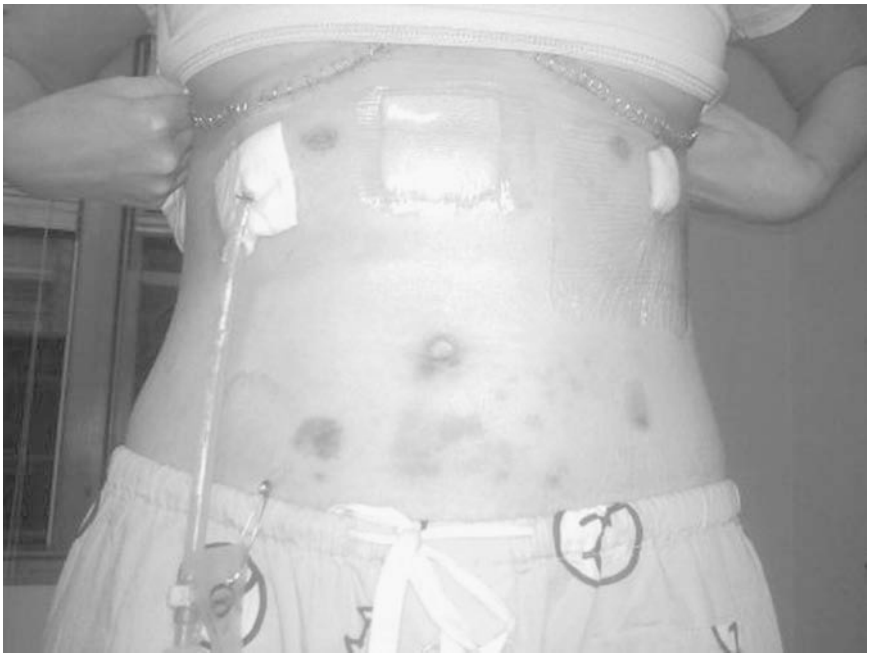


Figure 6.3 Stephanie Briggs's stitches and the scars from her chest tubes are apparent three weeks after her double lung transplant. One chest tube remained in place. Courtesy of Stephanie Briggs.

open. They want me to [cough] and I thought they were crazy." He said the nurses were yelling at him like a football coach to get him to cough, and if they hadn't been holding him, he would have collapsed from the pain. Then a little later, "This lady came in to do [therapy], and I said, 'Um, I just had a lung transplant, and my chest . . . you're going to beat on it?' She goes, 'We have to. Turn to your side.' And I said, 'I have chest tubes!' "[13]

Tiffany Christensen also struggled afterward. First, an x-ray technician slid blocks of film under her back, which was "unbelievably painful, but I was intubated and could not cry out for him to stop." Then respiratory therapists came in to loosen phlegm. This felt "like a jackhammer on my chest and I could barely stand it." When next they came to make her get up and walk, she could not hold back her tears. "Crying while intubated isn't pretty," she observed, and her tears frightened off the therapists. Christensen felt that hospital staff discouraged crying and did not appreciate that it was a perfectly natural and helpful release. Indeed, "After my cry, I was able to get up and take that walk." Christensen later wrote a book intended to help medical professionals better understand and treat lung transplant candidates and other seriously ill people. It suggested caretakers should honestly tell patients about things that could go wrong and how difficult experiences might be. When her doctors had warned her of difficulties, she knew her experience was normal and was "much better equipped to cope with

the pain." She also recommended that doctors and nurses observe and acknowledge (rather than ignore) what patients feel. In her experience, having her emotional state acknowledged calmed her down and made her feel "recognized and respected as a human being."[14]

Others had unusual causes for their pain. For Howell Graham, it was a small undetected crack in a vial that prevented his morphine from being delivered. One of Jasper Martin's vertebrae shattered during the surgery leading to "four days of total misery." Lynn developed "really really nasty" migraines from one of her medications. "These migraines were so bad and just wouldn't go away. You just wouldn't want to do anything but lay in the dark all day. That was pretty frustrating . . . At that point I was about ten days [post-transplant] and I'm thinking, 'This is not a good trade off. I can't live like this . . . ' I [was] freaking out." Regardless of special circumstances, it was fairly normal, as Carol White put it, that in "the first week, you feel sub-human."[15]

Often suffering was short-term, but some people experienced more serious complications during or shortly after the surgery. Bleeding, defects in the airway connections, infection, and "graft dysfunction" (caused by the process of removing the lung from its natural blood supply) were among the leading causes of early mortality.[16] Melodie Greene's trachea completely ripped apart, which required her to undergo a second transplant. Karen Fitchett fell into a coma after her surgery due to a problematic donor lung. Kelly Helms's surgeons were mystified about why she couldn't get off the ventilator. Eventually they figured out that she had an airway blockage that required another seven-hour operation. After that, she spent seven more weeks in intensive care on a ventilator. Helms recalled,

> It just is the most uncomfortable thing. You can't eat, you can't drink . . . I didn't have anything to drink for seven weeks. Everything has to be through feeding tubes. You can't talk; you can't do anything. You've got a huge hose all the way down your throat into your lungs. And you can't move; it's hard to turn. That's horrible. It's just so uncomfortable, and it's 24 hours a day. I wouldn't wish it upon my worst enemy. So I had some major, major complications after surgery, and at one point, during that time, I really thought, "Did I do the right thing? Should I have done this? I'm never going to get out of here." I was really depressed at that point, thinking, "This is not going to work. I had my chance, and it didn't work."

Lori Hughes also had to go back into surgery two times, once for bleeding and once for fluid in her pleural space. Stuck on the ventilator for an additional two weeks, Hughes also regretted the decision to be transplanted. "I did tell my mother at one point that I had felt like I had made a mistake." Her mother reassured her that things would get better, and indeed she was released from the

hospital after a month or so, but within a few weeks she suffered a seizure and had to be rehospitalized.[17] Digestive problems were also common, plaguing about half of lung recipients, and these were so serious for one-fifth of them that they required more surgery. Kathleen Feeney's gut "was not processing food through [and] was completely backed up," Joanne Schum had to have an indigestible mass of material blasted out, and Barbara Stepp required an ileostomy.[18]

Although the timing differed, recipients who survived eventually began rehabilitating and making significant progress. Typically a person's hospital stay lasted two–three weeks, but it depended upon complications and how much they had deteriorated before the transplant. Tim Choquette had been so near death that he had been on a ventilator for ten days before lungs came available. After transplant he "was in a really wasted kind of a body situation [from being] on my back and not moving a muscle, and my body had just fallen apart. I was down to like 79 pounds at the time so I had no muscle; I couldn't do anything." After Choquette was discharged from the hospital, he went to a rehabilitation facility for a couple of weeks. Even after that,

> I really couldn't hardly open a milk carton. I was sort of standing and getting to where I could go a couple of steps at a time, but it was really slow, and I was always kind of scared of falling down and not being able to get up. So it was pretty rough . . . There was a long time I was . . . just sitting in my chair and looking at my arms and going, "Where did my muscles go? Why aren't they coming back faster?" or "Why can't I pick up the soup can?"

"My body was like Jello," echoed Jan Travioli. "I've always thought of myself as a pretty strong, self-sufficient person, and to not be able to do the simplest things was really hard." Steve Brunson had such severe problems before and after transplant that he was bedridden and unconscious for months. He faced an extremely long road—first having to relearn how to sit up, then how to walk with a walker, using guardrails, without support, and then finally outside on uneven surfaces. He also needed occupational therapy to learn how to pick things up and eat. "For a while there everybody was having to feed me. I was like a little kid. I was a 38-year-old baby." When even the most basic of activities was hard, recipients could feel pessimistic. Barbara Stepp recalled, "Although they kept saying, 'It will come back; you will be able to walk,' I didn't believe them."[19]

They were encouraged by both therapists and their improvements. Of his first walk connected to tanks, chest tubes, and IV poles, Jasper Martin recalled, "It's a miserable walk, let me tell you. But I could still feel, even with all that misery, that things are getting better, all of this is just temporary. I could tell that I was getting better after the fifth day." Tom Fereday appreciated a nurse who challenged him after the surgery, telling him he was going to die and waste the donor lungs if he didn't do more to help himself. At first he thought, " 'Who the

hell do you think you are? Do you know what I've been through?' I was pissed off. But she was the one who turned out to be my best friend there. That's the nurse that motivated me." Though difficult, the rehab also could be gratifying. "It was amazing," said Pauline DeLuca, "because after the transplant I was able to do all the stuff that I couldn't do before. I mean really pushing yourself and then seeing results and stuff? It was great."[20]

A recipient's perspective might shift through the process. It might also depend on one's original expectations. For a contented M. L. Bryan, "it really went a lot faster than I figured it would go." For Jimmy Carroll, on the other hand, things were more difficult than he had anticipated, and he was depressed for a period. "I did go through some feelings of, 'I didn't know it was going to be this bad,' when I was tired for so long, and just had little energy for several months after the operation. I didn't realize it was going to take that long." In retrospect, a year and a half after his surgery, Carroll would conclude, "Overall, it's just been a great experience," but he certainly did not feel that way in the beginning. Similarly, Tom Fereday distinguished between how he felt in the short term and later. Although he would eventually be skydiving and running races, the recovery period was long and "tough. You know they say you're not going to feel normal for a year, and it took me every bit of that year before I finally got everything settled." Kathleen Feeney had a very difficult course, marred by both physical and emotional problems. Later she would describe her quality of life as excellent, but she wouldn't have done so shortly after the transplant.

> The first three months after my transplant, if you had asked me—and people did and I told them—I thought I had made the worst mistake of my life. My sister-in-law gave me some great advice. She said, "Look, you're making progress. You can't see it. It's like watching your hair grow. If you watch it, you're never going to see it. But one day you're going to look in the mirror and say, 'My God, I need a haircut.' " She said, "That's how your progress is going." And I sort of held on to that.[21]

Physical Challenges of Living with a Donor Lung

Whether they had a quick recovery or a slow and difficult one, all transplant recipients faced a common threat: rejection. The immune system's automatic response to a foreign object, rejection would normally destroy the lung (and kill the recipient) within a couple of weeks unless measures were taken to prevent it. By the turn of the twenty-first century, transplant teams had developed a standard drug regimen intended to suppress the immune system, which included daily doses of a calcineurin inhibitor (such as cyclosporine), an antimetabolite,

and corticosteroids. It was difficult for transplant teams to diagnose rejection because its early symptoms were subtle and mimicked those of infection. Doctors could confirm the diagnosis with a biopsy in which cells were obtained through a bronchoscopy, which is a short procedure (requiring local anesthesia) in which a tube with a light and lens is inserted through the nose or mouth and down the airways into the lungs. Transplant teams scheduled routine bronchoscopies in the early months because almost all recipients experienced acute rejection during their first year after transplant. Rejection was usually reversed by increasing the medications, but the risk would remain with lung transplant recipients for the rest of their lives.[22]

Suppression of the body's immune system meant that transplant recipients became highly susceptible to infections. Lung recipients were especially vulnerable, since with every breath, lungs are exposed to the outside world and all its germs. In addition, the damage caused by the surgery to the cough reflex and the lung's ability to move mucus made it difficult to remove foreign material. Medical teams prescribed drugs in the hopes of preventing or minimizing the damage of various types of infections, which, unless spotted early, were quite dangerous. Infections constituted one of the main causes of death among lung recipients both short-term and throughout their lives. One study concluded that about 16 percent of lung transplant recipients got bacterial pneumonia in the first month after transplant. One virus, cytamegalovirus (CMV), was so troubling that many centers would not give a donor lung that had been exposed to the virus to a recipient who had not. About 5 percent of recipients developed an opportunistic fungal infection, aspergillus, which was difficult to diagnosis and was sometimes fatal.[23]

To defend against these perils, physicians encouraged recipients to avoid risky situations in which they might catch infections. Frequently they asked them to wear surgical masks covering their mouths and noses shortly after transplant and when around sick people or crowds. Finally, the teams preached that recipients should closely monitor their own health by regularly taking their temperature (since elevated temperature could be a sign of either infection or rejection), breathing into a spirometer (to measure volume of air leaving the lungs), and reporting if they developed a cough or became short of breath. The stakes were high for correct diagnosis of the cause of any problems, since wrongly treating for rejection further suppressed the immune system and made infections even more dangerous.

The new medical regimen required adjustments. "I hated my face being covered," said Mary Ellen Smith, who was told to wear a surgical mask for three months. Some recipients also found it challenging to learn what medications to take and when and how to monitor their health. "I was pretty confused for a while," Tim Choquette remembered. "There was maybe eight or ten different [drugs] I was taking and it was pretty complicated. And at the time, I'm

sure, my brain was still pretty foggy." For people like Steven Bunsen, who had never even taken vitamins, the number of drugs was daunting. People who had grown up with CF were used to taking a lot of drugs, but even they could find it a lot to take in. "It was mostly new medications," Bob Festle explained. "The strangest thing was learning what these medicines do, learning how much you take, because you're in such a routine that it's difficult to learn a new routine."[24] Joanne Schum admitted she was on "tons of medicine"—at one point 72 pills a day—but she downplayed the difficulty of the new regimen, saying, "It's worth it. I know everyone's like, 'That's a lot of pills.' Big deal! I can swallow pills anytime. I just can breathe; that's the good part." A few people could barely endure the medications, however. Charles Tolchin became nauseous from the smell of the cyclosporine, and "the pill tasted far worse than it smelled . . . My gut would still wrench every time I swallowed a pill. It was as if my body considered it poison and instinctively rejected it." M. L. Bryan was concerned about the cost of his 23 pills a day, which was over $1,000 a month, and he admitted that the whole regimen of self-care was something he had to "work at." He got used to it, however:

> It's just a daily routine I get in; I just try to do everything at the same time . . . I take my blood pressure and temperature twice a day and I have to record that. Then I do what they call F.E.V. [forced expiratory volume], when I blow into this little machine and it records that, and then about once a week I give them these numbers, the blood pressure and all this.

The procedures usually got easier over time. Carol White remembered how she felt when a home health nurse first showed her how to set up her own IV.

> I'm sitting here going, "I'll never do it. Oh my God, I'm going to have a bubble in there and I'm going to kill myself." . . . I just wanted to sit here and cry. I thought, "There's no way I'm going to be able to do all this stuff. No way." But you did it. And now I don't think no more about it.[25]

The powerful immunosuppressive medications produced undesirable effects. As Carol Stimmel observed, "They're great drugs but they also create problems."[26] Many problems were long-term ones unrelated to lungs, which doctors hoped would not interfere too much in a probably limited lifespan. Because the immune system plays an important role in detecting and limiting precancerous growths, cancer could result from anti-rejection medicines. Transplant recipients developed lymphomas at a higher rate than the general population; 16 percent of lung recipients had some kind of malignancy by five years after the surgery, and 32 percent had cancer by ten years. In one study, kidney toxicity was a "nearly universal consequence"; over 90 percent experienced a decrease in renal functions within six months, and 5 percent required dialysis. About one-quarter had

neurological complications, including 5 percent who suffered a stroke. Almost three-quarters of lung recipients had significant bone density loss; 28 percent had sustained a fracture.[27] Both in the short and long term the drugs affected people quite differently. While Richard Throlson said, "The cyclosporine was pretty tough on me," Howell Graham reported, "I tolerate all my medicines very well. I'm very lucky." Not everyone got all the possible side effects, of course, but cyclosporine frequently gave people tremors. "You shake really, really bad and it deteriorates your eyesight," explained Cheryl Maxham. "Your eyesight comes and goes, because they are always playing with the doses of your medications. I mean I had tremors so bad I couldn't write. I couldn't hold a cup of coffee. Ugh, it was a terrible feeling."[28]

The drugs could cause other issues as well. Some recipients suffered with depression or anxiety. "In the months following my transplant I found myself overcome with severe fatigue, a lack of motivation, an unrelenting mental fog and an inability to concentrate," remembered Ana Stenzel, who was diagnosed with depression. People taking immunosuppressants could be susceptible to anxiety, and some studies found that psychiatric distress levels were higher in transplant recipients than in the general population and that such problems were highest in the first year after transplant.[29] For some people emotional issues were temporary or tolerable, but for Kathleen Feeney they were serious and continued after her release.

> I was having a lot of emotional problems and I started getting kind of like hyper and paranoid. I couldn't focus. I couldn't read. I couldn't work on the computer . . . I had nothing to do . . . I was going nuts and ended up getting very frightened. It was like, "I just can't deal with this anymore, I can't cope with this anymore." I just wanted to stop. It was like a nerve attack . . . They decided that I was losing stability, and I agreed with them.

Especially difficult side effects required a response that might include more medicines. Besides her immunosuppressants and anti-infectious agents, Joanne Schum explained with a laugh, "the rest of the drugs are to treat side effects of those drugs. And then some of those drugs give you side effects, then you've got to take another . . . "[30]

Steroids such as prednisone combated rejection effectively, but frequently caused unwanted effects. One was a moon-shaped face. "That made me look like a little chipmunk," noted Mary Peters. Steroids created such intense mood swings in Betty Harrington that her family established a code word to let her know when she was abnormally grouchy. Rosalie Gallogly had the same problem. "At first, with the high doses that you are on, you feel sometimes like you are crazy. I don't know how else to put it. You get confused . . . The steroids would make you cry one second and be laughing the next, or all of a sudden I'd just get angry for no reason whatsoever." In addition, noted Dare Reitz, "you feel like you are starving

to death, and you gain weight." Steve Brunson concurred, "Prednisone makes you hungry all the time. Sometimes [my wife] has to tackle me from going to the refrigerator every five minutes."[31] Other side effects of prednisone included headaches, acne, sleeping problems, diarrhea, swelling and water retention, joint pain, hearing loss, ulcers, dangerously heavy menstrual bleeding, and neurological problems.[32] Along with a swollen face, some of the more outwardly visible side effects were related to hair, which grew excessively or changed in color or texture. "I had hair, hair, and more hair everywhere!" exclaimed Betty Harrington. Ana Stenzel did not look or feel like herself.

> Dark hair the texture of peach fuzz grew on my nose, earlobes, and cheeks. My eyebrows became dark and bushy, forming a unibrow. The hair on my head became drier and thicker; one strand even formed a corkscrew curl that stuck out from my otherwise straight hair. Pimples erupted like bubbling lava from my oil-drenched skin . . . I look awful!"[33]

While they required some adjustment, recipients accepted all the side effects as a matter of course. It helped that some of the problems decreased with adjusted doses or with the passage of time, as the body got used to the drugs.[34] After a few weeks, for example, Charles Tolchin's body stopped revolting every time he took cyclosporine. Sometimes a different drug could be tried. In addition, many of the problems caused by the drugs could be treated. Ana Stenzel's doctor sent her to a psychiatrist who treated her with antidepressant medication and helped her feel the "old Ana coming back." Two weeks in a psychiatric ward helped Kathleen Feeney get stabilized and go home, back to work, and on to an "excellent" life. Lynn was relieved to hear her doctors reassure her, "We have drugs for migraines. It will take care of this." In addition, some recipients simply did not consider the side effects a very big deal. Howell Graham had always had thin hair and when his hair grew very thick, he considered it "completely cool." Most people were relieved when their side effects tapered off, but for Graham, "That was a sad, sad day when I realized that side effect was going out the window." Lynn was not excited about the bad rash on her chest, acne on her face, and hairiness, but, she reasoned, "I can live with that. I don't need to run around and show my stomach. I'm 35 years old. I'm beyond that . . . It's all manageable stuff. It's an okay tradeoff for breathing." Suzanne Tierney echoed that outlook. She admitted that some days she got depressed when she looked in the mirror, but noted, "I sure look better than any corpse I have ever seen."[35]

Lifestyle Choices

Having been "reborn," as some put it, or at least given a second wind, lung recipients had to consider who they were and how they wanted to live. In particular,

they needed to incorporate their new organs and immunosuppressed health status into their daily lives. Once released from the hospital, they were responsible for caring for themselves by taking their drugs and regularly monitoring their changed bodies. Charles Tolchin recalled that at first it was difficult to know exactly what to do and what to worry about.

> Everything is completely new after transplant: the medicines, the diet, the routine. The chemistry of the body changes dramatically. At first, I did not know if excessive ear wax or large nipples were dangerous side effects. It is hard to know when to page the lung transplant coordinator on call. My friends and I have paged them at all hours of the night and interrupted every life activity imaginable. Slowly, one learns.[36]

Beyond interpreting new bodily signs, recipients had to decide how they were going to respond to a world in which they were at high risk of both rejection and infection. Every day they faced choices about how to behave and the attitude with which they were going to approach their situations.

Many recipients chose a strategy of careful daily vigilance. Because she "went through so much just to get the transplant," Karen Couture chose not to work full-time and to use common sense, "stuff like the things that your mom told you when you were young: Eat well, sleep, get enough rest, and exercise. I wouldn't say [I live] a Spartan, monkish life, but I have to take care of myself." Bill Poplett stressed being aware of what the medications were doing and what his body was telling him, and to ward off infection, he reported,

> I do a lot of hand washing; we have a lot of anti-viral hand sanitizer, soaps, that kind of thing. I wash my hands continuously, and primarily watch out, staying away from smoke and other factors that might damage the lungs. It's taken me too long to get this; I'm not going to jeopardize it. It's a gift and I don't want to ruin it."

M. L. Bryan was willing to risk embarrassment in order to minimize his own risk of infection.

> If we go to a restaurant, I try to pick a table that is not so crowded or close to anybody. And if there is more than three or four people around, I wear my mask. If I go to a place like Walmart, I wear my mask. I know it looks stupid sometimes, but still, I know where I've been.[37]

Caution could require some changes to daily life. At a meeting, Kathleen Feeney explained to a coworker who had a cold why she donned a surgical mask. She said this honest, matter-of-fact approach worked best for her. "I have

personally found that if you treat things as normal for you, then people relax around you. If you are comfortable enough to let people ask you questions, then you can communicate with them and then they see you as a person and not as this weirdo with a mask on." Judy Ryan wore a surgical mask on plane trips, when she went to the hospital, and if she heard someone sneezing in a store. "[I] always worry about the germ factor," she said. "I use a lot of Lysol spray. You've got to be really super cautious." Melodie Greene, a former nurse, posted a sign on her front door nicely asking people harboring anything contagious not to come inside. Steve Brunson and his wife traded some household tasks. She mowed the yard, cleaned the bathrooms, and vacuumed so he would not inhale bad things; he admitted that he didn't always hold up his end of the bargain by doing the dishes and laundry. "So it's kind of rougher on her," he laughed. "It's easier for me, so I'm handling it real well."[38]

They took these precautions because they understood the risks. Laura Richards and Rosalie Gallogly were acutely aware of the dangers because of brothers who had problems with transplanted lungs. Mary Ellen Smith's wariness came from the strict instructions of her transplant team. Still, she admitted that, at times, "I [want to] just scream and say, 'I don't want to take any medicines anymore.' I just want to just go and do, and not worry about working in the garden or cutting the grass or playing with the cat or playing with the dogs." She resisted that temptation because "they have proven that if you're not compliant and [don't] follow all the rules that they set for you that you run into big trouble. A lot of the patients have died not taking their medications because they think if they don't feel sick then they don't have to."[39] The Cleveland Clinic underlined that same message in its recipient handbook. In response to the question, "Does it really matter if I miss a dose?" it declared, "Yes. It is very important to always follow the instructions for your medications every day to prevent rejection. The third major cause of transplant failure results from not taking anti-rejection medications as prescribed."[40] Kathryn Flynn got the message. "I still live with that idea that one infection could do me in at any time. I don't ever forget that. And I know my husband never forgets that . . . " Rejection also posed a constant danger, of course, and physicians and recipients alike worried about the invisibility and ambiguity of its symptoms. "It's funny," explained Karen Couture, "when people think rejection they think that it is a seizure or something. But basically you have no symptoms and sometimes it is just like a cold; you feel like you have a cold."[41]

Others were somewhat less intense in their approach. Complying with doctors' stringent recommendations could be impractical. Steve Brunson generally avoided people who were coughing, but occasionally didn't, because "it's not real polite to get up in church in the middle of the preacher's sermon and move to another pew." Other recipients could not adhere to all the guidelines because of their jobs. Because of the risk of a certain fungal infection, Steven Bunsen's

transplant team had instructed him to stay out of the garden and avoid getting soil under his fingernails. He replied, "That's going to be rather tough . . . [As a farmer] I definitely go out and dig in the soil. That's my livelihood." After he explained, Bunsen's doctors said he could keep farming but should take more precautions while working. He appreciated their overall message: "Go back and live a normal life. That's why we transplanted you." Brett Pearce knew that there were some sacrifices he simply would not make to protect himself.

> I know I'm not going to be very careful, because what I want after transplant is to be in a medical school, and I'll have to go into a hospital every day, and I'll be exposing myself to all types of garbage. But it's the only way I would enjoy what I was doing. To me, there's no point in getting a transplant unless I was going to do something afterwards that I enjoy, even if probably they wouldn't recommend it.[42]

Some people simply were willing to take more risks than others. Most took their medications religiously but drew a less stringent line on avoiding germs. Carol White recalled a recipient friend recommending that she not babysit her grandchildren because of the infection risk. White responded, "I didn't go through this to sit in a bubble. I went through this to have a halfway normal five–seven years, whatever the length of a regular transplant is. Why go through it if you're going to be an invalid afterward?" Similarly, Mary Ellen Smith knew that caring for her children increased her likelihood of catching something (indeed she contracted chicken pox from her son). She concluded, "I don't worry about those things as much as I should, but I find that the more I do not worry about them, the better I am." Tom Fereday wanted to care for himself, but resisted a few of the suggestions for how to do that.

> They said don't shake anybody's hand, to wear a mask for six months, be very cautious about going out, things like that. I didn't follow it at all. I was compliant with everything else, but I figured I never lived my life holding back, and I said, "Screw it. I'm not going to compromise the way I was." I got a new chance, granted, but I was going to live the way I did before, so that's what I did.[43]

A person's attitude or level of vigilance could change over time—and the changes could be in either direction. Joanne Schum's fear lessened as time passed. She had worried "germs would be waiting to attack whenever I set foot outside my door," but then only had one cold during her first two years. "Since then I've learned just how strong my immune system really is," she observed, and opted to be "sensible" but not paranoid. Two and a half years after her transplant, Kathryn Flynn explained that her behavior had changed.

She no longer took her temperature twice a day because it made her "neurotic," and instead did it and her microspirometry around three times a week. Carol White concurred, "I think you get complacent. You think, 'Yea, I've done it.' " Frank Avila said that six years after his transplant, he had started taking some things "a little bit more for granted now . . . You worry less about certain things so over time it definitely gets better."[44] One study suggested that early in the post-transplant period some recipients enjoyed a "honeymoon period" when they felt elated by the fact that their lungs were functioning so well. During this period, they could be fooled into thinking they'd achieved "normalcy" and become less vigilant.[45]

The willingness to take risks sometimes changed after recipients experienced a setback that forced them to face their continued vulnerability. "I slipped up lately," admitted a participant in a study given the pseudonym Mr. Victor. "If I had been paying closer attention I might have noticed that my spirometer had dropped considerably over the past weeks [but] I kind of ignored it." After being diagnosed with rejection, he concluded, "It could've been a deep regret. I need to notice how I feel, watch the numbers. I learned the hard way."[46] A setback convinced M. L. Bryan of his doctors' wisdom. He had pushed his doctors for permission to attend a wedding shortly after transplant, and then, "the next week or so, after my blood work, I had some kind of infection. And I had to take IVs three times a day for ten days. See, that's the reason you have to be so particular about crowds." Judy Ryan pointed out that when you're doing well, as she was three and a half years post-transplant, "you forget you have the transplant. Then something brings you right up sharp that says, 'Hey, you do have a transplant.' " Tiffany Vuncannon was sobered by the "worst-case scenario," having so many serious problems that she had to undergo a second transplant.

> After the first transplant I thought, "Okay, I've gotten through this, I made it! This was so horrible and so bad and so painful, nothing bad could possibly ever happen to me ever again because I've paid my dues to life and I'm done. Woo hoo!" And then you know two years later I had to go through it all again. I have learned that having one disease doesn't protect you from another and I am very diligent about other areas of my health . . . I have a lot more anxiety this time around. I have chronic insomnia . . . I have a lot more nervousness and fear. It's sort of like the rug was pulled out from under me. I'm always on my guard; I'm always on my guard.[47]

Compliance required a willingness to assume personal responsibility and partner with one's medical team. After the long ordeal leading up to transplant, candidates may have wished for freedom from doctors, but this was not possible. "I didn't want to face the fact that after transplant I was still connected to the

team," said Mr. Gerrard. After some problems, "I realized that it was truly up to me to take responsibility for what happened to me, not that I could do it independently, but I knew what my part was. I was on the front line so to speak, and the team was there to back me up." Mr. Barr concurred, "If anybody wants to get a lung, they might as well resign themselves to being married to the transplant people up there."[48]

Recipients dealt with their shortened life expectancy in different ways. While some were haunted by the dangers of rejection or a suppressed immune system, Lynn asserted that it was "the shorter life that freaks me out." She was very aware that only 50 percent of lung recipients lived for five years after transplant.

> I really need to assume that I'll live a whole lot longer than that. But it's very scary. I still find it scary to think about a potential cap on your life. I understand that anybody can die any day; some things happen. I get that, but you don't run around and think about that every day. But when you've had a big surgery, you can't help but be conscious of the path your life is taking.

Cheryl Maxham, on the other hand, consciously chose *not* to think about the future. Two years after her transplant, she tried to explain the life expectancy odds the way the doctors had explained them to her, but found she couldn't.

> I don't know how it works. I don't want to know the statistics, because I don't want to know if I'm going to die or not. I just live obliviously every day thinking, "Oh, I got up another day," you know? I don't know the statistics, but I figure each year they're coming out with new medications all the time, and I'm one of the luckier ones. I think I'm going to have a good chance. I think I may live 20 years. I really think I will. I can't see myself even going through rejection or infection. I think maybe they have enough knowledge now and experience with the lung transplants that I'll survive. That's my thoughts . . . because that's the way I want to think.[49]

Judy Ryan did not deny the reality. "Eventually it's going to reject and you're going to die, but you've got to focus on something else, not to be [overly] aware of that. The only way after transplant that you can function is to realize what a gift you have and to live your life to the fullest." Laura Richards opted for an intermediate sort of position, acknowledging the risks but choosing not to dwell on them until she had to. "There's going to come a time when my body's going to start rejecting this lung for good and that's something that I have to deal with when that time comes." Carol Stimmel was doing so well she had to actively resist the temptation of denial. She explained her approach: "I take each day as a blessing that I'm here, because it all could change."[50]

Nonphysical Challenges of Living with a Donor Lung

Life after transplant required more than just physical adjustments; it often meant recipients faced basic issues related to identity. "Ironically, I was left with a feeling of emptiness after my transplant," explained Ana Stenzel. "For so long, my reason to live was to 'fight' CF and to sustain my body so that I would be strong enough to survive my transplant. Now that it was over, I was in a state of limbo wondering, 'now what'?" After being treated for depression, Stenzel succeeded in finding many meaningful ways to spend her time. Similarly, early on Jan Travioli struggled with depression since she did not want to return to the job she'd had before transplant and was not sure how to use her newfound freedom. "It's kind of set me back mentally a little bit because I don't know where to start," she reported. "I guess that's normal among transplant patients—at least that's what they tell me—so I don't feel like an oddball anyway." Psychologists have noted that reestablishing one's niche within family and society and fulfilling expectations proved overwhelming for some recipients.[51] In addition, their loved ones had to adjust. Some of Steve Brunson's family

> treated me with kid gloves. They thought I couldn't do anything for myself. They don't let me lift things or stuff like that; they try to make sure that I've got enough clothes on in the winter and stuff like that. You know, I'm 40 years old now and I think I can handle most of that stuff on my own.

Kathryn Flynn noticed a similar phenomenon. "My husband was used to doing all this stuff for me and he no longer had to do it. I kind of had to say, 'You don't have to do that,' and to push him away and say, 'I can do this now.' " Flynn said it took time to figure out who she was, who she wanted to be, and how to take control of her new life. "I spent so many years disabled that you almost have to learn to be 'abled' again."[52]

Although any lifesaving treatment can provoke strong emotions, lung transplant recipients' feelings were complicated by the fact that their survival came thanks to a donated organ. Sociologists Renee Fox and Judith Swazey, who studied kidney and heart transplantation starting in the early years of the procedures, asserted that the circumstances of organ donation create a unique and emotionally laden situation for recipients. They noted that gift exchanges are rooted in cultural norms for symmetrical and reciprocal obligations, including an expectation that a person find an appropriate way to repay a gift. The gift of life that comes with a donated organ, however, is extraordinary, priceless, and not repayable. It has no monetary, physical, or symbolic equivalent so it is impossible for the recipient to reciprocate. This leaves the recipient with an "awesome sense of obligation" that can be difficult to deal with, so much so that Fox and

Swazey referred to this "burden" as the "tyranny of the gift."[53] Interviews and other reflections show that, as Fox and Swazey would have predicted, lung transplant recipients were profoundly aware of the sacrifice of their donors and donor families and they had strong feelings about their donors' gifts, but those feelings varied, as did lung recipients' responses to them.

Since the vast majority of lung recipients received their lungs from unknown donors who died in a sudden and tragic way, it is not surprising that many felt sad for the donors and their families. In the days and weeks shortly after her transplant, Judy Ryan was so upset thinking about the donor family's loss that she required counseling.

> I knew what the family was going through. A young woman minister counseled me for two or three sessions because I was having a hard time dealing with . . . I know the family's going through the funeral. I know what it is like. I have lost people in my family, and that was really hard.

Danelle DeCiantis had a similar reaction. "I'm saddened because another family is grieving. The anguish I felt for that family was overwhelming." She noted that every anniversary of her transplant was bittersweet—a cause for celebrating her own life but mourning her donor's loss. Dare Reitz was distressed as well.

> It upsets me that he had to die for me to live. It's upsetting that *anybody* has to die, but somebody so young, and be robbed of his life. That's very upsetting to think it was caused from someone else's carelessness that doesn't care about anybody else in the world and has to go around shooting guns all over the place. That's upsetting. You think that he was 21 years old; he had his whole life ahead of him. That's very upsetting at times.[54]

A number of others had survivor guilt. Ana Stenzel said she felt "guilty and overwhelmed" after her surgery. Cheryl Maxham pondered why she got a second chance when others did not. "I feel guilty sometimes because I caused my own disease [by smoking], yet I get [a transplant] and I get to live a normal life." Laura Scott Ferris dwelt on the fate of her donor, a young woman killed in an accident. "The one [difficult question] that kept replaying in my mind was, why had she died and why had I lived? After all, I had been born with a terminal illness. She had been born full of life."[55]

Some recipients felt curiosity about who their donors had been and how that might affect them. Sociologists Fox and Swazey reported that early transplant physicians had been surprised by the strong emotions recipients felt and the irrational and magical ways in which they sometimes thought about their new organs and donors. Wanting to protect donor families and recipients from having to cope with complex expectations or obligations to people they had not

known or chosen to be in a relationship with, medical professionals had designed a system that insured anonymity for both parties throughout the donation process.[56] By the time lung transplant recipients in the 1990s received organs, this system was well-entrenched and transplant teams encouraged them to see their donated lung as simply functional biological entities that helped them breathe. Still, that didn't stop some recipients from imagining details about their donors. Frank Spears knew nothing about his donor but felt so good after the transplant that he was convinced it had belonged to "either a young person or someone who was athletic." Occasionally recipients felt the donor organ somehow altered their identities. "There was one body before the transplant and one after. I don't think you can go through something like that without it affecting your mind. Who am I now?" asked Laura Rothenberg.[57] Others joked about now being "part Cherokee" or "part Amish" because of their donor's background. A few superstitiously attributed their good or bad fortune post-transplant not to the lung's biological and immunologic characteristics but to their donor's personal ones. Ana Stenzel wondered whether she had avoided organ rejection because she shared the characteristics of strength, independence, and determination with her donor. During an episode with rejection, Shirley Jewett decided that she should formally incorporate the foreign lung and make it her own. "I ceremoniously welcomed my new lung into my body," she wrote. "I gave it a name." She called it "Tina," inspired by singer Tina Turner, a survivor of hardships.[58]

A few recipients believed they had inherited more than just an organ. Since she'd developed a strong urge to go fishing, Isa Stenzel speculated her donor had liked fishing. Like some others, Laura Scott Ferris embraced a notion she called "cellular memory" (a term borrowed from immunologists who used it in a very different manner), referring to the notion that some parts of her donor's personality and memory would be transferred to her through the cells of the organ. Ferris reported being overcome by a terrified feeling at a certain intersection, which she later learned was the place her donor had been hit by a car. "I knew. I was carrying an intense memory from her."[59] Although scientists dismiss them, anthropologist Lesley Sharp reports that such stories of inherited characteristics are fairly common lore in the transplant community, and she sees them as a way society and individual recipients "naturalize" the relatively new and "unnatural" process of mingling two bodies in transplantation.[60] However, most recipients had no such experiences, and as their physicians encouraged, saw the new lungs as impersonal objects, now their own. "If God was good enough to bless me to have educated people on this earth who knew what to do and were willing [to donate lungs], and he gave me that kind of blessing," said Mary Ellen Smith, "then they're mine." Jasper Martin, whose donor was female, ridiculed the notion of inheriting donor characteristics, joking sarcastically that after transplant, "My voice is a squeaky soprano, my pecs are a 'C' cup, my member has shrunk up to a nub and I have an overwhelming urge to squat when I pee." Jan Travioli said

people wondered if because she had a 14-year-old girl's lungs in her she would start reading teen magazines. She scoffed at the idea, but said, "The fact that I have somebody else's organs in my body is just weird. I can't describe the feeling; it just amazes me."[61]

Profound gratitude was a ubiquitous feeling. "I just thank God every day for the donor who made the decision to do that for me," said Kelly Helms. "He made the decision to be a donor, but his family also made the decision to donate. And I'm only here because of that! I don't ever forget that." Frank Spears felt very fortunate, too.

> Every now and then, I have this wash of gratitude, you know, hitting my knees, because it really is a gift; it's a stone gift. I didn't do anything to deserve it; I didn't need to earn it; all I did was get sick to death. And I was privileged to get in the program, to go through the program, and to come out the other end a winner.

"I would not be alive basically if it wasn't for the donor," stated an appreciative Steve Brunson. "So I owe my life to someone else who passed away. I'd at least like to say thank you to the family." Laura Scott Ferris, who went through two transplants, declared, "I have been blessed twice, and I am so very grateful for that."[62]

Recipients acted upon this gratitude in different ways. Kathryn Foss made a point to regularly and privately acknowledge it. "I wake up every morning, take a deep breath, and say 'thank you' to my donor. Then I'm ready for the new day." William Poplett echoed, "[I'm] always thinking every day, thinking about the person and what his life meant to me." Judy Ryan began work on a garden to serve as a marker of remembrance for her donor. "Her name was Karen," Ryan explained as she broke down in tears, "It's going to be Karen's garden."[63] Don Hawkins attended the Donor Recognition Ceremony at the biennial Transplant Games and cried as he described visiting the donor quilt displayed there.

> I first started walking down and I got to a point where I had to stop; I couldn't go any further. I got to one panel, I looked at that and I had to stop. I couldn't go on; the dates [of the infant's birth and death] were February 9th, 1991, February 10th, 1991. She was a donor. That was it; I couldn't take it anymore, I had to walk away. Every one of those that were on that wall helped a whole lot of people live. Excuse me [wiping tears]. Without them a lot of us wouldn't be there.

Howell Graham readily agreed to any invitation to talk to groups about his experience with organ donation because of his desire "to give something back." Laura Scott Ferris did the same type of public speaking and expressed her gratitude in

another way as well. "I choose to honor the two people that donated their lungs to me, by living my life to the fullest."[64]

Many people thanked their specific donor families by writing them with their organ procurement organization (OPO) serving as intermediary. Every year on the anniversary of her transplant, Kathryn Flynn wrote her donor's family basically trying to convey, "I'm alive. I appreciate your gift. Thank you." Danielle DiCiantis wrote a couple of letters saying "what a difference they made in my life" and "how grateful I am." Many recipients never heard a response from the donor family, and they respected the family's privacy and feelings. "I've never heard from them but I understand if they can't [write] and it doesn't upset me," said Dare Reitz. Kelly Helms agreed, "If they never do [respond], that's fine. I just don't want them to ever think I ever forgot."[65] Some recipients did get a response—or heard from the OPO that the donor family received and appreciated the letter. A thrilled Pauline DeLuca reported she soon would be meeting the donor family. "We're right on the brink! Right on the brink!" DeLuca explained that the process, facilitated by her OPO, was a slow and careful one. First DeLuca wrote a letter to the family that did not provide personal details or her last name. (OPOs would screen the letters and delete any inappropriate inclusions.) If the family decided to reply (still anonymously and via the OPO), they could go through additional rounds of more revealing correspondence. In DeLuca's case, both sides began moving toward giving up anonymity rather quickly. Before permitting that, the OPO sent DeLuca a consent form intended to make sure she understood that the donor family might want things of her. She summarized its warning.

> Once you do this, that these people are going to know who you are and if they feel like they want to have a close relationship with you because they feel that their loved one's living on in you, you've got to be prepared for that . . . Be aware of what you're getting yourself into kind of thing, which is not an issue. I mean, I would never deny them anything that they wanted. So I have to send that back, sign it and send it back, and then they'll put us in touch.[66]

Making contact with the donor family could be gratifying but was not necessarily easy. "While I was thrilled to get the letter, it was also very sad at the same time," said Jimmy Carroll. Ana Stenzel was very glad she got to meet and personally thank the family of her donor, but at the same time, learning more about him made his loss more real and difficult. "I cried for James, for the stranger-turned-self, for the heartache of his family, for the love he never knew, and the children he never had among a family of many. I cried for the wishes he was never granted and the unfairness of it all." Don Hawkins and his donor family agreed to meet and did so while driving together to Washington, D.C. for an organ donation event. "I thought it was going to be very difficult," he said. "As

it turned out, it was just very natural, and on the way up to D.C. we did a lot of talking. I don't even remember what we talked about; we just talked." They continued a relationship, usually via email, keeping up with the major events in one another's lives. Although face-to-face meetings did not occur frequently, other recipients also reported being welcomed by their donors' relatives and creating strong and continuing bonds that anthropologist Lesley Sharp said approximated family ties.[67] Sharp thought these relationships represented a creative and human response to an unusual situation, but said they were not for the faint of heart. Still, almost all the interactions she'd researched had gone well. In the best ones, recipients listened to the donor kin's painful story, acknowledged their inability to truly understand the donor family's suffering, told of their own struggles, and expressed gratitude for the difference the organ made in their health. Survivors of a shared trauma that few outsiders fully understood, recipients and donor kin built trust, intimacy, and a new type of community.[68]

For many years, transplant professionals generally discouraged recipients from contacting their donors' families. The system of preserving donor anonymity was intended to protect both donors (from being bothered during their grief or reliving their traumatic experiences) and recipients (from being wracked by guilt or confused by complex new relationships). Surgeons suspected recipients who wanted to contact donor families had a problem moving on with their new lives and believed it was more helpful to view the body as a machine and donor organs as impersonal parts for it. Not surprisingly, many recipients were afraid to contact their donor families. Some feared starting a relationship with people who might want something of them. Six years after his transplant, an ambivalent Howell Graham had actually written a long letter but not mailed it, and struggled to articulate why he hadn't.

> I just want them to know that I'm putting these babies to good use and doing a lot with my life and trying to give something back. Yeah, I would like to meet them . . . I don't know. You just kind of wonder . . . people can be funny sometimes, and I sure don't want some psycho—not that that's what this family would be—trying to hunt me down or think that I owe anything. [Still,] I would like to and will at some point mail my letter to say thanks.

Although extremely grateful, Kathleen Feeney doubted that she wanted to meet or develop a relationship with her donor family. She wrote one letter but did not initiate any further contact.

> I can't be the loved one that someone [lost], and I can never, ever repay the gift that's been given me. I can't. I wrote my donor family a very heartfelt thank you letter and wished them some solace in their grief of losing their loved one. [But] I'm not interested in meeting them because of this. They may not like me.

> They may be disappointed or upset. They may have an idea of who received their son, daughter, husband, wife's, whatever, lungs. I don't want to try to have to live up to an expectation. I feel that there should be closure, they should be able to go on with life. It could be a very, very rewarding experience but it could be . . . a borderline stalker trying to find me. I just don't feel in my case it's appropriate.[69]

Others feared the impact they might make on donor families. Would a letter simply remind them of their loss? For a long time Steven Bunsen could not make himself write. "You don't know the circumstances of the death on the donor's part, and I sure don't want to open up some bad wounds for the family." Mary Ellen Smith wrote once, but no more after that. "I just don't want to try it because I don't want to bring back pain to somebody." A few recipients were reluctant to pass along bad news. Judy Ryan wrote a letter and received one back, but then did not continue writing. "How do you tell somebody that gave so much of themselves that you're not doing well, you're in rejection?" Tiffany Vuncannon, who ended up needing a second transplant less than two years after the first, had the same dilemma. "Every day I'm alive it will be because that family donated . . . [but] by the time it came time for the second exchange [of letters] I was already waiting for another transplant. I've never contacted that family again because I didn't want to have to tell them, 'Those lungs are gone.' "[70]

Clearly the topic posed difficulties for some recipients. "I've tried writing a letter to them several times but have not been able to," admitted Rosalie Gallogly, who said the problem was a simple one: "I don't know how to tell them how much I appreciate them doing this." Carol White had the same issue. "It's not that I'm not grateful; I'm the most grateful person in the world. I just don't know what to say." Tom Fereday confessed with embarrassment that a donor letter was a "sticky subject." Fereday felt bad about the circumstances of his donor's sudden death and also feared that the family would reject his efforts to make contact. Mostly, though, he struggled with what to say.

> To be honest with you, for six and a half years I have tried to write a letter. It's very emotional. How do you thank somebody for giving you your life? I've sat down ten times to write this letter, and I get very emotional and it's too hard for me to write. I have a life—a wonderful life—a wonderful wife, a house, a job, everything I could ever ask for, more than I had ever hoped for, just because of this person. "Thank you" is just not enough.[71]

Though not necessarily in the "tyrannical" way Fox and Swazey described, this profound appreciation for the gift often did provoke a sense of obligation. In the months after her transplant, Laura Rothenberg endured problem after problem, including infection, a bowel obstruction, rejection, and kidney issues.

Discouraged, she wondered if somehow she was supposed to suffer because she could not repay her donor. A miserable Rothenberg also admitted, "One of the hardest parts about this transplant is that I feel like I should be grateful for every second, you know? Like if I'm not then I don't deserve these lungs." Healthier recipients also strove to live in a way that made them worthy. "I want [the donor family] to know that I feel a special obligation to do the very best to take care of myself and not to take this lightly," said Randy Sims. Laura Scott Ferris also believed that a transplant brought responsibility. "There is more to receiving a transplant than just hosting an organ," she wrote. "It is my feeling that I must honor my gift by sharing more of myself, lead[ing] a purposeful life and mak[ing] a conscious effort to reach out and help others." When she was able to return to work post-transplant, Karen Couture made helping others a priority instead of earning money. She wrote a book for the lung transplant community, and reflected, "I think I may have just begun to repay my rather large debt to society. I feel like I owe the universe for what I have been given." While Lynn did not think she needed to become a new person, she echoed the language of obligation.

> I don't feel a need to go out and change my life and live a more useful life and be a better person. I think I was a pretty good person [already]. But I feel a huge obligation to use these lungs and treat them with the respect they deserve and like the gift that they are and get them as healthy as possible and get full use out of them . . . That's what the obligation feels like to me. You can't think about any of that without thinking about the person that gave them up for you.[72]

* * *

Life was different after transplant, forever changed. Recipients often spoke of being reborn, as though they were new people, and it is no wonder. The physical effects of a lung transplant went well beyond the impact of the surgery, which left some people enjoying amazingly better breathing almost immediately and others suffering so much they questioned—usually temporarily—whether the transplant had been a good idea. Recovery might take longer for different individuals, but usually over time, the lungs breathed without assistance, pain diminished, scars formed, and muscles returned. The longer-term impact of transplant resulted from the reality of life with a different person's organ residing in the chest. That meant that for the rest of their lives, recipients would have to suppress their body's natural immune system, depend upon a host of powerful (and sometimes nasty) drugs, and face daily decisions about how cautious to be. "One must learn to balance hypochondria with vigilance," explained Charles Tolchin, who, like many others, opted for a middling strategy of compliant self-care while still enjoying the more vigorous life the new lungs made possible.[73] The transplant also made a significant psychological impact, both because it afforded the

opportunity to live and because recipients owed their survival to a donor who was usually unknown and now dead. This latter fact provoked a host of emotions, often including sadness, guilt, curiosity, and most commonly, profound gratitude, and it often weighed heavily on recipients. They thought about and behaved in different ways regarding donors; some contacted the donor's kin, while others struggled to express their appreciation, and many committed themselves to being worthy of their gift.

Lung transplant recipients had to adapt to their changed bodies, new circumstances, and altered identities. They were no longer transplant candidates, no longer sufferers of their lung disease in the same way as before transplant.[74] They were now "lung recipients." This was a unique status, one in which they were no longer in the end stages of an illness, but still not free of medical issues. "It's a mental adjustment," noted Mary Peters, "because I feel like I have one half of me that's in the healthy, normal world. The other foot is in the not-really-sick-but-I-have-to-be-vigilant world."[75] Coming to terms with the many physical and psychological changes could be challenging. Much like when they were transplant candidates, lung recipients found themselves in a situation where crucial things such as rejection, infection, and side effects were beyond their control. Although they were still vulnerable, they had choices about how to manage some of the risks and how to cope with their new status. For those survivors fortunate enough to recover good health, there would be choices about how to spend their time. Appreciative of the efforts made on their behalf, they hoped for enough perspective, resilience, and good luck to weather the storms of the post-transplant period and achieve a life that was longer than previously expected and filled with "quality."

CHAPTER 7

Quality of Life after Transplant

> The transplant itself is not the goal. The goal is to regain some quality of life for whatever period of time that is.
>
> —Kathleen Feeney[1]

After her double lung transplant for lymphangioleiomyomatosis, Karen Couture went through a "major adjustment period." The first year in particular was "rough" as she went through numerous rejection episodes and the drugs were "a big problem" with "bad side effects." Very high levels of steroids made it hard to sleep and kept her "really hyped"; early on she was crying all the time and the drugs made it feel like her blood was boiling in her veins. She developed nerve problems in her feet, hypoglycemia, and chronic migraines. Four months post-transplant, she took a job, but found she had attempted too much too soon and had to quit. In addition, the fact that lung transplant recipients tended to live only about five years after their operation was "always hanging over my head." Eventually she was diagnosed with chronic rejection. She described the transplant as "one of the hardest things I have ever gone through."

Given this description, one might reasonably ask whether Karen Couture was happy she'd undergone a transplant. In fact she was very glad she had, and noted, "I am pretty sure everybody will tell you that they would definitely do [the transplant] again." Despite her difficulties, she found much to appreciate. She could breathe easily for the first time in years. Once she made it through the first year, she discovered she could push her lungs and even participated in a swimming event at the World Transplant Games (figure 7.1). She came in last place, but called it "one of my proudest moments." Although recovering from the transplant was very hard, she also appreciated that compared to

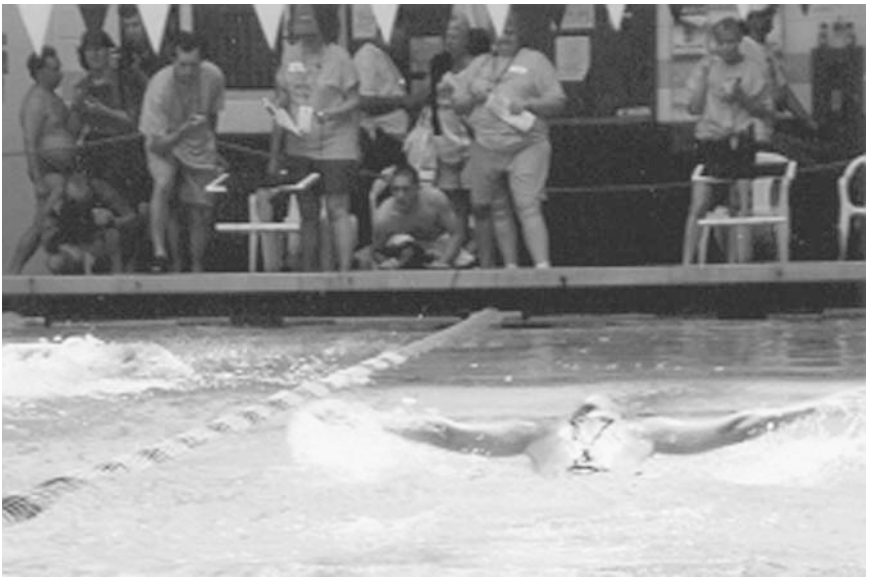


Figure 7.1 Karen Couture wins a silver medal in the 50-yard butterfly at the US Transplant Games six years after her transplant. With permission of Karen Couture.

others, her course was relatively easy. Since her old job no longer appealed to her, she reassessed how she wanted to spend her remaining years and opted against a high-pressure, high-salary job. "My life goals are so different than most people my age. I just want to be a good person and help other people. That's it." She became a part-time massage therapist, wrote a guide for lung transplant candidates, and volunteered at her local organ procurement organization (OPO). "Funny what a near-death experience can do for teaching you what is really important." She met and became close to her donor's family, who she proudly introduced to other organ recipients (figure 7.2). Five years after her transplant, she reflected, "If I died today, I would be happy. I think I have made good use of these lungs and the extra time I have been given by transplantation."[2]

For people with end-stage lung disease, a lung transplant represented more than simply a last-ditch effort to survive; it was hope for some time with less suffering and more possibilities, for a life with better quality than what they'd had before the surgery. Given all that they had to go through—the long, nerve-wracking wait, recovery from major surgery, a new permanent medical regimen of immunosuppression, which left them vulnerable to other serious health risks, complex feelings related to hosting an organ from someone else, and an uncertain lifespan—it is natural to ask, "Was it all worth it?" Was life after transplant long enough and good enough to warrant all the efforts,

Figure 7.2 At the US Transplant Games in 2002, transplant recipient Karen Couture (left) stands with her organ donor's family, Carson, Ronnie, and Anita Richards. All are wearing photos remembering donor Justin Richards. With permission of Karen Couture.

anxiety, and costs? Many people, including people with lung disease and their loved ones, surgeons and medical personnel, governments, and insurance companies, had a stake in the answer to that question, and as a result, a scholarly field arose to try to quantitatively measure and assess patients' "quality of life" (QOL). However, as Karen Couture's story illustrates, a lung recipient's assessment of the quality of his or her life after transplant was a profoundly personal and individual matter, dependent upon one's experiences, health, identity, values, and goals, and therefore difficult to quantify. Qualitative sources help illuminate the many factors they considered as they reflected upon this important issue.

Quantitative Quality of Life Studies

How should one determine the value of lung transplants? Until the 1970s, it was a significant achievement for a recipient to survive long enough to be discharged from the hospital. For many years, delaying death was considered a sufficient reason to administer a medical treatment, and survival time was the criterion by which the success of lung transplantation was judged.[3] In lung transplants performed worldwide between 1994 and 2005, 78 percent of recipients were alive

after one year, 62 percent at three years, 50 percent at five years, and 26 percent at ten years.[4] Thus for the majority of recipients in the modern period, a lung transplant provided a pretty good chance of extended survival. Those objective numbers were subject to interpretation, however. Would an individual recipient consider a transplant worthwhile if she or he lived only six months? As noted previously, the early months after surgery were quite difficult for some recipients, leading them (temporarily, at least) to question whether it had been worth it. Did a year of additional life make the transplant worthwhile? Two years? Five? Different individuals might well answer those questions differently based on their life situations, perspectives, willingness to tolerate risk, and whether the additional time lived was characterized by misery or by breathing easily. "Those who care for lung transplant patients recognize improvement in health-related quality of life as perhaps the major reason patients choose to undergo lung transplantation," wrote Toronto transplanter Lianne Singer. "Although prolongation of survival is also an important goal, most patients would not choose longer survival if it were associated with worse quality of life."[5] Conversely, even if they did not live longer than they would have without surgery, some could consider a transplant worthwhile if the QOL substantially improved during that period. According to one researcher, "Many patients facing lung transplant will trade *quantity* for *quality* of life."[6]

But what exactly is "quality of life," and how should one measure it? In the 1990s, many scholars in the medical and social sciences began trying to assess "QOL" for lung transplant recipients. They were part of "a large academic enterprise," which asked whether medical treatments in general—especially controversial ones—actually improved the quality of life of patients.[7] Scores of research studies focused on the QOL of lung transplant recipients, probably because it was a new, expensive, and complicated procedure requiring two surgical teams, an OPO, the United Network for Organ Sharing, and continuous drug treatment post-transplant. Researchers could easily measure recipients' lung functioning with FEV_1 scores (showing the volume of air forced out in one second) and the distance a person could walk in six minutes (evidence of the ability of the lungs to support basic movement and exercise). These data confirmed that transplant survivors experienced marked improvement in their respiratory functioning and they achieved an average of 78–85 percent of the levels predicted for healthy people. They increased their exercise capacity 60–75 percent, and most recipients reported it was leg fatigue, not shortness of breath, holding them back.[8] But did improved respiratory functioning necessarily mean better quality of life? Did recipients *feel* better after transplant?[9] Were they content with the life they were living? Were they pleased with their decision to undergo the transplant?

The deeper they dug, the clearer it became to researchers that "QOL" was difficult to measure—because it relied on individual interpretations of many

aspects of life. One's overall health mattered, of course, but health encompassed more than just one's lungs, a significant issue since other health problems typically accompanied transplants. In addition, people's perceptions of their health and the quality of their lives also varied. Just as individuals experience pain in different ways, new lungs might feel differently to different people, who could have different expectations for how they wanted to feel and live as well as varying tolerance for the new problems and risks after transplant. One's satisfaction with transplant also might be related to other things going on in one's life and one's emotional state. The World Health Organization (WHO) recognized this complexity when it defined "quality of life" as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns." WHO said QOL was affected by a person's physical health, psychological state, level of independence, social relationships, beliefs, and environment. Thus quality of life is an individual, personal, cultural, social, and subjective phenomenon. As scholar Lianne Singer noted, years survived and lung functioning were relatively easy to measure and unambiguous, but assessing quality of life was "fraught with difficulty."[10]

Nevertheless, researchers designed studies to try to quantitatively measure this admittedly qualitative phenomenon, borrowing instruments and concepts from psychology, epidemiology, biostatistics, decision theory, and economics.[11] A typical study involved surveys that explored various aspects of physical functioning, such as physical mobility, energy, home management, sex life, ability to perform daily activities, and symptoms such as breathlessness or pain. Other instruments explored psychological domains, examining issues such as distress, depression, anxiety, cognition, body image, self-esteem, and insomnia. Still others looked at social adaptation—how recipients were handling relationships, work, school, and recreation—or satisfaction with one's health, one's treatment, or life in general.[12] Often patients were asked to answer multiple choice questions or rate a feeling or symptom on a scale (from one to five). One might have to answer, "During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?" The potential answers were "not at all," "slightly," "moderately," "quite a bit," or "extremely." The results could be examined for statistical significance.[13]

A 2005 study asking, "Does Lung Transplantation Improve Health-Related Quality of Life?" illustrates quantitative research methods. University of Florida investigators examined medical records and asked sixty-six mainly white and middle-aged recipients to complete two surveys by mail or phone. Researchers had excluded from the study ten recipients who were less than six months post-transplant, five who were hospitalized when the study began, three who had no telephone, and four who could not speak English.[14] The FEV_1 and six-minute

walk tests indicated that recipients' lungs were functioning better and they had significantly fewer breathing problems after transplant. Survey responses indicated significant improvements in seven of eight subscales related to physical and social functioning, emotional issues, pain, general health, and vitality. Although improvements over their pre-transplant conditions were substantial, recipients' scores post-transplant were lower than a sample of "normal" adults. Compared with pre-transplant levels, recipients reported less frequent affective distress, though they did experience some problematic neurocognitive and gastrointestinal symptoms. Participants who were three–five years post-transplant were more likely to report occurrence of depression, headaches, and breathing difficulties than those transplanted more recently. Finally, patients with bronchiolitis obliterans syndrome or "chronic rejection" had worse functioning and symptoms in a couple of areas. The authors concluded that the answer to their question was mainly *yes*: "Lung transplantation appears to yield significant HRQoL [health-related quality of life] benefits for patients." However, they acknowledged, "Many patients do . . . experience frequent symptoms associated with immunosuppression that may limit the full benefit of transplantation, and some of these symptoms appear to worsen over time."[15]

Overall, the body of QOL literature reinforced the Florida study's results. Dramatic improvements in recipients' lung capacity were "widely demonstrated," and recipients reported marked gains in their ability to do physical activities. Researchers concluded the changes from pre- to post-transplant were "significant and pervasive" and included significantly better physical functioning, fewer restrictions on social activities, more energy, and less pain and discomfort.[16] There were less data on psychological or emotional aspects of life after transplant, but anxiety or depression may have occurred more in recipients than in nonpatient groups and might have been more prevalent shortly after transplant.[17] The studies also suggested that timing mattered; that is, *when* recipients were asked about their quality of life made a difference in their assessment. The dramatic improvements enjoyed by recipients were maintained for several years, but problematic symptoms related to transplant complications, development of other health problems, and the effects of immunosuppression could become more severe three to four years after transplantation.[18]

Limitations of the QOL Studies

While these results seem unsurprising, there were a number of problems with QOL studies. First, most were done at a single transplant center, meaning they examined a very small (often just a dozen or two) and unrepresentative population.[19] This made it impossible to make generalizations or to analyze whether various subgroups (like people with different lung diseases, ages, sex,

ethnic background, socioeconomic class, or type of transplant) had different experiences. Many studies compared one group of people pre-transplant with a different group of people post-transplant, a less effective method than following the same people before and after transplant. The handful of more effective longitudinal design studies collectively studied less than 125 people.[20] Critics also pointed out that although research methods have improved, many of the earlier studies were statistically unsophisticated or conceptually ambiguous, and some of the survey instruments were not designed specifically for lung diseases. Most studies did not measure whether the expected improvements from transplant outweighed expected disability and mortality, which might have underappreciated the value of transplants.[21] Finally, by not including data on subjects who were hospitalized or died before the study was complete, researchers potentially exaggerated the benefits of transplantation.[22]

Assessing recipients' quality of life of is a worthwhile endeavor, but the studies should be viewed with caution for reasons beyond methodology. Some of the early QOL studies resulted from concerns that lung transplants were not as effective as other organ transplants. In transplants done before 2003, 70 percent of heart recipients lived at least five years, while only 45 percent of lung recipients did, and lung recipients also suffered more complications than recipients of other organs. As a result, lung transplants were quite expensive, and insurers and governments questioned whether they were worth it.[23] "Although quality of life matters to the patient, cost effectiveness matters to society," noted Toronto's Lianne Singer. "In this era of limited health care dollars and increasingly expensive medical technologies, it is important to understand and maximize the overall value of lung transplantation compared with other alternatives." Indeed, the Dutch Health Care Insurance Board undertook a QOL study in order to evaluate whether the nation should continue paying for lung transplants. Economists in the United Kingdom considered the same issue.[24] In the mid-1990s, the United States was grappling with rising medical costs and limited resources. Many believed Americans too eagerly embraced new high-tech medical procedures that actually provided limited benefits, which was especially problematic when millions of citizens went without basic and preventive medical care. In this context, Scott Ramsey published one of the first cost-effectiveness studies of lung transplantation in the United States in the medical journal *Chest* in 1995. Although his methods for estimating survival time were criticized, Ramsey concluded that lung transplantation did not significantly improve the life expectancy of recipients, though it could substantially improve their quality of life. Doing so, however, was quite expensive.[25]

Angered by Ramsey's article, surgeon Thomas Egan responded. In a letter to the editor of *Chest*, Egan sarcastically noted, "In the interest of health economy and cost-effectiveness, we should probably all die in our sleep without the benefit of a call to 911."[26] A few years later, Egan responded similarly to the UK

study. He acknowledged the need to evaluate expensive medical procedures to ensure that they provide value to society and to patients, but he objected to such studies being used as the basis for resource allocation decisions, especially since there were problems with their methods and assumptions. In particular, Egan felt comparing lung transplant recipients with those on the waiting list was inappropriate because of "the inescapable fact that death is relatively cheap." He asserted physicians should not stand idly by when someone's life was in danger and could be saved. In addition, he pointed out, "The implicit assumption that lung transplantation must increase life expectancy to be valuable may be flawed." End-stage lung disease caused incapacitating and intolerable shortness of breath, and transplantation could relieve that. "What value should we attach to being able to breathe comfortably?" he asked rhetorically. "If a young adult who has never enjoyed good health enjoys 9 of the best months he or she has had in the past decade after lung transplantation and then dies of a viral illness, what is this worth to the patient? To the family? To society?" Egan suggested that efforts to quantify this value were not exactly "quackery," but were misguided. "In our zeal to be objective, have we lost touch with what is important? How do we put a value on watching another sunset, hearing another song, sharing time with a loved one, or pursuing (and attaining) a lifetime dream?"[27]

Debate continued over the value of the QOL studies. Responding to comments that transplant surgeons did not want to compare their operations to other procedures, the lead author of the UK study asserted,

> Whether we like it or not, we live in the real world. To you spending, say £1 million to save a life might seem to be the right thing to do; somebody with arthritis might rather have 50,000 pounds spent for a hip replacement. We live in the real world and compete for resources, not only with health care sectors but with non-health care sectors.[28]

Defenders of the studies also noted that they had developed sophisticated methods to incorporate quality of life issues in determining the effectiveness of transplant. They developed a number referred to as a quality-adjusted life year (QALY). QALY scores were derived by starting with life expectancy in terms of years, then adjusting it based on the average perceived health-related QOL over that time period. Then they added information about financial costs to determine a single bottom line number that was a ratio representing the dollars spent per amount gained in duration and QOL. This number could be used to compare the benefit of lung transplantation with the benefits of no treatment or other treatments. Besides defending their methods, proponents maintained that the QOL studies could prove useful to others besides those concerned with cost-effectiveness. Medical clinicians could better understand what their patients were going through and potentially provide better service. Transplant candidates could

better understand what they might encounter. Indeed, the Florida researchers stated, QOL "outcomes are important to all stakeholders in transplantation."[29] Despite these assertions of potential benefits, however, it does not appear that transplant programs designed interventions to help patients based on QOL studies.[30] Thus the intent of the studies often seemed to be bolstering a preexisting position about the value of lung transplantation, whether done by critics or advocates (who began using them to document the benefits of transplant once they became aware that QOL studies could be used against them).[31]

With competing motives and high stakes, it is not surprising that debate ensued over the details of QOL methodology, such as how to calculate crucial variables. "Dramatic variations in results among cost-effectiveness studies occur when different assumptions, criteria, and analytic approaches are used to determine costs and health outcomes," observed researcher Cynthia Gross. Concerned, the US Public Health Service convened a committee of specialists to propose standards for cost-effectiveness studies. Even after making recommendations, the panelists warned that such formulas should be used with care.

> QOL, mortality, and cost represent a powerful combination, and the many ethical assumptions and value judgments upon which such analyses depend may be overlooked in comparing final dollar amounts. Leading advocates of cost-effectiveness analysis are well aware of its limitations.[32]

In 2009, surgeon Roger Yusen reviewed the studies of outcomes assessment in lung transplantation and also found many limitations. He concluded, "After two decades of publications involving many large cohort studies and a few small randomized controlled trials, many questions remain unanswered."[33]

The most significant limitation of QOL studies is that they try to quantify something that is inherently qualitative, and in the process, lose people's voices. The urge to quantify makes sense because counting makes it possible to make generalizations and because transplant teams, candidates, and policymakers need to base their decisions upon more than simply anecdotal evidence. However, in reducing complex experiences to basic, impersonal numbers, we do not get the full picture of what recipients were thinking and feeling. Some QOL experts recognized the problems of relying on quantitative surveys, admitting that "most of the instruments consist of simple, self-administered questionnaires and are chosen for simplicity, the ease in application and analyses, and the cost savings that result from self-administered questionnaires."[34] They knew that more detailed questions, and more open-ended questions—or better yet, interviews—would result in richer information. However, they said transplant centers did not have the time, budget, expertise, or personnel to conduct such studies. Because they did not, we cannot know what a recipient was thinking when she chose a three instead of a five on a seven-point scale. We also do not know if she found the

question clear or even relevant to her experience. QOL studies almost never included open-ended questions or other opportunities for respondents to offer an extended answer or to critique the surveys.[35] As another researcher noted, most QOL studies "have relied mainly on professionals' opinions of what is important to patients, despite evidence that there may be a significant discrepancy between patients' and physicians' perspectives regarding important determinants of quality of life."[36] A third scholar criticized the studies for not giving individual patients the opportunity to express their individual opinions and reactions. "Quality of life is inherently an attribute of the patient," Thomas Gill asserted. "The need to incorporate patients' values and preferences is what distinguishes quality of life from all other measures of health."[37]

Using Oral History Interviews and Other Qualitative Sources to Assess Quality of Life

Ideally quantitative studies should be supplemented by research using qualitative methods that allow recipients to speak in a less structured format and to relate their experiences in the way that most makes sense to them. As a methodology, oral history has distinct advantages.[38] The open-ended nature of good oral history questioning means that individual recipients provide their own definitions of quality of life, determine for themselves in what areas they are doing well or not, and assign their own values to the aspects of life they consider most important. For one person that might be running a marathon while for another it might be playing with his grandchild. Oral history insures that respondents can address complexities without forcing their experiences into predetermined categories. Rather than prescribing the length and language of their answers, oral history interviews allow a free-ranging conversation. Interviews that are open-ended allow people the space to reflect more deeply and raise issues that survey designers might not think to include. In addition, when the conversation is flexible, lengthy, and covers many topics, an interviewer can show respect and concern for a respondent as a whole person. Most importantly, when people talk, they can provide clearer, subtler, and fuller explanations than quantitative data permit. The presence of an interviewer makes it possible to clarify ambiguous answers with follow-up questions. An interviewer can discover what someone *means* when choosing a particular number on a scale. While numbers can suggest a general sense of a lot or a little, words can come closer to conveying the intensity of feelings and experiences. We are accustomed to using language every day to express ourselves. When we talk, we can use examples to illustrate what we mean; we can laugh, cry, frown, and exclaim; we can hesitate, change our minds, and be ambivalent. Listening to people speak in their own language allows us to hear whatever positive, negative, or ambiguous details lung transplant recipients

find important enough to tell. Spoken words more richly convey the *quality* of their lives.

The qualitative data used in this project often confirmed the basic direction of the QOL studies while providing a fuller, more textured, more subtle understanding of recipients' lives after transplant. For this project, trained interviewers talked with 46 lung transplant recipients for an hour to two hours each. They tended to ask open-ended questions and to follow up and delve more deeply when they or the recipient desired. The conversations were free-flowing and covered many topics, though all touched upon the quality of health and life post-transplant. These interviews, supplemented by some written first-person accounts, form the basis for the rest of this chapter. Although the data were not in a form that lent itself to being counted, some clear trends emerged. Recipients thoughtfully reflected upon their lives post-transplant and considered many factors as they assessed their quality of life and whether the transplant was worthwhile. As seen in the previous chapter, they remembered that they owed their lives to their donor and donor families, and their gratitude and sense of obligation affected them throughout their post-transplant lives. This was one phenomenon not recognized by QOL studies. We also saw that recipients willingly described the challenges they faced in learning a new medical regimen and dealing with complications, side effects, and the risks of being immunosuppressed.

In their interviews, recipients readily acknowledged both difficulties and improvements in their post-transplant lives. Cheryl Maxham proclaimed, "My quality of life is 100 percent," and undoubtedly on a survey would have checked off high ratings. Yet she also reported that she experienced acute rejection, cytomegalovirus, tremors, diarrhea, and problems with her weight and eyesight. Maxham downplayed those problems, however, in the same way that she minimized the challenges of taking so much medication. "What's the big deal? What's the alternative? You take five [doses] of medication a day or you sit on oxygen all [day] your whole life. It's a trade . . . I'll take the pills, thank you."[39] Over and over, lung recipients used this same language of tradeoffs. Prepared by their medical teams and others in the lung transplant community, they knew beforehand that a transplant did not guarantee extended years or ease. Howell Graham recalled his doctors telling him that the transplant would not be a panacea.

> It's like trading one set of problems for another. I heard a physician say a good analogy was trading one disease that's unmanageable for a disease that's manageable. But to me it's nothing, because growing up I always wished that I could just get out of this whole disease by taking a pill and making it right. Essentially that's what's happened. Yeah, I've got to take some medicine every day, but who cares?

Many similarly minimized their problems. Lynn's doctors prepared her for problems: "They make it very clear there's going to be bumps in the road." Karen

Couture acknowledged "all these little annoying things from the meds," but appreciated the payoff. "I still have a lot of medical things to manage," but "I am alive." On the other hand, Joanne Schum actually thought that the language of "tradeoffs" overemphasized the problems that resulted.

> I know a lot of people refer to a transplant as trading one illness for another, but . . . in my own experience, that is not true. I got rid of some really bad, damaged, very sick lungs. In return I didn't get another illness, I got the capability to breathe, to do stuff I've never done. I'm healthy and I don't like it when they say you trade one illness for another because I don't feel ill. I'm definitely not ill.[40]

Like Schum, lung transplant recipients often measured the quality of their lives by how they *felt*. Not surprisingly, they often measured that in comparison to before transplant and raved about the difference. Trying to explain the change to others awaiting transplant, Danelle DeCiantis said it was like "night and day. Picture yourself seeing in black and white your entire life, then waking up just one day and being able to see in color. That's how dramatic the difference is." Mary Ellen Smith concurred, "I never realized how badly I was breathing before because I lived with it all my life. It's quite a difference. I'm amazed." Kathryn Flynn described her quality of life as "excellent," agreeing "there's no comparison [to my previous condition]." Pauline DeLuca described her quality of life as "A hundred percent better" and said she had "better lung function than I've had since I was a teenager. It's quite miraculous." Cheryl Maxham said, "Your quality of life is so great, it's unbelievable." Howell Graham said it was "awesome." These superlatives expressed in recipients' own language were powerful, but some recipients offered statistics to confirm their improvement. Karen Couture noted that her lung function pre-transplant had been about 20 percent. Two weeks after the operation, though, "Here I am, I have been split open, and all of my muscles have been cut, and it went all the way up to 67 percent in that short amount of time. It was pretty amazing." Howell Graham showed his pulmonary function tests, which had him at around 100 percent. "My lungs are completely normal. Before my surgery I was like 23 percent of predicted normal . . . I would get out of breath just brushing my teeth. [To go from that] to these norms, it was just completely freakazoid." Tim Choquette summarized, "There's not really any comparison now. I mean it's just living like a normal person—which may not sound too great to a normal person, but gosh, when you've been miserable for 15 or 20 years, then it's pretty nice."[41]

When asked to characterize the quality of their lives, only a couple of the 46 interviewees used negative terms. One was Richard Throlson, whose health had recently declined. He reported that he was feeling exhausted and "not very normal." While he was still able to work half days, he felt much worse and was about to go back on supplemental oxygen due to the development of chronic

rejection. He was disappointed with the changes that had taken place in a short period. "You would have got a different story if you would have been here a year ago . . . Last summer I was walking six miles in a stretch. This summer if I did two miles I was doing pretty good. Now if I do 200 feet I'm pushing it."[42] Tiffany Vuncannon had such serious problems that she required a second transplant less than two years after her first. The second transplant proved difficult to recover from and she lost much of her hearing. She reported, "That's probably been the biggest sacrifice. Some people say, 'Well, that's a small price to pay.' It wasn't; it was a huge price to pay." Vuncannon acknowledged, "Every day there is at least one thing wrong [with my health.]" She hesitated to admit that, however, noting, "If it's a choice between being able to breathe or having a really bad stomachache, I'll take the really bad stomachache." Indeed, she offered, "On a scale of one to ten, ten being the highest, I would say my quality of life is about an eight."[43] Five years after Ruth Hall's transplant, she was unhappy with the way her health had declined.

> Right now I'm thinking I might as well be dead as to live how I'm living . . . Taking a bath is just exertion to me. It takes me an hour, hour and a half to take a bath and get dressed because I have to sit still before I can get my breath. And washing my hair is worse. Eating sometimes gets me out of breath. Do you think taking an oxygen tank, going out that door, and you get to the vehicle and you have to sit there for five minutes before you can drive anywhere to get your breath—is that quality of life? I don't think so.[44]

Recipients associated much of their quality of life with what they were able to *do*. This too was usually measured from the perspective of life pre-transplant. Tracy Raub described her quality of life as "a lot better," explaining, "I don't have oxygen. I can breathe. I can do things. I can breathe—when before you couldn't do anything." Mary Peters agreed, "One thing a transplant really does is make you appreciate the most stupid simple little things. I would feel thrilled if I had to get up and I had to use the bathroom in the middle of the night because I could do it myself. I wasn't tied to oxygen; I wasn't in a hospital bed in my living room."[45] Many expressed similar relief at being rid of oxygen and the complicated medical routines they'd previously needed. "I never imagined how easy living free of CF could be," said Ana Stenzel, who hiked mountains in various national parks. Shirley Jewett appreciated being able to "walk and talk at the same time," do her own housework, and go shopping and sailing. Kathryn Flynn could fulfill a heartfelt promise to her daughter.

> After she hit about ten pounds, I could no longer carry her up the stairs because it was too much for me. That was what I told her: "When I have this transplant, I'll be able to carry you up the stairs." And I had the transplant and she's made me do it forever.[46]

Many recipients took full advantage of their newfound health to push themselves physically. Jasper Martin reported doing "a lot of heavy mechanical work," laying a patio, and gardening. "You start digging and can dig and dig and dig like you were 22 years old and you're a 64-year-old man. It's the most elating thing that one could experience." Joanne Schum tried new activities, including biking, running, swimming, and volleyball. "I was never sports-minded before my transplant. Now you can just about get me to do anything." For her whole life, Kelly Helms had enjoyed being very fit, even working a second job as an aerobics instructor until her lung disease had made that impossible. During months of weakness post-transplant, she had longingly watched exercise shows on television. Naturally, as soon as she could, she participated in the US Transplant Games in 1994, 1996, and 1998, and the World Games in Australia in 1997, winning nine swimming medals. After his transplant, Tom Fereday went skydiving, participated in golf tournaments, and though he'd never run before, did a 5K race. He went to the Transplant Games every two years, and declared, "I do everything."[47]

Not everyone said their functioning was entirely back to normal, however. Jimmy Carroll said, "I feel good. [But] I wouldn't say there's little I can't do, because that's not really true." In particular, the drugs had caused weakness in his joints and muscles so he couldn't run.[48] Kathyrn Flynn could do almost anything she wanted, but agreed, "It's not quite like being 'normal.'" Jack Snyder admitted that he might feel a little tired after walking up a hill, but was thrilled that at least he could do it. "My breathing's at about 65–66 percent of a normal person my age. That is plenty. I can do just about anything I want to." The limitation for Kelly Helms was that she could not get pregnant because it would be dangerous.

> Sometimes I'm fine with it, and sometimes I get a little sad, I can't handle it. Sometimes I just can't believe that I'm not going to have any [children]. You're just always thinking, "I'm only 34. Most of my friends are having kids now. I'm never going to experience that." But it's a tradeoff—you know, some people aren't even here.

Still numb from where surgery cut the nerves in her chest, Jan Travioli worried that the transplant would interfere with her sexuality. And describing the scars running under her breasts from armpit to armpit and from belly button upward, she observed, " "I'll never wear a bikini, that's for sure."[49] The International Society for Heart and Lung Transplantation asserted that over 80 percent of one-, three-, five-, and ten-year survivors reported no activity limitation at their follow-up appointments.[50] Clearly among the other 20 percent were people like Richard Throlson and Ruth Hall, who found that everyday activities were getting harder, and Tiffany Vuncannon, whose deafness made

conversations difficult. Such changes and losses affected one's body, daily life, and identity.

For some people, work was an important component of quality of life. Employment could affect one's standard of living. Ana Stenzel worked to pull herself "out of the financial misery that had plagued me as a sick person." For many people, though, work also constituted valuable activity or a significant part of their identity. Don Hawkins, who went back to work full-time 60 days after transplant, was eager "to get back to my normal routine." Frank Spears was 68 and retired, but working was important enough to him that after transplant he found a new part-time job. Kelly Helms never considered quitting.

> A lot of people after transplant, they go, "Woe is me, I've had a transplant, I can't work again . . . " [But] I couldn't wait. I was like, "When can I go back to work?" And my doctors really believe that's why I've done so well: I went back to living. I don't dwell on my transplant. I don't talk about it every day; I go on living. People that meet me would have no idea in a million years that I've had a transplant and I don't want it to be the center of my life. Am I a person that has a medical problem? Yeah. But am I a person that works full-time, and has a husband, and dogs, and a family, and other interests? Yeah.[51]

Post-transplant Carol White enjoyed her job more than ever, even though "it's hard work, it's physical." Mary Peters, on the other hand, found that she couldn't maintain the typical 40–50 hour week engineers usually put in, but could manage a four-day week. For Steve Brunson, on the other hand, the transition back to work was almost too easy.

> A lot of people at the office kind of treated me with kid gloves. They just didn't assign me much work . . . so for a while I was kind of bored. Slowly, I guess it was a month or so, they realized that I could do all the things I did before. Because I have a desk job—it was not like I had to drive a forklift or anything like that—I push a pencil. They realized that I didn't get a brain transplant; it was a double lung transplant. I could do the same things I did before, so I got reassigned all my old job duties [and] I've been promoted a couple of times since then.[52]

Many recipients did not work for pay after transplant, however. Although there aren't many studies of the employment status of lung transplant recipients, a 2007 multinational one reported that 59 percent of one-year, 50 percent of three-year, 47 percent of five-year, and 42 percent of ten-year survivors were not working.[53] This suggests that it was more difficult to work during the first year after transplant, but that about half of surviving recipients were employed in the middle-range years. For those who were not employed, the reasons varied. About 10 percent had retired.[54] Others were not physically able to work. Barbara Stepp

had been a social worker, but complications left her weak and required frequent doctors' appointments and extensive rehabilitation. Her physicians declared her unable to work. "I have wished that I could," she declared with disappointment. Recipients were more likely to be employed post-transplant if they had worked before their surgery. Some people, however, could not return to their previous jobs. Melodie Greene had been a nurse and recognized that contact with so many people with infections would not be wise. Kathryn Flynn had been a medical researcher working on viruses that could cause serious problems in transplant recipients. "Between those two viruses, [my doctors] just said, 'Forget it.' "[55]

Difficulty finding jobs could certainly help explain why some recipients were medically able to work but were not employed. In one study this group comprised about 29 percent of recipients.[56] While some people had employers who held their jobs for them until they recovered, many did not, and finding a job was especially hard if one lacked education, skills, or experience. Danelle DeCiantis eventually found a job, but said the gap of three years before her transplant in which she had not been able to work had been difficult to explain to potential employers. Acquaintances helped Howell Graham find a job, but he remained frustrated with his situation regarding insurance. Although his health was quite good, his monthly premiums were astronomical and ever-increasing.

> I just don't know where it's going to stop. It's completely unfair because I'm lumped in with AIDS patients and a bunch of terminal patients, and I'm not like that. Granted my drugs are kind of expensive, but they still make money off of me. I've had a lot of discrimination in not only health insurance but in life insurance. It's been tough for me to get disability. If I was disabled and couldn't work, it would be devastating. That's why I want to get disability to cover some of my income if at some point that may happen, God forbid.

Jack Snyder was also angry with insurance companies. "I had 156 different billings from the hospital with many charges on each one of these bills. And I had to write or call 126 times to get them resolved. It was a nightmare. It was like you had to fight everything."

Undoubtedly many chose not to work because of the very reasons Howell Graham described—concerns about health insurance and the risk of financial ruin if one's health were to take a turn for the worse. A significant percentage of recipients needed Medicare to pay for their transplants and Social Security to survive. Government rules, however, limited the amount of hours disabled people could work. Tiffany Christensen felt this put her and others like her

> between a rock and a hard place. If I work, I run the risk of losing necessary, life-sustaining government funded coverage. If I don't work I'm not fulfilling

> the entire goal of transplant: to live a more normal life . . . I didn't get this transplant so that I could sit at home on the couch and collect government money. I also didn't go through all of the pain and suffering so that I could live a more normal life, get a job, and turn around and lose my insurance. How silly it would be, after all of this, to die because I couldn't afford to buy my transplant medications![57]

Despite knowing government rules, Mary Peters chose to take the chance. "I gave up my disability income to go back to work. So I could be at financial risk if I had to go on disability again because the plan where I work isn't good . . . There are still a lot of things to worry about." Given the reality that only about half of recipients lived five years (and all were immunosuppressed), the odds were good that they would eventually experience health problems, making them less attractive to employers concerned about the cost of providing insurance. To make matters worse, immunosuppressant drugs were quite expensive, and in many cases insurers only covered them for a couple of years. Laura Richards loved the data entry job she'd found, but she explained,

> It's just part-time, which is fine because I have to watch my Social Security and my Medicaid. There's a cap on the insurance at work and the one medicine I take is almost $3,000 a month. That's just one of the medicines. So I'm choosing to stay on Medicare/Medicaid so I can get my prescriptions paid for.

For Jack Snyder, working was too risky because of his high white blood cell counts and susceptibility to infection. This decision took a toll, however. His and his wife's incomes decreased to one-third of what they had been previously and the medical bills had him very concerned. "We're living right on the end of the line, I'm telling you." Medicare would pay for his immunosuppressive drugs, but those constituted only three of the thirteen medications he took, and it would only pay for them for three years. "And then we must die, I guess."[58]

Others opted not to work—or worked differently—because they had other priorities. Before his transplant, Neil Kauten used to work from 7:00 a.m. to 8:00 p.m. for a Fortune 500 company. His goals changed after the transplant.

> When God gave me my second life, I changed my priorities. God first, family second, and job third. I was now there during my children's most important years to encourage and teach them. I had the opportunity to help raise our children and participate in their lives instead of sitting on the sidelines. I loved it! More importantly, I'm a better person for it.

Karen Couture changed fields, switching to massage therapy, an area she felt was more meaningful work because it could "help people get out of pain." Jan

Travioli refused to return to her previous position because it was so stressful. Kathleen Feeney altered the way she worked.

> At work, they say don't sweat the small stuff. Ha! Nothing else is big stuff when you're talking about life and death; that's the big stuff. So I'm not any less energetic about work, but I'm not as stressed, or tense, or frustrated at work because it's like, "Oh well, I'll do what I can do."

Feeney's whole outlook on life had changed, too. "I know the value of friends, I know how tremendously important your connections are. I know that I am married to the most wonderful man in the universe."[59]

Given that they probably only had a limited number of years remaining, some people opted not to work at all, preferring to spend their time doing more enjoyable or meaningful activities. For some, those things were leisure activities. Randy Sims was especially thrilled that he could resume golfing a couple of months after transplant. He joked, "Not only did the surgery let me breathe again, I think it fixed my slice too." Nancy Hulet and her husband were crossing the country in a motor home. Enjoying her newfound mobility, Carol White went to California, the mountains, the beach, and twice to an amusement park with her grandchildren. Daniel Martini restored a house, went to a reunion, and hoped to travel to Africa and China in the future. "Future," he noted, is a "nice word."[60]

Many people reprioritized so that relationships took a more central role in their lives. Lori Hughes was happy to report she spent her time "run[ning] around after my two-year old" and characterized transplant as "a wonderful experience" because she'd been able to adopt a child. Steven Bunsen said the transplant had "brought the kids and I a lot closer together" and Jimmy Carroll also reported being closer with his wife and friends. Rosalie Gallogly explained,

> I feel very strongly towards my immediate family, towards my children and my husband. We've become very close. Raising them has become very important to me, doing things with them. I just feel like I don't want to waste a moment. I feel like I've been given life, and I wasn't able to do a whole lot of anything before. So just the simple things like gardening, taking a walk, are all wonderful still to me."

Carol Stimmel was thankful for the transplant because of what it meant for her relationship with her daughter. "I got to see Stephanie get married, and I'm going to see Stephanie have her baby in April. It makes it all worthwhile."[61]

Many transplant recipients felt the transplant experience had fundamentally changed them. Frequently they said it altered their perspective. "I don't take as many things for granted as I used to," explained Steve Brunson. Jack Snyder's

wife insisted he was "not the same person" because he enjoyed new things, had a different attitude, and worried less. Pauline DeLuca said, "I'm more aware of my mortality, so it changes how I make decisions, changes how I look at things in life. I'm not as frivolous as I used to be, and I try not to procrastinate as much as I used to." Carol White reported she became more thankful, positive, and aware of her surroundings.

> The first spring after my transplant, I'd get up in the mornings and I'd come open the door and I'd look out and [think], "I didn't know these trees were that green before. I've never seen the sky as blue before." Just everything just looked so good. There's no way if I lived 100 years that I could express how grateful I am for the last three years I've had. I look at every day, every morning when I get up, in awe.

Barbara Stepp had rather poor health compared to many recipients, yet still was altered by the transplant experience.

> I've found an inner peace with myself. Some people could look at it and say, "Ooh, your life is terrible." Everything around me may be falling apart, but for me personally, I feel good. I feel very thankful to be alive. I think that I do have a sense of real appreciation of life after going through all of this.

For Joanne Schum, the physical changes led to social ones.

> My personality has changed. If you were talking to me pre-transplant, you wouldn't have gotten three words out of me. First of all, I couldn't breathe; I couldn't spare the breath. But I was so shy and withdrawn because I just had no confidence, because I thought I would start coughing or my voice would just die out in the middle of something. I'm much more social than I was.[62]

Grateful for the bonus time they had been given, many recipients wanted to spend some of it helping others. "I feel much more of a sense of direction and purpose since I've been transplanted," said Kathryn Flynn. "I feel like before the transplant I just walked through life not really knowing why I was doing what I was doing. Now I really feel like I have a direction that makes more sense to me than what I was doing before."[63] As a result, Flynn spent her time volunteering as a tutor at her daughter's school, taking a class in American Sign Language, assisting at a preschool for deaf and hearing-impaired children, helping local transplant recipients and candidates, and serving as an officer for the national Second Wind Lung Transplant Association. When she later decided to go back to paid work, it was at a school for the blind. Others felt a similar calling. "I feel like I was brought back from death. I feel like I was that far gone physically and this

whole process has brought me back and probably for a purpose and I'm working toward that purpose now," said Jasper Martin. "I do want to give back in a bigger way." While Melodie Greene knew it was unwise to return to her job as a nurse, she also had no desire to. "The main reason is because I feel very compelled to continue with speaking and involvement and volunteer[ing]."[64] Like many who wanted to give something back, Greene directed her efforts to the lung transplant community, starting a new organization in her hometown for transplant candidates, recipients, and their families and friends. She also spoke about organ transplantation to civic groups and churches.

Many recipients felt eager to assist others in the transplant community. Well aware of the donor shortage and acquainted with people desperate for a transplant, they enthusiastically promoted organ donation. Frank Spears also would return to the hospital to seek out "anybody who looks like they're immediately post-transplant, or looks scared." Remembering how much seeing others doing well post-transplant had helped him, he "tried to see if I could just help someone get through this." Recalling how much he craved information before deciding on a transplant, Steven Bunsen welcomed anyone to visit or call him any time. He clarified that he was not a medical professional. "I am just a good old dirt farmer. But I will do my best to help some people out with some answers and try to steer them in the right direction to find the answers, if I can't find them myself. People did that to me years ago, and now it's my turn." After her transplant, Joanne Schum spoke to schools and nurses promoting organ donation and served as a mentor and chat room coordinator for Second Wind. Volunteering was "my job, practically." Concerned that lung candidates did not hear enough stories about the successes, adventures, work, and abilities of lung transplant recipients, Schum compiled scores of stories in a book entitled *Taking Flight; Inspirational Stories of Lung Transplantation*.[65] Karen Couture also wrote a book that provided information about what someone could expect from lung transplantation in every stage from evaluation to after surgery. Her *Lung Transplantation Handbook* sold 700 copies the first year, went into a second edition, and was recommended by many patients and transplant centers. These volunteers felt comfortable sharing their experiences and enjoyed listening to the stories of people whose unique circumstances they understood. They further cultivated the community they had joined pre-transplant, but did so with new roles; instead of being fearful candidates awaiting transplant, they were now recipients and mentors.

Doing generous deeds generally brought satisfaction to recipients. Bob Festle's physicians sometimes asked him to talk with people who were considering transplantation about its costs and benefits. "It is the easiest thing in the world for me to tell my story to somebody . . . and it makes me feel good because I can help somebody out." Similarly, Jasper Martin believed, "The more I serve, the more I am automatically being blessed." Karen Couture enjoyed knowing

that her book had helped others with end-stage lung disease. Don Hawkins felt volunteering for his OPO was "very worthwhile." Ron Peterson served by producing a video of advice for emphysema sufferers and another one that discouraged teens from smoking. He asserted, "Helping others has been very helpful to me."[66]

Recipients also evaluated their quality of life in comparison to others, affected not only by their post-transplant paths but by the knowledge that many died while waiting and did not get any second chance at all. The existence of a lung transplant community meant they frequently were familiar with the wide spectrum of outcomes. While occasionally they spoke of taking longer to recover than others, usually their knowledge of others' negative experiences led them to better appreciate their own relative good fortune. Frank Spears knew many recipients at his transplant center. "There are those people who go in who don't come out on the other end . . . And there are those people who go through and have massive amounts of trouble afterwards. I have been very lucky, very blessed. They kid that I'm the poster boy in lung transplants." Spears spoke at length about a particular friend who had been waiting at the same time, received a transplant much later, struggled mightily afterward, and died. In addition to contrasting their health outcomes, Spears felt fortunate economically. "His total expenses were over a million and a half. I figure hospital, medications, and everything on mine—if I had to pay it, probably would have been a quarter of a million . . . I got very lucky." Cheryl Maxham also considered herself atypical. "I'm their poster child. I was the sickest person they ever operated on and I healed the fastest of anybody." Tom Fereday reported that he was able to thrive on the minimum amount of anti-rejection drugs. "I'm darn close to being sure I'm on the least amount of medication of any transplant [recipient], period."[67]

It was not just the luckier recipients who made comparisons. Frank Avila reported that "one of the rejection medicines had a huge side effect on my kidneys and it just tore them up." The problem was so bad that he needed dialysis and eventually a kidney transplant. Still, he contrasted his experience to a friend whose lung transplant didn't go well.

> After a few years it just kind of . . . he had so many problems with it that it was time for him to get a new [transplant]. But it was too late by then. His family donated part of their lobes so it was able to keep him alive for a little longer but there was too many complications so he ended up not making it . . . It's hard. You always ask yourself, "Why did it have to happen to them?"

Post-transplant, Danelle DeCiantis suffered with a lot of pain, difficulty sleeping, and a bad response to the antiviral medications. She was hospitalized four times during her first year. Yet her assessment was tempered by the experience of a friend.

> My good friend had her transplant a few months ago [and] had awful pneumonia and she was so sick for like a month where she was on oxygen and everything. In that regard I did a lot better. I mean it wasn't easy, but compared to other people, I did really well. And compared to the way I was living before my transplant, there's no comparison. It was a lot easier to deal with.[68]

Because of preparation by their medical teams and awareness of others' experiences, recipients knew that deterioration was to be expected over time, and that it was frequently caused by the scourge known as chronic rejection. Some of the QOL studies suggested that a lung recipient's health (and corresponding quality of life) declined after a few years with development of chronic rejection.[69] While infection and other problems remained serious risks throughout the lives of recipients after transplant, the chances of developing chronic rejection (bronchiolitis obliterans syndrome or BOS) increased over time. Chronic rejection differs from acute rejection in that it does not appear to be a dramatic attack by one's own immune system, but specialists are not sure what causes it and have difficulty making a definitive diagnosis of it. They do know that it is characterized by chronic scarring of the walls of the small airways in the lungs, which progressively obliterates them and results in an irreversible decline in pulmonary functioning. Chronic rejection has been the "primary obstacle to better long-term outcomes" and the "leading cause of death beyond the first year after transplantation."[70] Perhaps as many as two-thirds of lung transplant survivors developed it. In the first decade of the twenty-first century, efforts to prevent or treat BOS were ineffective.[71] One's course with BOS could vary; often the pattern was characterized by insidious and progressive deterioration, but sometimes people temporarily stabilized after an initial rapid decline. While the exact timing was unpredictable, the final outcome was inevitable. Recipients' health worsened and they eventually died, usually from respiratory failure or infection within about two and a half years from onset.[72] Based on different hypotheses about the causes, transplant teams tried a number of different experimental treatments,[73] but given how poorly understood the condition was, it is not surprising that none proved widely effective. Some centers were willing to retransplant otherwise healthy recipients, but that option was problematic as well and performed infrequently. The donor organ shortage created an ethical dilemma since there were those waiting for a first chance at a transplant. In addition, retransplant did not work as well as a first transplant.[74]

Not surprisingly, receiving the diagnosis of chronic rejection was difficult. A year and a half after her surgery, Marcia Roenigk's lung function tests showed a slight but steady decline that indicated chronic rejection. "I was pretty angry with God about that," Roenigk said. "I was in denial a long time. I had been feeling great; I had not noticed any change in my lung function at all, so I didn't really want to believe it." A "confused, scared, and devastated" Tiffany

Christensen "couldn't believe I'd been given this tremendous gift and the ride was over already . . . I rode the roller coaster of emotions . . . I experienced denial, anger, sadness, bargaining and acceptance in many different shapes and forms." Christensen wished her physicians had offered her a bit more guidance about what her remaining time would be like and how she might approach it. She recognized their discomfort with giving bad news but thought doctors should realize the pivotal role they could still play in a patient's last stages. Ruth Hall felt dismayed at her weakness and difficulty breathing and angry that her transplant center did not consider her a suitable candidate for retransplantation because of advanced kidney disease. She felt "like I was not worth a second lung transplant, that other people were more important." Richard Throlson's treatments to combat BOS caused painful side effects and infections and none solved the problem. He was disappointed, of course. "I was hoping that [good health] would last and [bad health] stay away for awhile, that I would be able to keep up for at least a few more years before having to [go on oxygen] again. I was hoping, but I wasn't expecting." Kelly Helms had been a fanatical exerciser and careful about following her medical regimen, yet she developed chronic rejection anyway. She struggled with this development being out of her control. "That's very frustrating as a patient, to think I'm doing everything I can do. I'm being the good patient, I'm living the good lifestyle, I'm doing everything you're asking me to do, and I'm still losing my organs. That is real frustrating."[75]

Kelly Helms's situation illustrates the peaks and valleys of one person's path after transplant. After an inauspicious beginning in which it took seven weeks to get off the ventilator, Helms had seven wonderful years in which she was amazingly healthy. Then she began to decline.

> Ever since last October, I've been losing lung function. I used to have like 40–50 percent; now I'm between 20–30 percent lung function. So my lung function right now isn't good . . . I do notice a change in the way I feel. I used to go and do anything I wanted, and I still can, but I just get tired quicker, and my workouts take a little longer. I just notice that I'm short of breath a lot of times when I didn't used to be.

Helms's doctors changed her immunosuppressant drugs and tried some experimental treatments, but pessimistic about their chances, took the precaution of listing her for another transplant. This change in status came as a surprise and a blow.

> It's real frustrating for me, because for a lung patient I have done so well . . . I mean, a lot of people aren't living five years, and I'm totally beating the odds. I did so well for so long, and then all of a sudden to have this happen . . . I thought I was kind of over that chronic rejection window. They used to say if you got

> between two and five years, you'd probably get it if you were going to get it at all. At the end of my five years, I'm thinking, "Hey, I'm one of the lucky ones, I didn't get it, and I'm going to be fine." Now it's like, "Oh God, I may have to do this again."

Helms was willing to undertake another transplant if it were the only way to save her life, but not eager. "I am totally not ready to do it again, because I know what it's like. It's the hardest thing you'll ever do in your life. It was painful, and it was hard, and it was a long road back…" In addition to dreading the difficulty of undergoing and recovering from the transplant itself, Helms had other fears.

> What scares me about this chronic rejection thing is I'm so scared about losing my health again. Because I've been so healthy for so long again; I'm used to feeling good. I'm not ready to get up in the morning and be exhausted by the time I get out of the shower because I don't have any air. Or going back into the state where I'm going to have to move back to [my transplant center] and somebody is going to have to take care of me. I'm not ready to give up my independence. I work full-time, I teach exercise class, I go like a banshee, and I'm not ready to give all that up again. I'm not ready to be sick again…The list is long, and what happens if I don't get another one? What happens if I end up back on oxygen and I become un-transplantable? This is just the lifestyle I live until I die. And that's a hard thing to face.[76]

Ironically, dealing with her deteriorating health was difficult precisely because the transplant had improved the quality of Helms's life so much. Tiffany Vuncannon felt similar lows after having experienced highs. She actually had undergone a second transplant, which was something she had not predicted she would have been willing to do. She said that if someone had told her she would need to do that, "I'd [have] shot them. And then told them they were a liar. I never thought I would go through that ever again." At that time, she was disappointed, because,

> I had experienced health for the first time, I was in school full time, I was in a fraternity, I had become an officer in that fraternity. I had just [gotten] my own apartment. I was very independent and had created this little life for myself and was very happy, very happy. I felt like it came out of nowhere, just blindsided me.

Ana Stenzel was healthy after her transplant but worried about a future downturn. She suggested having to face death a second time might actually seem worse than if she had died without having received a transplant. "Having tasted normalcy, there will be more to lose then." Others adopted a different perspective, however. Tiffany Christensen thought her previous experience facing death instructed her

in how to "die well." Despite having lost 50 percent of lung capacity ten months after her transplant, Kathryn Foss still considered herself a "success story." "Even though I lost a lot of lung function due to the [chronic] rejection, I am still much better than before transplant. Getting some quality of life back was the whole purpose of having a transplant." She did not feel as good as she might have, but she was better than she was, and appreciated that. "I see every single day as a gift. I may have many or not many days left, but when my time comes, I'm not going to have any regrets."[77]

Recommending a Lung Transplant

Recipients' descriptions provide a powerful, rich, and complex vision of their health, experiences, and attitudes post-transplant, reflecting lives that had changed dramatically and included both hardships and enormous benefits. But what was the bottom line? Did they find it worthwhile to have undergone a lung transplant? The quantitative QOL studies rarely asked that question directly. In fact, in 1995, the editor of *Chest* admitted, "One question that I have always been somewhat reluctant to ask is whether lung transplant recipients have regrets regarding their decision to undergo lung transplantation."[78] In one study, however, researchers went beyond the typical survey questions to the heart of the matter. They asked 54 lung recipients to choose one of two verbs in the following statement: "I would discourage/encourage a friend with a problem similar to mine to seek a transplant." They also asked them whether they were "comfortable with" or "questioning" their decision to have a transplant. The results suggested that most of these recipients found the transplant worthwhile—87 percent of them chose the statement, "I am comfortable with my decision to have a transplant." An even larger majority (91 percent) selected, "I would encourage [as opposed to discourage] a friend with a problem similar to mine to seek a transplant."[79]

Oral history interviews suggested the same bottom line—that lung recipients were content with their decision to have had a transplant—but also painted a somewhat more complex picture. Some did give a ringing endorsement. "It was the best decision I ever made," said Joanne Schum. "I would do it again in a second." Carol Stimmel concluded, "It was a good experience and I'm glad I went through it." Thomas Bullard echoed that sentiment. "It was very much worth it. Had I known how it turned out, I would have done it sooner, but you don't know these things. I'm living my life probably more now than I ever had." Tim Choquette concurred, "No question. I would've done it a whole lot faster if I could." Others were satisfied with their decision (and undoubtedly would have checked "comfortable with" on a survey that offered them only two choices), but qualified their answers a bit. "It hasn't been a completely smooth path, but it's been better, more often a good path than not," Mary Peters concluded. "I'm glad

I did it. I don't want to imply otherwise, but it's not white hat/dark hat kind of tradeoff. There's a little bit of grey in both sides." Lynn was asked if she would make the same decision again if she knew all that was awaiting her. "Yeah, I think I would," she said, less certain than others. The rest of her answer underscored the fact that a person's assessment might well change over time. At the time she was interviewed, she was struggling with a serious virus.

> You catch me at a week when I am having some difficulty; it's hard for me to say that. But if you'd asked me this two weeks ago, I would have said, "Absolutely." You know when you're going through a bump, it's very easy to think, "Oh, my God, how did I get into this?"

Clearly complications could make one vacillate. Richard Throlson's chronic rejection had him feeling bad and dispirited, and his answer was filled with ambivalence. "Yeah, [the transplant] was worth it—except for when it really starts hurting and I start thinking, 'Well, maybe it wasn't worth it.' "[80]

Because post-transplant health could change over time, the moment in time when patients were asked could easily affect their answers. When Laura Rothenberg finally got good test results, she reacted with "utter JOY," thrilled she had gotten well enough to resume her college studies. But in the months before and after that semester, Rothenberg was demoralized by one serious problem after another, including rejection, intestinal blockages, bad reactions to drugs, and post-transplant lymphoproliferative disease. "Sometimes you just want it to stop," she wrote. "You just want to ask God or whoever is up there to give you a break." At some point she pessimistically concluded, "Illness is not leaving my life, though I tried so hard to rid myself of it . . . I know it's only a matter of time before I lose out."[81] Rothenberg's prediction was correct; she lived only a couple of years post-transplant, and those years were difficult and discouraging. Tiffany Christensen's assessment of transplant also changed over time. At one point, after being diagnosed with chronic rejection, she concluded that lung transplantation was primarily destructive and cruel and should be banned. Later she realized this perspective was temporary, resulting from her grief and desire to blame something. Later still, after a second transplant, she felt profound appreciation for the surgery and her medical team for providing her with an opportunity to pursue her dreams, breathe deeply, fall in love, work, write, and do "so many wonderful things."[82]

Many who had serious problems readily acknowledged them but still were satisfied with the transplant. After her transplant, 20-year-old Kimberly Pearce lost a lot of her hearing and developed diabetes, high blood pressure, kidney problems, and osteoporosis, and she almost died a number of times. "If I were going back in time or whatever, and [someone said,] 'Would you do it again?' I would." Asked about quality of life, she replied, "Now it's good. It's not where it

was right after my transplant, but it's better than before my transplant certainly." Like Pearce, Dare Reitz struggled more than many others and she died within two years of her interview. At the time she was interviewed, though, Reitz said, "Yes, I would do it all over again. I have a lot to live for. Even if I knew that I'd go through what I've been through with it, I still would do it again." Mary Ellen Smith's answer incorporated both the difficulties and the benefits. "It's not an easy road. But it's a good road." Jimmy Carroll's assessment allowed for changes over time.

> It is a tough battle, but . . . to me it certainly [has] been worth it. I remember after the surgery, in the few days after the surgery, telling people, "If I die in six months, I'll still be glad I did this." And I certainly still feel that way today. There were days in the six to eight months afterward that I might have wondered about that. It felt pretty rotten for a long time.[83]

When asked whether they would recommend a lung transplant to someone who had end-stage lung disease, recipients' answers illuminated the same general positive orientation tempered by realism and a desire to tell the truth. The quantitative survey had offered just two choices—encouraging or discouraging the hypothetical person—but a more open-ended question resulted in thoughtful answers that reflected the complexity of the transplant process and individual variation. Again some gave an unqualified recommendation. "I would tell them to go for it," said Dare Reitz. Pauline DeLuca agreed, "Definitely pursue it because it can make such a difference in your life. If you qualify and they're willing to do it for you, you should absolutely do it. Absolutely." Frank Spears concurred, "I would recommend it to anybody." However, many others qualified their answers to this question as well. "My first reaction is to say, 'Absolutely,' " said Jimmy Carroll, but upon further consideration, he added, "I guess maybe it's just not for everyone." Cheryl Maxham felt transplant had given her a wonderful new life, saying her recommendation was, "Hell yeah, have the operation." Yet she also realized, "I'm not your normal candidate for asking somebody that question. Not everybody fares that well." This awareness of individual differences clearly affected many recipients' answers. "I won't [recommend] unequivocally," said Carol Stimmel, "because I think it depends on the person. I've seen people who were not emotionally able to go through it." Frank Avila's long response started with a strong recommendation. "I would tell them to go for it. There's so much out there to do that it's worth it. It's definitely worth it." As he continued, however, he demonstrated some ambivalence.

> It's hard; it's not easy. There's going to be those days where you wish you didn't do it. And there's days [beforehand] that you can't take it no more, that you're not going to wait anymore, but in the long run it's definitely worth it . . . I'd

> recommend it to everybody, but it's definitely not for everybody . . . It's up to the person. If they're willing to work for it, if they're willing to deal with all of the emotions . . . You always got to tell them, "These are the goods and these are the bads. It's basically up to you."[84]

In their hypothetical recommendations, many recipients thought it important to make clear that there were no guarantees. They mentioned specific things potential candidates should be aware of. "There's some things to realize," said Carol Stimmel. "The drugs afterwards are extremely expensive." Laura Richards pointed out other potential issues. "You know it is a long wait at times. It's a cure-all by no means. It's just something to prolong your life a little bit longer and if you realize that, I think you'll be okay." Recipients clearly wanted to help others in the transplant community—in part by not raising expectations unrealistically high. Melodie Greene advised, "It's very important for everyone to see what would be the best scenario, someone that gets out of the hospital within a few weeks and is back on their feet again, and those who are debilitated for months." Kathleen Feeney's recommendation was also careful. "I would definitely recommend that people explore it as an option," she said. "I think you need to educate yourself about it and know what's in store for you before you decide to do it—because it is not just going to cure all your problems." Steven Bunsen's response reflected his compassion and awareness of the difficulty of the process: "I hope deep down I never have a close friend that has to go through that, but if I did I would say, 'Go for it,' and I would be there as much as I could for them."[85]

For many recipients the question of whether they would recommend a transplant to others was not a hypothetical issue; they had already spoken with potential candidates and took that responsibility seriously. Tom Fereday had endorsed transplantation, and explained,

> I always feel as if I have a strong influence when I talk to these people. They become my friends. They'll call me . . . I just want them to get through it, but the hardest thing is when they wait and wait and it doesn't happen. I've had that happen three times, and I feel bad because I feel like I gave them false hope. That's the only down side of anything I've done as far as my transplant.

Like Fereday, Tim Choquette recommended transplantation but knew it did not always pan out. "Sometimes I'll feel bad because I've told people that and it hasn't worked out for them and they died after their surgery, and you have to kind of weigh that." Still, Choquette had come to peace with his recommendation. "Some people would consider that a weight on their shoulders, but to me it's like, 'Well, they probably would have died more miserably without having a chance.' "

Rosalie Gallogly said she used the language of tradeoffs. "I tell them the things they told me, and that is you're just exchanging one set of problems for another, but these you can live with. It's work, but it's worth the work."[86]

Recipients' responses were also revealing when they considered whether they themselves would undergo a second transplant if need be. If she got chronic rejection, Kathryn Flynn noted, she would agree to a second transplant "in a New York minute." Joanne Schum gave a similar answer. "I would do it again in a second. If I ever have to get a retransplant, which is likely someday because lungs don't last forever, I'll do it again. It's a huge thing to go through, but it's certainly worth it." Steve Brunson only hesitated a bit in comparison. "Without a doubt. It may take me two or three minutes longer to make the decision, but yes I'd do it again if I had to." Even as they insisted they would be retransplanted if they had to, some recipients had qualified their answers. Steven Bunsen explained, "If [my transplant center] would consider retransplantation and life could be as good as it has been these past ten years, you bet . . . I hope I never have to, but if the time would come, you bet I would." Not everyone was so sure, however, including Mary Peters, who explained, "I'm not ready to just hop in there and say, 'Oh, yes, of course I'd do it again.' Every instance would be different and I'd have to look at that." Richard Throlson, whose results had been disappointing, sounded doubtful. "I don't know if I really want to go through it again—because it's been a lot of trouble." For a very different reason, Tom Fereday said he would decline a second transplant "because I was lucky—I had a second chance. Give it to somebody else. I never thought I'd get six and a half years, well at this rate who knows how long I'll get, but somebody else deserves a chance. I got my chance."[87]

Conclusions

Oral history interviews and other first-person accounts richly paint a picture of lung recipients' experiences, feelings, and concerns in a way that numbers cannot convey, but these interviews have their own limitations. This sample of 46 recipients was neither large nor representative. While interviewers were trained in oral history methods, they differed in their abilities and did not all ask the same questions in the same manner. While trends could be observed, there was no way to compile measurable data. The oral history interviews also shared one of the same limitations as the QOL studies in that people with serious health problems were probably underrepresented. This was not a conscious decision (in the way that some QOL studies intentionally excluded people who were hospitalized) but a result of asking people to volunteer to be interviewed; those who were not well were probably less likely to offer their

time. Although many recipients willingly shared stories of complications, it is possible that some of the difficulties of transplantation were underreported, which may have resulted in an overestimation of the quality of life after transplant. In addition, of course, no one could interview those who did not survive the transplant surgery or the short-term postoperative period. To state the obvious, the quality of life of a person who is dead must be assumed to be nonexistent.

Oral history and other first-person accounts also shared a few limitations with the quantitative studies. First, the responses usually represented a single moment in time. The path of a transplant recipient could have peaks and valleys, and the answers given on a survey or in an interview could well differ from those they might give on another (better or worse) day. Lori Hughes asserted on the day she was interviewed that she was totally happy with her decision to be transplanted, but added, "Even if I wasn't at first, I am now!" There may be another limitation of any reporting by transplant recipients: their enormous gratitude for all the effort made on their behalf by donors, donor families, multiple medical teams, organ procurement agencies, and loved ones. This gratitude may have made them reluctant to complain, express disappointment, or criticize their quality of life. They may have privately had second thoughts but been unwilling to share them publicly. This theory is speculative, based on a few hints. It appeared that when asked early in their post-transplant period, some recipients raved about their quality of life, but later they admitted that those early days of recovery were extremely difficult and that they had had second thoughts. A couple of other comments were suggestive. In discussing how people viewed her after the transplant, Mary Peters said, "I was, 'Oh, what a miracle!' you know." She laughed, but suggested that such an identity brought expectations for how she should behave: "When you're a miracle, you're not supposed to complain if you bump your knee." Anthropologist Lesley Sharp agreed that one reason many organ recipients censored their stories was because they learned that few people really want to learn of their continuing troubles, especially after the operation saved their lives.[88] Tiffany Vuncannon admitted that she had hesitated to discuss her significant health problems post-transplant, partly because they were outweighed by the benefits, but partly for another reason: "because I don't want to be a complainer or a whiner or to not appear grateful." Two QOL scholars noted this possibility as well. Dorothy Lanuza thought high QOL ratings in the months after surgery might be "simply because the subjects were grateful and relieved that they received a transplant." Larissa Myaskovsky observed that while one might expect the post-transplant regimen and treatment side effects to cause recipients to report a poorer quality of life, the fact that "many recipients feel that they have literally received a gift of life" instead led to "a revision in patients' standards of reference, or a revision in the way they characterize their [QOL]."[89] This would not be surprising,

since interviews certainly suggested that the transplant had been a powerful, life-changing experience.

* * *

Assessing the quality of life of lung recipients is a worthwhile endeavor. There are many people, especially people with end-stage lung disease who are considering a transplant, who ask, "Is a lung transplant worth it?" Their loved ones, transplant centers, health care workers, insurers, and governments also have an interest in the answer. QOL studies have relied upon survey data to try to quantify aspects of quality of life. These studies should be used cautiously because of their motives and problems with their methods, including the problem of trying to quantify something so personal and subjective. Unfortunately, people's voices have usually been absent from QOL studies. All methods for ascertaining quality of life have limitations, but supplementing the QOL studies with oral history interviews offers a richer, more detailed, and more complex glimpse into the perspectives of lung transplant recipients. Their experiences were profoundly individual.

Still, both quantitative and qualitative methods yielded some similar conclusions. The majority of lung transplant *survivors* enjoyed substantially improved lung functions. They could perform far more physical activities and do them with much greater ease. They enjoyed emotional, psychological, and social gains as well. They felt better. Some struggled with depression and anxiety or with physical problems, not all of them related to their lungs. Fortunate individuals could do very strenuous activities and their lives approached "normalcy." Timing mattered, though. Even for those who rose to the greatest heights, it was difficult to know how long the many positive changes would last; there were some long-term survivors, but less than one-quarter lived over ten years.[90] One's health could shift suddenly, as Pauline DeLuca noted. "Sometimes I feel like I'm on borrowed time, that even though I feel so good, it can be snatched away in a second."[91] Poorer quality of life was strongly correlated with the diagnosis of chronic rejection, an all-too-frequent, disappointing development that eventually led to death. Despite continued challenges, the vast majority of recipients who participated in surveys or interviews or wrote about their experiences were satisfied with their decision to undergo a lung transplant and would recommend that someone facing end-stage lung disease do the same.

Going beyond the numbers and listening to recipient voices yielded some additional insights. As they assessed the quality of their lives, lung recipients considered many factors, including how they felt and what they could do, but what particular individuals wanted to do differed a great deal. For some it included employment, but others placed higher priority on relationships, enjoying life, and service to others. A transplant often led to changed priorities or a new perspective on life—a matter that QOL studies did not mention. First-person accounts

also made clear exactly how dramatic the changes were that many recipients experienced, how thrilled they were with the improvements, and how grateful they were for a second chance. In addition, quality of life was often evaluated in a relative manner—relative to life pre-transplant, their expectations, how they would have been without transplant (dead), and others' experiences. Indeed, the existence of a lung transplant community provided not only information and support, but a sense of perspective, since recipients knew people waiting who never received a donor lung or those who experienced worse luck than they did after surgery. They also continued to be aware and appreciative of the sacrifice made by the donors and their families. Many felt a continued bond with the lung transplant community post-transplant and wanted to help others in it. While the quantitative QOL studies suggested an almost universal and unreserved contentment with transplant, interviews suggested a more complex point of view. Some recipients raved, but many others qualified their answers. They frequently mentioned the many obstacles that accompanied a transplant. When asked if they would recommend a transplant to someone else, many emphasized what a serious decision it should be and that no one should undertake it without understanding the risks and difficulties that were involved, including the possibility of a long wait, financial hardships, side effects, and complications. Not surprisingly, many recipients used the language that their medical personnel did—that a lung transplant was not a cure, but constituted a "tradeoff" in which they exchanged their formerly terminal disease for a more manageable set of medical challenges characterized by many unknowns. These more qualified answers could be interpreted as undermining the statistics that indicated 90 percent expressed satisfaction, but they can also be interpreted as making those statistics more reliable. Even though they qualified their answers, they did so as part of a fuller, reasoned, and realistic assessment based on experience and knowledge of others' experiences: Even though it was hard, it was still worth it. This honest answer spoke volumes.

We can learn much by listening to lung recipients' voices. Recipients had faced death and reflected upon life. They tended to be very appreciative and believed all the strenuous efforts—on the part of others and themselves—had been worth it. Despite her deterioration and disappointment that she could not have another transplant, Ruth Hall philosophized, "I fought a good battle. I tried, I fought, and I won . . . by trying to do what's best for myself." Charles Tolchin felt very grateful for the countless nurses, doctors, respiratory therapists, physical therapists, and previous recipients whose labors had made his second chance possible, as well as the many family members and friends who had supported him. He thought transplantation validated the meaning of individual lives. "In our society, human life sometimes carries very little value. People kill over a pair of sneakers or a traffic dispute. Transplant repudiates that mentality. With transplant, life has an immense value. So many people work incredibly hard just to save one life." Some insurers, governments, and cost-benefit analysts

questioned whether those efforts were worth it, but lung transplant survivors valued their lives—even though these lives might be short—because usually their lives had much improved quality. Recipients consciously chose how to use their time, and spent little of it feeling sorry for themselves—even though they readily acknowledged the hardships that were part of their tradeoff. Pauline DeLuca felt good about her choice. "Life has no guarantees to begin with. So if you've got a chance at something to improve the quality of your life and those around you, your loved ones, then you should take it and not let the fear get in the way." After transplant, Karen Couture noted, "Your life is prolonged, but not necessarily problem-free. [However,] problem-free is a luxury few people experience with or without transplant." Others would undoubtedly agree with her conclusion that lung transplant could be described as "a mixed miracle."[92]

CHAPTER 8

Lung Transplants in the Twenty-First Century

On February 7, 2003, surgeons at Duke University Medical Center transplanted a heart and lungs into 17-year-old Jesica Santillan, a thin, quiet, and very weak girl who had struggled for years with restrictive cardiomyopathy. During the surgery, they learned that the organs came from a donor with a different blood type from Jesica. This was a horrible mistake, something that was not supposed to occur with the computerized matching system used by the United Network for Organ Sharing (UNOS). Within an hour, Santillan began suffering from hyperacute rejection, a rare, rapid, and serious phenomenon that no drugs were strong enough to combat. After the surgery, she lay comatose, while her family, physicians, and much of the world watched, heartbroken and powerless.[1] Hope unexpectedly reappeared less than two weeks later, when against long odds, new organs became available and Jesica received a second transplant. Unfortunately, it didn't work well. Soon her brain was swelling and bleeding, and within two days, she was dead. Santillan's case was unusual because of the unlikely error, the type of surgery (heart-lung transplants were rarely done anymore), who she was, and the media attention. The incident became especially charged and remained in the headlines for a month. Early media coverage focused on the family's roller coaster and who was responsible for the mistake, but over time, it shifted to ethical, social, and political issues. Commentators asked: Was it fair to give Jesica organs for a second transplant when so many were waiting for a first chance? How were organs found so quickly for her second transplant; had Duke somehow manipulated the normal procedures system in order to atone for its mistake? Given her desperate condition and status as an undocumented Mexican immigrant, did Santillan really deserve to get organs?[2]

Although Jesica Santillan's story was far from typical, it did reveal some important truths. As was the case for other transplant candidates in earlier periods, her life was affected not only by her personal, local, and physical circumstances but by national sociomedical factors, including the state of medical knowledge, the actions of government officials, the forces of supply and demand, and societal debates about ethics. Her story also revealed that despite the widespread use of lung transplantation and its life-changing impact for thousands of people, difficult questions remained. Some of the questions the media asked about Santillan's case were quite specific to her situation, but many echoed ones that the field had dealt with for decades, such as: How should donor lungs be allocated? Is transplantation being conducted in an ethical manner? What can be done about the organ shortage? In addition, just as James Hardy had asked in the mid-1960s and Joel Cooper in the 1980s, transplant teams still asked: How can we help lung transplant recipients survive longer? Although many of the questions remained the same, some of the answers looked different. Organ allocation politics greatly intensified in the mid-1990s as government officials proposed significant changes in policies and practices. Events in the larger field of organ transplantation would impact the specific field of lung transplantation and eventually trickle down to touch the lives of individuals with lung disease. As they surveyed the landscape in the early twenty-first century, people who cared about the success of lung transplants would see both recurring challenges and dizzying changes.

National Political Debate over Organ Transplantation Allocation

The mid-1990s began a new era in government oversight of organ transplantation. Change came partly because President Bill Clinton's administration believed the federal government should have a more active role. Since its origins in the mid-1980s, UNOS policies had been only voluntary, unenforceable because during the Reagan and Bush presidential administrations, the Department of Health and Human Services (HHS) had neglected to issue regulations that would have given them the power of law.[3] Change also resulted from divisions within the transplant community over UNOS's *liver* allocation policies. Some people accused UNOS of ignoring up-to-date data, discriminating against people with chronic (as opposed to acute) liver failure, and putting the needs of transplant centers above those of patients. Counter-accusations implied that those who did not benefit from UNOS policies were sore losers who appealed to the federal government to overturn them. Surgeons contended that some of their colleagues stretched the truth to push their patients higher on the waiting list. All maintained that more people would die under their opponents' policies. Senator Bill Frist, who had been a cardiothoracic transplant surgeon before running for office,

reported, "When you go into board meetings at UNOS, there are more politics there than there are here [in Congress]."[4] After a couple of years of consideration, HHS finally issued proposed new regulations in March 1998. HHS Secretary Donna Shalala said the regulations were intended to remedy inequities in the current system, such as the fact that patients in some parts of the country were waiting much longer for an organ than people elsewhere. The regulations did not specify a particular method of organ allocation but decreed that UNOS should develop a policy that would use medical urgency, not geography, as the main criterion, and they insisted that ranking on waiting lists be uniform across the country and based on objective nonmanipulable medical factors.[5]

The regulations prompted fierce debate. UNOS's leadership fought them with no holds barred, warning of dire consequences and hiring lobbyists to block them. It was unusual for a federal contractor to be publicly at odds with the federal agency charged with overseeing it; nonetheless, UNOS denounced the regulations as an unnecessary, unwarranted power grab by unqualified bureaucrats. Liver surgeon Anthony D'Alessandro agreed. "Miss Shalala is determined to anoint herself federal organ transplant czar," he complained, which meant "political appointees" would make the final decisions about who would live and die. "The doctor is out and Miss Shalala will decide what is good for us."[6] However, many patient groups, surgeons, and transplant centers supported the regulations. They thought they would be good for transplant candidates and wanted government oversight over UNOS, which had no checks on its authority. To some degree, the debate was understandable because it dealt with such difficult decisions. Reasonable people who cared deeply about transplant candidates could easily differ about who should get priority for receiving scarce donor organs. To some degree, though, the conflict was about power: Who should make the decisions and the role of the federal government. Shalala asserted that over a decade of Congressional actions clearly had given HHS a key role, and that the regulations struck a balance "between the responsibility that we have for oversight of a very sensitive issue and the very important role of the medical professionals in providing for the system."[7] But the conflict was also about power in a different sense—related to the market share of transplant centers. Underscoring the economic interests at stake, regulation opponent Rep. Thomas Barrett asserted, "This is about the financial life and death of transplant centers around the country." Smaller and medium-sized centers argued that larger centers wanted to put them out of business and the regulations would help them do that. Larger ones accused the smaller ones of inefficiency and of hoarding organs for patients who were not as desperately ill. Worries about losing their "fair share" of organs suggested a sense that donated organs belonged to a certain group of people (those who secured the donation) or a particular organization or locale.[8]

Characterized by shrewd political maneuvering on both sides, the regulation controversy continued for a couple of years, but HHS emerged victorious. In the

eyes of participants and observers, though, the conflict had been "adversarial," "polarized," "fierce," and "nasty." The bruising battle exposed and irritated fissures in the larger transplant community, and according to the Institute of Medicine, "increased public skepticism about the integrity and fairness of the system."[9] Although the conflict over them was unfortunate, the new regulations took effect on March 16, 2000, and yielded some positive outcomes. They gave UNOS the power it needed to make its policies mandatory rather than voluntary, which all parties had agreed was needed. In addition, the regulations insured that the criteria for listing patients and for establishing their ranking on the list would become standard everywhere in the nation and be based on objective medical factors. These two aspects were of enormous significance in insuring fairness for patients. They eliminated the subjectivity and wiggle room that existed in the old system and reassured candidates around the country that their place on their regional list would be based on the same measures as everyone else. The regulations also forced UNOS to share information more widely, including posting data on its website about the length of the waiting list and survival rates at each center. This information could educate and empower patients, hold centers accountable, and provide key data for scientific study. The regulations also clarified the role of the federal government and reiterated the position of the National Task Force on Organ Transplantation, which had declared in 1986 that organs were a *national resource* that required careful stewardship. Finally, the regulations also spurred UNOS to reevaluate its allocation policies for each organ.

New Lung Allocation Rules

By the turn of the twenty-first century, many lung transplant professionals agreed with HHS that the system for lung allocation, in which priority was based primarily on waiting time, needed reform. By 2003, almost 4,000 patients were on the waiting list while less than 1,000 transplants were being performed annually. The list had grown 300 percent in a decade, and a longer list created a longer and more difficult waiting period for each person on it. The median waiting time for those who were transplanted in 2004 was around two years and two months.[10] As waiting times increased, concerned doctors listed their patients as early as possible so that those candidates could accrue waiting time and survive long enough to make it to the top of the list. This strategy made sense for an individual person, but was "not necessarily in the best interest of the larger community of wait-listed patients," argued surgeon Richard Pierson. Some patients were not fortunate enough to be wait-listed early in their disease. Others, such as those with idiopathic pulmonary fibrosis (IPF), were severely disadvantaged because of the sudden and aggressive nature of their diseases. The percentage of patients with IPF, cystic fibrosis (CF), and pulmonary hypertension (PPH) who

died while waiting (30–40 percent) also was much higher than that of those with chronic obstructive pulmonary disease (COPD) (5–10 percent). As one surgeon put it, the system "favored those who could survive long enough to have a transplant rather than those most in need of a transplant." Many felt this system was not the best for stewardship of scarce organs. Although waiting in line was easy to understand and seemed fair, it was not the usual method for apportioning medical care. Instead, physicians usually used the concept of "triage" in which those most urgently in need of care who had a good chance of surviving received priority; the point of triage was maximizing the number of survivors. "If a given patient is well enough to continue waiting, wouldn't it be more equitable to allocate the organ to the patient most at risk of death, assuming the likelihood of survival is similar?" asked one proponent of change.[11] Sentiment for change grew as studies showed that there was no association between one's place on the lung waiting list and the severity of one's disease. Another problem with the practice of early listing meant that sometimes people at the top of the list were actually too well to accept a donor organ when they were offered one, which resulted in transplant coordinators wasting valuable time by calling them, being turned down, and then having to go further down the list. This "turn down rate" was higher for lungs than for other organs, which was especially bad given the short length of time donor lungs remained viable.[12]

In response to discontent and the expected push from the federal government, in 1999 the UNOS Thoracic Subcommittee appointed a Lung Allocation Subcommittee to develop a new system. The committee first set its goals: reducing the number of deaths on the waiting list, prioritizing candidates based on medical urgency, and deemphasizing the role of waiting time and geography in allocation.[13] For a couple of years, the subcommittee analyzed data, aiming to design an algorithm that would get organs to the candidates at the highest risk of dying. They found that 80 percent of all lung transplant patients fell into four disease categories—COPD, PPH, CF, and IPF—and pinpointed certain factors that served as predictors of death for each particular disease. The committee did not want to base allocation solely on urgency, however, since sometimes people got too sick to survive a transplant. Using a statistical model that could predict the expected number of days an individual candidate would live on the waiting list (an urgency measure) and the expected number of days lived in the first year after transplant (a transplant survival measure), the committee came up with the concept of a net "transplant survival benefit." The transplant benefit measure was defined as the difference between the transplant survival measure and the wait-list urgency measure. "By offering donor lungs to candidates according to their medical characteristics instead of their waiting time," explained UNOS, "lungs will be directed first to candidates who have the most urgent need and who will have the greatest chance of success after transplantation."[14]

The committee proposed a method that translated the concept of transplant benefit into a number on a scale from one to one hundred, a patient's "lung allocation score" (LAS). The higher a person's lung allocation score, the higher priority she or he had in receiving donor lungs. When a donor lung came available, coordinators would call the matching candidate in the same geographic area with the highest lung allocation score. Waiting time would no longer matter—except in the case of a tie where two patients in the same locality had the same LAS. The new system required that a patient's medical information be updated every six months, and if a patient got sicker, it could be submitted as needed so the score could be recalculated. This system used objective medical measures, such as forced vital capacity of the lungs, pulmonary artery pressure, age, body mass index, kidney functions, use of oxygen at rest, and functional status. The committee thought such measures would prevent manipulation by centers trying to increase their patients' odds of receiving a transplant. The system used fairly sophisticated statistical modeling based on experience with thousands of people who had already been transplanted or listed.

The committee unveiled the new plan at a forum in March 2003, where those in attendance generally supported the goals but wanted a more substantial data set. A few months later, the committee released a revised draft for public comment, and at that time, concerns were raised, which prompted the committee to make a few more adjustments.[15] It set up a Lung Review Board to consider appeals in cases where a physician felt a particular patient's LAS did not adequately reflect his or her needs, and established a national data collection project to gather additional information. Finally, it reassured the larger lung transplant community that the algorithm would be reassessed every six months with the most current data. In June 2004, the UNOS board of directors formally approved the new system, and after a year of education and computer programming, implemented it on May 4, 2005. UNOS lauded the new concept of transplant benefit as "revolutionary."[16]

Not everyone embraced the new system, however, including pulmonologist Robert Kotloff, who pointed out that sophisticated studies performed on patients with CF had not proven very reliable at predicting when an individual person would die. In addition, he thought the way the system dealt with diseases other than the four most common ones was "highly unorthodox and seemingly unsubstantiated." He also found fault with using patient's expected one-year survival to evaluate transplant benefit. Since recipients did not gain many years of life, Kotloff thought the greatest benefit of a lung transplant was related to *quality of life*, not the duration of life. He argued that "a COPD patient who achieves 5 years of quality life with transplantation in place of 5 years of misery without it has realized immeasurable benefit from the procedure even if there is no net benefit in absolute number of days lived." He concluded the committee had made changes too quickly and unnecessarily.[17]

Some patients also disliked the new system. For one thing, when it was implemented, the list changed overnight. Some who had been waiting for years found their place on the list dramatically altered (and the change could be in either direction). Recipient Steve Sparks observed, "If someone is No. 3 on the list and they come and say, 'Now you're 120,' that's scary." Dr. Kenneth McCurry admitted, "We tried our best to educate and communicate, but many felt they had been cheated." A few patient groups complained. The Alpha-$_1$Association observed that the number of people transplanted who had alpha-$_1$antitrypsin deficiency (a genetically based form of COPD) decreased in the new system and suggested they should be categorized separately from people who got COPD from smoking. There were too many alphas "languishing on the UNOS waiting list," asserted spokesperson Bettina Irvine. "This is simply wrong." UNOS investigated, but the data showed that although fewer alpha-$_1$ candidates were being transplanted, there was actually a decrease in the number of deaths among that group on the waiting list. Nor did they find any significant differences between alpha-$_1$ recipients and other patients in their category. Patients with PPH, on the other hand, received a more sympathetic hearing. From the outset, there was concern that the LAS failed to accurately depict the severity of their illness (because of limited data), and additional statistics soon proved them correct. They were the only group for whom death rates on the waiting list actually rose. Persuaded by the evidence, UNOS's lung subcommittee agreed to work closely with experts in PH, who were conducting an extensive national study, and proposed adding two variables to the LAS. Advocates for pediatric patients also expressed concern since there was little data and much difficulty finding donor lungs for them. As a result, the committee made reforms intended to increase the chances for urgently ill children.[18]

Overall, though, the early response to the new system was quite positive. "It's almost as if it's a whole new day for lung transplantation," said surgeon Cynthia Herrington. "It's amazing." The new lung allocation system clearly began achieving many of its goals. First, the waiting list got shorter; indeed, almost immediately after implementation, the list was cut almost in half. Because waiting time no longer mattered, people were no longer being listed early just to hold a place for themselves. That translated into more efficiency, reducing the number of wasted calls coordinators had to make offering donor lungs to people who were not actually ready to be transplanted. The median number of offers made for each donor organ dropped from ten to four. Equally significantly, the median amount of time spent by recipients on the waiting list was reduced dramatically, from 792 days in 2004 to 141 in 2007. Given the stressful nature of the waiting period, this shortening could be extraordinarily beneficial to transplant candidates. At the same time, the new system was achieving its goals of reducing the absolute number of deaths on the waiting list.[19]

Allocating organs on the basis of medical urgency meant the new system also had a significant impact on the number of people receiving transplants for different diagnoses. In particular, more people with idiopathic pulmonary fibrosis began receiving lung transplants. They now received 33.1 percent of them as opposed to 23.9 percent under the old system. While people with COPD continued to constitute a large percentage of transplant recipients, their percentage decreased about 20 percent in the first years of the new system. The greater flexibility of the LAS meant transplant centers had the ability to transplant individuals with advanced disease more quickly, which, as intended, provided more transplants and hope for anyone whose disease took an unpredictable deadly turn.[20] Hannah Olson was a 20-year-old with CF whose status had been "inactive" on the old list because her condition seemed stable, but quite suddenly she deteriorated to the point where she had to be put on a respirator. Under the old system she would have had to wait years more, but under the new one, her decline increased her lung allocation score and shot her to the top of the list. One day later, she received a transplant. "I'd probably be gone if the list was the way it was before," Olson said, and her physician concurred. UNOS asserted that the new system was "more responsive to the needs of individual patients."[21] The risk in performing transplants on more people who were extremely ill, however, was that the overall survival rate might decline. Only with more time will it be clear whether the new system transplants some people who are too sick to benefit, but statistical analyses performed in the first three years suggested that was not happening. One-year survival rates did not change much, if at all. The Scientific Registry of Transplant Recipients' report on the state of lung transplantation in 2008 concluded that smaller waiting lists, shorter waiting times, reduced wait-list mortality, and greater efficiency were all accomplished without a clear negative impact on survival rates.[22]

The new lung allocation system could not ameliorate every problem, however. The key challenge of timing still existed, as it always had. Pioneers James Hardy and Joel Cooper would have agreed with surgeon Jonathan Orens, who said in 2007, "The trick here is to get it just right so that you transplant patients when they are sick enough that they are going to die from their disease, but not so sick that their chance of surviving the operation is very low." Undoubtedly the system is better at predicting urgency and trying to give transplants to candidates before it is too late for them, but no one can take uncertainty out of the process, and it will take time to know whether in the long term new problems will arise because of the new system. The committee also failed to reach consensus about the role of geography in lung allocation. Some members suggested the system for offering lungs locally first is neither the best method for getting available lungs to appropriate recipients nor consistent with the intent of HHS regulations.[23] Practical and methodological debates will abound if the UNOS lung subcommittee attempts to include quality of life in the definition of "transplant benefit."

Finally, ethical issues remained regarding smoking, maximum age for candidates, retransplantation, and multiple listing, and likely will remain given the shortage of donor organs. Since one of the remarkable aspects about the history of lung transplantation was the way a community formed among very different people (by age and disease), it is hoped that the new system—which sensibly studied the diseases differently since they tend to take different courses—will not lead people with some diseases to feel they are pitted against people with others.

Despite ongoing challenges, there was much to be pleased with. Consistent with HHS's decree, UNOS's lung subcommittee made dramatic changes using objective medical criteria based on collection of up-to-date evidence. It created a system that inspired trust. While not everyone agreed with the principles that guided its actions, the vast majority did, and the committee thoughtfully and explicitly grappled with those principles. Then it had unbiased statisticians develop the most sophisticated algorithm possible given the available data. The committee was transparent in publicly announcing and explaining its assumptions, processes, and conclusions. As promised, the UNOS Thoracic Committee continued to assess the data and make adjustments to the system and score, a process that was reassuring. By 2010, lung allocation was a far cry from the early years when surgeons and centers acted independently, and also an improvement over the pre-2005 first-come, first-served system that created a hopelessly long and inefficient list and benefitted some types of people more than others. The leaders of the lung subcommittee, who were medical personnel accustomed to fighting for their patients' lives, appeared less defensive and more open to change than the high-level UNOS staff did in their battle with HHS. The result was that for the first time, the field of lung transplantation actually had progressed further than that for other organs. Indeed, the liver and kidney fields began imitating the lung model, moving toward more sophisticated allocation algorithms of their own that similarly attempted to balance medical urgency with probable benefit.

Efforts to Ameliorate the Donor Organ Shortage

Reforming the lung allocation system, however, did not address the fundamental question of how to find a sufficient number of suitable donor organs, a problem that continued to plague the field of transplantation as a whole. To remedy it, advocates floated proposals such as providing economic incentives to the families of organ donors or adopting a system of "presumed consent," in which a brain-dead person would be *assumed* to have agreed to donate his/her organs instead of requiring explicit consent from family members at the time of death. These proposals were considered but not adopted because they were seen as undercutting the voluntary nature of the system in the United States. In their labs, a few

researchers investigated ways organs from carefully bred animals might one day be used for donation.[24] With better luck, some transplant centers loosened the criteria for human donor lungs by using ones from people who were a little older, had smoked a bit more, or harbored minor infections. Researchers also developed improved methods for preserving donor organs, resulting in better quality lungs and a much longer window of time before they deteriorate.[25] In a more controversial move, some transplant surgeons also expanded the pool of donor organs by accepting some from people who had not been declared brain dead but were "non-heart-beating donors." In this practice known as "donation after cardiac death," donors were those whose death was declared on the basis of cardiopulmonary criteria. These donors were usually on a ventilator due to irreversible brain injuries and did not quite fulfill all the criteria for brain death (because they retained some minor brain stem function). Medical organizations and transplant teams insisted that donation after cardiac death was both sensible and ethical if done carefully and that many grief-stricken families appreciated the opportunity to donate.[26] Others raised ethical concerns, and the discussion sounded eerily like the brain-death controversy that started in the late 1960s and persisted through the mid-1980s. "There's a fine line between methods that are pioneering and methods that are predatory," said opponent and bioethicist Leslie M. Whetstine. Despite the concerns, the practice became fairly common in kidney and liver transplants in the twenty-first century, but it had not yet been tried very much with donor lungs (only about 60 examples as of 2010).[27]

The federal government also initiated less controversial methods to increase the number of donor organs. In 1997, Vice President Al Gore and Donna Shalala launched a public relations campaign with the message: "Share Your Life. Share Your Decision." This was based on poll data that suggested nearly all Americans would consent to donate their loved ones' organs if they knew beforehand that this was the person's preference. In addition, HHS issued new federal regulations requiring all hospitals participating in Medicaid and Medicare to notify OPOs in a timely manner of all deaths and imminent deaths so that potential donors could be identified. In 2001, Tommy Thompson, the next HHS secretary, took the efforts a step further with an "Organ Donation Breakthrough Collaborative" intended to improve the "conversion rate," which is the percentage of eligible donors who actually become donors, by analyzing and then sharing the practices of hospitals that were extremely effective. The national average rate of organ donation rose an unprecedented 10.4 percent in 2004 and then an additional 6.2 percent in 2005.[28]

Social and Cultural Trends

It was right in the middle of these significant improvements for lung transplantation that Jesica Santillan's tragedy occurred. The event had negative effects

beyond her family circle. Even though claims that Duke had manipulated the system were unsubstantiated, the case replanted in the public mind the idea that organ allocation might be unfair, which was especially problematic in a system that relies on public goodwill. Although UNOS policy limited immigrants to receiving no more than 5 percent of transplants at any one center and statistics showed illegal immigrants donated far more organs than they received, some commentators angrily denounced foreign "transplant tourists" for taking organs away from US citizens. According to two scholars who analyzed it, much of the media coverage "was deeply problematic, uninformed, wildly speculative, or just plain wrong." In addition, the mistakes made in the case may well have frightened transplant candidates, who were already quite vulnerable. Media coverage could have shaken practitioners as well; the *Washington Post* described Santillan's surgeon as "a figure both noble and detestable . . . a confirmation that Americans mythologize doctors while deeply suspecting them of the capacity for great arrogance and harm."[29] Ironically, these doubts about the nation's transplant system revived just as it actually was becoming more scientifically based, more reliant upon objective criteria, and less vulnerable to manipulation by overly eager surgeons.

Some good came from the case, however. UNOS implemented reforms to guard against mistakes. In addition, the incident provoked journalists to investigate transplant programs, and they uncovered a couple of scandals in California and another in Illinois. Most advocates believed public scrutiny would keep programs on their toes and UNOS proactive in dealing with problems. Media attention also prompted further government action, with the Centers for Medicare and Medicaid Services (an agency of HHS) concluding it should become a more active regulator. In 2005, it developed a set of explicit conditions for hospitals wanting to be certified (and thus eligible for reimbursement) by Medicare for transplant services and pledged to strictly enforce the rules.[30]

Despite the rarity of such problems and the efforts to eliminate them, twenty-first-century popular culture often portrayed organ transplantation in a negative manner. Movies and television shows featured plots that, in the words of one analyst, were often "based upon the worst myths, urban legends, and scenarios imaginable." Common themes included corruption in the medical system, undeserving or ungrateful recipients, rich or famous people getting preferential treatment, and donors being treated as simply sources of spare parts. The daytime soap opera "One Life to Live" had a months-long story line in which a surgeon secretly sold transplantable organs to the highest bidder; surgeons misdiagnosed brain death and considered taking the patient's organs anyway on an episode of "Chicago Hope"; in 2006, an estimated 22.6 million people watched a doctor on "Grey's Anatomy" cut the wire on a heart pump of a candidate so that his status would become more urgent, moving him to the top of the list. It is not surprising that fictional shows ignore facts in order to heighten drama and interest, but it turns out that many people believed the information on such shows was accurate

and it influenced viewers' general sense of cynicism and suspicion about organ donation.[31]

Not all the cultural trends were negative, however. Newspaper coverage of transplantation was both more accurate and more positive than portrayals from Hollywood, and although there were many negative plotlines in movies and television, there were also inspiring stories of hope and redemption. Some accurately portrayed the pain that waiting candidates feel and the joys and difficulties of receiving a second chance. Such stories could have real influence, as when the family of a teenager donated her organs because she had talked to them about donation after watching an episode of "Three Rivers." In addition, even though dramatic shows disproportionately explored darker themes, they did tend to portray organ donors as good people, and sometimes the very same television show simultaneously hurt and helped the cause. In recent years, new transplant watchdog groups began disseminating information about the impact of misleading portrayals, offering accurate information to scriptwriters, and honoring shows that treated the topic fairly.[32]

Community formation was another important cultural trend. A small group of people in Florida founded the Second Wind Lung Transplant Association in 1995 because they wanted to provide support and information for lung transplant candidates, recipients, and caregivers. They started by creating a newsletter, a directory of members, and a website, and also hosted five educational conferences. Like any nonprofit organization, Second Wind faced challenges, especially financial ones, which were exacerbated by the health problems and short life expectancy of many of its members, but Second Wind weathered storms, growing in 2005 to 700 members in 45 states and 5 countries. It flourished through the dedication of its volunteers, many of whom were grateful for a second chance and had adopted the motto "Support Through Service." Second Wind reached many others through its website, which contained individual stories, memorials, resources, and names of support groups; it also had hosted a chat room, a message board, a peer support program (including for caregivers), and liaisons with many transplant centers.[33] New media presented other opportunities for the lung transplant community. UNOS, transplant programs, and nonprofit organizations associated with particular lung diseases created informative websites, and scores of discussion groups, blogs, and social networking sites appeared. In the spring of 2010, a Pulmonary Fibrosis Foundation Facebook page had over 2,500 "fans," and the Cystic Fibrosis Foundation one had over 60,000. Individuals used Facebook or MySpace to tell their stories, thank their donors, raise money, reach out to others, request information, and share updates. Short videos on YouTube showed excerpts of transplant surgery and dramatic accounts of restoration to health.

The US Transplant Games proved to be another valuable new cultural development. In 1990, the National Kidney Foundation sponsored a national event in

which 400 athletes who had undergone any kind of organ transplant competed in different sports competitions. The event grew into a popular biennial occurrence demonstrating the rejuvenating potential of transplantation to people outside the transplant community, who had no idea that organ recipients could swim the butterfly or run long distances. Besides showcasing athletic ability, the Games served as a celebration of life. While some of the athletes were extremely gifted, others were novices who attended simply for the purpose of being with other survivors and the entire transplant community. "Being at the Games empowered me," said Kimberly Harrington in 2008. "Complete strangers cheered when I finished. I finished last, but was blessed to be there to finish." The Transplant Games also provided a chance for medical professionals, patients, donor families, living donors, and related organizations to gather for the benefit of organ donation. Participants made a point of honoring donors and donor families, giving a rousing, emotional ovation during opening ceremonies, and more recently offering a donor recognition ceremony, a quilt-pinning ceremony, and grief workshops. "It gave us so much hope, healing, and passion for moving forward in our lives after our loss," Mary Jo Rozmenoski recalled. "The sadness and loss will always be there for us but attending the Games and seeing such enthusiasm and life helped us feel grateful that our son had the opportunity to give the Gift of Life." Changes at the Games fit a recent trend in the field of organ transplantation to give donor families more support, voice, and recognition. By 2008, the Games had expanded to include over 1,200 athletes and 7,000 participants.[34]

Medical Trends

Not surprisingly, medical knowledge continued to be a key factor affecting lung transplant recipients. In the twenty-first century, short-term survival rates improved somewhat and remained strong, but the long-term survival rates still disappointed, especially when compared to other organs. In 2003, 73.3 percent of transplanted hearts had survived for at least five years, while only 53.3 percent of lungs survived that long. Significant challenges regarding long-term care persisted, especially with regard to infection, rejection, and medication toxicity, all of which caused everyday medical problems and psychological hurdles. Indeed, one researcher noted in 2009 that "significant breakthroughs" were "desperately needed."[35] While these were serious problems, the "Achilles Heel" of lung transplantation continued to be chronic rejection. Over half of recipients developed chronic rejection, and it was not reversible; they typically died two–three years after diagnosis. The phenomenon was poorly understood and even hard to diagnose with certainty until it was well-established. Although there were some theories, the specific causes remained elusive.[36] Hoping to prevent it from developing, some centers performed a surgical "stomach wrap" on recipients to

keep stomach acids from entering and damaging the lungs. Once they suspected chronic rejection, they tried a variety of strategies, including intensifying or changing the methods of immunosuppressive therapy and using photopheresis, in which a patient's immune cells were removed and irradiated and then returned to the body. Still, no single treatment solved the problem, and frustrated doctors described their therapies as "powerless against the tide of chronic rejection," "singularly unrewarding," and "disheartening."[37]

Yet there were reasons for optimism. Waiting times shortened, deaths on the waiting list decreased, and more urgent patients were getting the chance to receive lung transplants. Surgeons also were able to perform more lung transplants. In 1998 there were 840 lung transplants done with organs from deceased donors in the United States, and in 2007, there were 1,465. Presumably this growth resulted from more donor organs, more specialists, and a more efficient system. In addition, survival rates improved. Between 1990 and 2006, one-year survival rates in the United States increased from 73 to 86 percent and five-year survival rates increased from 40 to 56 percent. Although chronic rejection was a stubborn problem, many researchers were focusing intense efforts on how to diagnose it, predict its course, and understand its physiological mechanisms. The lung transplant medical community participated in "tremendous worldwide collaboration" and although it did not result in any breakthrough discoveries—no "home runs," as one reviewer put it in 2007—there were many "base hits." While some saw the metaphorical glass as half empty, other medical experts noted that progress was being made, and that recent years were "an exciting period of change and innovation."[38]

People with serious lung diseases could also feel hopeful for reasons unrelated to transplants. In the mid-1990s, Joel Cooper resurrected a long-discarded surgical procedure known as lung volume reduction surgery (LVRS), which after some controversy was proven to help some COPD sufferers improve their exercise capacity, lung functioning, and quality of life. Compared to transplantation, the procedure led to smaller improvements but also had fewer side effects.[39] Although many people with alpha-$_1$ antitrypsin deficiency did not meet the specific criteria for LVRS, some of them benefitted from intravenous administration of purified alpha-$_1$ antitrypsin.[40] Strides were being made for cystic fibrosis as well, particularly after 1989, when researchers identified the specific defective gene responsible for the disease and subsequently made their first attempts with gene therapy. Recently some scholars criticized the misleading culture of "hype and promise" that shaped the discussion of gene therapy for CF in the 1990s, however, pointing out that the research studies on the new treatments had problems and poor results.[41] Still, new knowledge and treatments made a significant difference in the lives of people with the disease. The median age of survival for people with CF was 10 years in 1962; in the late twentieth century it rose to 37 years; and it was predicted to be 50 for those born in the twenty-first century.[42] For people with

pulmonary arterial hypertension (PAH), scientists were still not sure how or why pulmonary blood vessels came to be so damaged, but there was a recent "explosion of understanding." Twenty years ago there were no treatments available for PAH patients, but in 2010 there were eight to consider, with more in developmental stages.[43] For people with pulmonary fibrosis, researchers experimented with therapies intended to process oxygen more efficiently and to slow progression of the disease, especially the formation of scar tissue.[44] Eventually scientists hope gene therapy may be used to help "recondition" or immunologically prepare donor lungs before they are implanted in order to improve transplant results or to use radical new regenerative medicine to grow healthy replacement cells for lungs. Researchers around the world also worked on developing an artificial lung that would be safer and last longer than the current options and help more candidates survive (and live more comfortably) until transplant. They hoped that such temporary "bridge to transplant" devices would eventually lead to more permanent devices that could assist or even replace diseased lungs, making transplant unnecessary.[45]

* * *

Not surprisingly, in the first decade of the twenty-first century the daily lives of people with end-stage lung disease continued to depend heavily upon the state of medical knowledge. The field made incremental progress in the period, but no great leaps forward, probably due to both the complexity of the remaining problems and the fact that transplant teams had already overcome the most basic obstacles by the mid-1990s. Though it remained difficult and risky, lung transplantation became an accepted and widely practiced treatment for many types of end-stage lung disease. The number of people who were saved by the procedure increased dramatically in the 1990s and 2000s, as did the number of candidates for it and the number of medical personnel who had expertise in it.

Candidates for lung transplant were not just affected by medical factors, however. The politics of organ transplantation heated up in the late twentieth century, resulting in fiercely polarized debate about how scarce organs should be allocated and the roles of UNOS and the federal government. The transplant community itself, which included both patients and medical personnel from different types of institutions, was divided over these matters. Led by the secretary of the Department of Health and Human Services, Donna Shalala, the federal government succeeded in asserting oversight over UNOS. HHS created significant change by insisting that organ allocation be more standardized across the country and based on objective medical criteria. Leaders of the lung transplant community, which was not divided like the liver transplant world, seized the opportunity provided by the government and discarded the first-come, first-served lung waiting list. The new lung allocation system, based on the idea that

organs should go to the most urgently ill candidates who could benefit from a transplant, marked a great improvement over the old one. It could not eliminate uncertainty for people waiting, but it shortened the list and decreased the number of deaths among those who waited. The new system was based on medical criteria, and seemed to be fair, flexible, efficient, and to better serve all kinds of patients. For the first time in its history, the field of lung transplantation was at the cutting edge of organ transplantation practices.

The new lung allocation system could not solve the problem of the donor organ shortage, which had always been somewhat worse for lung transplants. In the new century, the transplant community and the federal government tried to increase the supply of donor organs, sometimes in noncontroversial ways, such as by educating the public and medical personnel, and sometimes in ways that proved controversial, such as donation after cardiac death. The discussions about donation after cardiac death—especially the concerns that surgeons might go too far—echoed the debate over brain death that occurred decades earlier. Thanks to targeted efforts, the number of donated organs increased in the twenty-first century, but the need grew, too. Portrayals of transplantation in the popular media and coverage of occasional scandals and tragedies, like the death of Jesica Santillan, suggested that Americans still were fascinated by organ transplantation but also harbored some doubts about the integrity of the system and the surgeons. Macro-level social and cultural factors mattered precisely because this unique medical procedure depended upon public acceptance. Still, there were positive cultural trends as well, especially in the development of community for candidates, recipients and donor families, and in rituals that demonstrated public appreciation of the difference made by the gift of life. In practical, medical, and cultural matters, the first part of the century witnessed both change and continuity, both significant challenges and hopeful steps.

Conclusion

Many sociomedical factors affected people pursuing lung transplantation in the United States, both at the personal and local "micro level" and at the national and more distant "macro level." At the micro level, the fact of being a lung transplant candidate or recipient exerted a powerful influence over their lives. It meant they encountered many unusual experiences, different ones from people who had other life-threatening diseases or life-saving medical procedures. Their unusual experiences included having to wait a long and uncertain amount of time for their treatment, enduring false alarms, being saved by an organ from an unknown dead person, and living the remainder of their lives with a suppressed immune system. When added to extreme shortness of breath and other difficulties of end-stage lung disease, those experiences posed many personal and psychological challenges. In particular, both candidates and recipients were forced to rethink their identities and deal with uncertainty, powerlessness, and guilt. They were also affected by their specific lung diseases and individual circumstances related to their loved ones, medical teams, finances, length of the waiting list in their area, and the impact of their new lung(s), especially with regard to side effects and complications. Some were luckier than others.

Despite widely varying outcomes, surviving recipients shared many observations about the ways lung transplant affected them. They saw transplant as a tradeoff rather than a cure, a sort of mixed miracle that left them with uncertainty and ongoing medical issues, but significantly improved the quality of their lives. They did not live entirely "normal" lives, but knew that would be the case, and they were extremely grateful for the actions of their transplant teams, loved ones, and donors and donor families. Surviving recipients were glad they had undergone the procedure and recommended it (cautiously) to others similarly situated. They were very aware that one of the bittersweet facts of lung transplantation is that usually a family was grieving at the very moment someone else was given a second chance. They wanted to express their appreciation for the gifts of life they'd received and wished the public knew more about the needs of transplant candidates and the life-changing benefits of organ donation.

Many of the factors affecting people pursuing lung transplantation were out of their control, including macro-level factors such as the state of medical knowledge. Lung transplantation has its own unique history, and much changed in the half century after James Hardy first inserted a new lung in John Richard Russell in 1963. Until doctors knew how to perform the surgery safely, preserve donor lungs, and thwart organ rejection, those hoping for a lung transplant would be frustrated. For almost two decades, surgeons' early efforts resulted in one failure after another, with recipients usually dying in less than two weeks; and critics raised questions about whether their efforts were premature and/or unethical. Finally in the early 1980s, teams at Stanford and Toronto General triumphed, extending the lives of a number of human recipients of heart-lung and single lung transplants, due to persistent experimentation with animals, new procedures, well-chosen recipients, and cutting-edge immunosuppressant drugs. Over the next decade, transplant teams learned more lessons, resulting in longer survival times. The time period one lived in affected those hoping for a transplant.

More than medical knowledge was necessary, however. Before lung transplants could become an option for people with end-stage lung disease, organs had to be available. Donor organs had to come from members of the general public, who would only donate if they believed organ transplantation was worthwhile. Thus acceptance of the procedure was another key macro-level factor. Laws and an administrative infrastructure were also necessary to make feasible the donation, sharing, and distribution of large numbers of organs. Developing these took time, and as with medical knowledge, there were bumps in the road. Most Americans considered organ donation a generous gift, but some had qualms about using brain-dead donors, and ethical and legal issues related to brain death were not resolved until the mid-1980s. Around the same time, organ distribution became politicized in response to concerns that it was not being conducted in a sufficiently effective or fair manner. Congress created a national organ transplantation network, which promoted enormous growth in the number of donors and transplants. In the mid-1990s, however, intense conflict arose over the difficult issue of how donor organs should be allocated. In the early years of the procedure, individual surgeons made the decisions, and from the mid-1980s through 2005, the voluntary guidelines of the United Network for Organ Sharing (UNOS) deemed lungs should be allocated on a first-come, first-served basis. After the Department of Health and Human Services exerted authority over UNOS, UNOS altered its now mandatory policies, decreeing lungs should be allocated based on medical urgency. Changing allocation policies clearly impacted people pursuing lung transplantation. A final factor affecting them was economics. Only after the federal government and insurance companies were persuaded that lung transplants were effective would they agree to pay most of the expenses for transplants for them—for those fortunate enough to have coverage. Thus over the course of almost 50 years, significant change occurred in the

macro-level sociomedical factors that affected people pursuing lung transplantation. Although the history included serious failures and conflicts, most of the changes eventually proved positive, leading to greater effectiveness, more acceptance, greater availability, and more consistency and fairness.

Not all challenges were overcome, however. Medical obstacles remain, especially related to the effects of immunosuppression and the problems of chronic rejection. Lung recipients still do not enjoy the survival rates of heart, liver, and kidney recipients. As long as there is an organ shortage, there are likely to be ethical challenges as well. Particular groups of patients may feel disadvantaged as the new lung allocation system evolves. Retransplantation poses an ongoing dilemma. Discussions continue about whether an individual's history of smoking should be considered in prioritization for transplant and about the maximum age for candidates. UNOS has yet to take on the issue of multiple listing, in which those who have the knowledge, finances, and flexibility can get themselves placed on the waiting list at more than one transplant center. Nor has UNOS yet achieved the much wider geographic sharing proposed in the federal government's twenty-first-century regulations. These issues are not simply about physiology and data, but about values and priorities, and may be quite difficult to resolve.

Although patients had little control over most of the factors influencing their prospects, they had choices about how to cope with their circumstances. If they were fortunate enough to receive transplants, they also had choices about how carefully they monitored their bodies, how much risk they were willing to expose themselves to, how to think about donor families and whether to try to contact them, and how to spend their remaining time. Despite individual differences, there were many shared experiences, perspectives, and coping strategies. One of the most noteworthy and creative coping mechanisms was relying upon a lung transplant community. This community formed thanks to the circumstances of rehab, encouragement of early medical teams, growth of the Internet, and the needs and efforts of its members. Candidates gained information, empathy, comfort, and hope from one another. Recipients gained perspective and often wanted to give back to others facing the same challenges they had experienced.

One reason to listen to the narratives of candidates and recipients is to assess the value of lung transplantation. The nation's rising health care costs have prompted debates about rationing expensive medical procedures such as organ transplants, and lung transplants may be especially vulnerable since they are perceived as less "successful" than some others. Americans and their governmental representatives will need to consider how to evaluate effectiveness, success, and value—and whether the assessment should focus on survival time, costs versus benefits, or quality of life. If quality of life is deemed an important criterion, there will be debate about how best to evaluate such a personal and qualitative issue, but surely recipient voices should be heard and considered. The number of people with a stake in lung transplantation has grown significantly since the days

when only a handful of surgeons and patients dreamed it might be possible. Now medical personnel nationwide, federal bureaucrats and state legislators, insurance executives and employers are invested in the procedure. The general public also has a crucial interest, since lungs from dead people are currently the source of almost all the donor organs used in lung transplants. At times some Americans have expressed mistrust of the nation's organ transplant system, and they deserve honest and accurate information about the experiences of transplant candidates and recipients so they can make decisions about donation. This is especially true since popular culture sometimes portrays transplantation in a skewed and negative manner. The many doctors, nurses, and therapists conscientiously working to extend lives also deserve to have their labors accurately perceived.

Another reason to listen to patient stories is so that candidates and their caregivers may anticipate their needs. Although candidates differed in the amount of negative information they wanted, transplant programs and interested individuals should know that candidates benefitted from knowing a great deal about the stages of the process, the best and worst outcomes, the many things that can go wrong, and the many ways post-transplant life can be better than dying tethered to an oxygen tank. Because waiting is so difficult, it would be helpful for candidates to know the different ways people have coped with uncertainty and decline (whether it be reliance on loved ones, spirituality, planning, positive thinking, denial, etc.) so that they may consider their own coping strategies. Candidates should also know that having a community that understands what they are going through has proven extremely valuable for many people. That community might consist of people exercising together, participating in a facilitated support group, or communicating online through Second Wind or other discussion groups, chat rooms, or social networking sites. While medical teams are very effective at helping lung patients fight for life, they tend to see death as a failure and shy away from conversations about it. Candidates need support and resources not only to prepare for a possible life-transforming transplant, but also for simultaneously preparing for the possibility of dying. Since lung transplants cannot extend life indefinitely, reflecting upon how one wants to die is useful for both candidates and recipients alike.

Patient narratives suggest other ways medical caregivers might help recipients. Beyond just treating their physical problems during the difficult recovery period, doctors, nurses, and therapists can explain the obstacles and allow struggling recipients to express their natural fears and frustrations. Ignoring the unique origins of transplanted organs might not be realistic or wise given the curiosity, guilt, and sense of obligation many recipients felt. Allowing transplant survivors to discuss the possible psychological impact of their foreign lung and the implications of communication and relationships with donor families seems as wise as educating them about the risks of rejection and infection and their complex new medical regimen. Finally, transplant personnel should know that

people with end-stage lung disease appreciate them not only for their medical knowledge but for the interest and concern they demonstrate. Although it may be difficult for very busy professionals to listen carefully to the stories and not just the symptoms of each individual patient, transplant teams who understand their patients' experience of illness and quality of life are perceived as better caregivers. When such authentic interpersonal interactions have taken place, it has proven to be very rewarding and meaningful for the patients and may prove the same for the medical personnel as well.

Lung narratives can benefit those considering transplant, their families, and the storytellers themselves. Candidates raved about the difference such stories made in their decision-making and waiting period. The stories can also help the loved ones of transplant candidates understand what they are likely to experience. In addition, those in the growing field of narrative medicine argue that the people who do the telling of their stories benefit; their physical and mental health is better. Many of our interviewees confirmed that they enjoyed and felt gratified by sharing their time and perspectives with others. I believe this is not simply because their stories might promote organ donation and help others, but because when someone listens to and really hears a person's story, it honors the individuality and humanity of the storyteller. Everyone deserves to be validated in this way. Telling one's story can be especially helpful when traumatic experiences are involved, as is usually the case for people struggling with serious illness.

We should listen to patients' stories for another reason, too: because they can help people beyond the transplant community. Just as popular media sometimes demonizes supposedly corrupt surgeons, it sometimes indulges in sentimental heroification of people who have organ transplants. People we interviewed resisted such oversimplified portrayals. They knew they were unlucky to have been so sick and were very fortunate if they got the opportunity to live a longer, though different, life. They didn't see themselves as heroes or as more courageous than anyone else facing a difficult situation. If anything, they preferred that donors be portrayed as heroes. Despite their reluctance to be portrayed as courageous role models, it clearly requires enormous fortitude to go through the long process of lung transplantation. Thus the situation of transplant survivors can help others reflect upon the human condition. Whether we think about it or not, we all live with uncertainty; we lack control over many things, but especially over how long we will live. We all rely on others, no matter how much we value independence. We can also profit from thinking about how to cope with challenges, whether those are physical, social, economic, or psychological. As a society and as individuals, we can benefit from reflecting upon "quality of life" and what that term means to us, what we value, and how we want to take advantage of our chances in life.

Epilogue

Like many other families, mine never imagined that it would be touched by the larger historical narrative of lung transplantation. When my brother John was told a transplant was his only hope, the only place in the Midwest that performed them was Barnes-Jewish Hospital in St. Louis, which is where Joel Cooper had relocated. We were told that if John were accepted as a candidate, he would have to move there. The hospital scheduled an appointment for an evaluation for transplant for mid-January 1991, and the family scrambled to make arrangements. I recall draining phone conversations with John as I tried to ascertain how he was doing both physically and mentally. He didn't give much indication of how he was feeling. He declined my offer to move to St. Louis with him, but knowing how limited my finances were as a struggling graduate student, he offered to pay for my airfare home for the Christmas holidays. Though touched, I also thought it was a bad sign that he was willing to spend his limited money on me.

When I arrived home around December 22, John was in the hospital. I spent the day with him, taking my turn while other family members worked or did last-minute shopping. At times he was his usual funny self, but he was quite tired, weak, and short of breath, despite being given high levels of supplemental oxygen. He was plagued by a severe headache, which was an entirely new symptom (apparently caused by high levels of carbon dioxide in his brain). Over the next day or two, he rapidly declined. The headache was agonizing and doctors said administering stronger painkillers would kill him. I was shocked to find myself wondering if death might actually be a relief for him. A group of family members visited him on Christmas Eve fruitlessly trying to give him some comfort. We left when he finally slept. Around 12:30 a.m. on December 25, doctors called to say the end was near, and we awkwardly stood beside his bed and watched as he lay unconscious, his breaths coming further and further apart until he simply didn't breathe again. He never made that appointment to be evaluated for a transplant.

We were devastated, of course, upset that John was gone from our lives. We grieved that at 24 years old, he lost his life before he had much chance to live it.

In addition, John's death intensified our concerns for my youngest brother, Bob, who also had cystic fibrosis (CF).

Bob was in some ways like John, who he looked up to and emulated in a way that sometimes annoyed John. Bob was athletic, dressed nicely, was funny and a great storyteller, but his wit didn't have quite the edge that John's did, and he was a little more tolerant. Indeed, as he grew up, Bob expressed a passion for social justice. He advocated for oppressed people and lived out his principles when it came to valuing diversity. Like John, Bob was accustomed to a medicalized life and knew his body well. He could save his doctors the trouble of looking up which antibiotics they'd recently tried and how well they and experimental treatments had worked for him; he knew how long he could last before he needed another "tune-up" in the hospital. Unfortunately, he had a couple of additional problems, including diabetes, which he learned to manage well, and nasal polyps, which he had to have surgically removed before his teens. He began being hospitalized at a younger age than John had been. Like John, Bob seemed to have fond, teasing, and trusting relationships with many of his nurses, doctors, and therapists.

Bob was 13 years younger than I was, and perhaps our age difference contributed to our close relationship. When he was a baby, we shared a crowded bedroom and I changed scores of CF diarrhea-filled diapers. I tried to influence the way he grew up with choices of music, cartoons, and stuffed animals, and he didn't seem to mind; I even taught him to be a switch-hitter in baseball, which he appreciated. The apple of my eye, it was very hard to leave him when it was time for me to go to college. During summers we hung out a lot together, enjoying running errands, making up games, and watching the Cubs; and when I was away, I spent a lot of time on the phone laughing at his accounts about his teachers, work, friends, and random Chicagoans he had encountered. He grew up fascinated by cars and couldn't get his driver's license fast enough. He was active in sports until he no longer was big or fit enough to make the high school basketball team. Even then, though, he pushed himself to run on the cross country team, a choice I thought both courageous and crazy. Practicing in the cold Chicago weather was tortuous, and finishing a race was extremely difficult, and he almost always came in last. As Bob matured, we continued to be close, and I vowed to try to know what he was thinking and feeling. When he went to college, Bob opted to study psychology and both through study and temperament was more open to talking about his feelings than John. He also had good friends. A job in customer support at Ticketmaster facilitated these friendships, his love of music, attendance at concerts, and many funny stories.

No one wanted the same thing to happen to Bob that had happened to John. So when a new young doctor named Susanna McColley recommended that Bob get evaluated for a transplant—long before any of us thought he was sick enough to be thinking of such things—we moved beyond our shock

into action. I'm very grateful for her foresight. I tended to be skeptical of the medical profession, wary of what I expected would be promises of miracles that neglected to mention risks, suffering, and side effects. Once he made it through the evaluation, the whole family was invited to a meeting with Mary McCabe, who served as the lung transplant coordinator at Loyola University Medical Center. This meeting defied my expectations, because in plain language she told us sobering facts about every stage of the process, including the potential length of the wait, the twin dangers of rejection and infection, and the host of likely side effects from the extensive drug regimen post-transplant.

Much proceeded as she described, though Bob almost didn't survive long enough to get a transplant. He suffered dramatic instances of coughing up blood; during one he hid from a coworker so he wouldn't scare him, drove himself to the hospital and parked illegally, and then turned it into a humorous anecdote. Like many transplant candidates, Bob also had a false alarm when they thought they had donor lungs for him. At the time, I was on the North Carolina coast and drove three and a half hours like a bat out of hell endangering the life of anyone in my path to try to get to an airport, only to learn that they'd called the surgery off. Although he tried to last though the semester, in the middle of the fall of his senior year of college in 1995, Bob had to withdraw because of his health. Soon he was hospitalized long-term and declining seriously. Doctors made it clear that he wouldn't be leaving the hospital without a transplant, but of course they couldn't predict if or when his turn would come. I was teaching 800 miles away, but able to visit him for a few days and was quite frightened by what I saw. Gaunt, unshaven, and sporting a temperature of 104 degrees, his entire body shook. At times he sat in an awkward position, cross-legged in the bed, leaning forward to try to get more air. We tried not to look too often at the monitor showing his oxygen saturation rates dropping lower and lower, but when they dropped to a dangerous point, the machine beeped. That started happening so frequently that we just turned the alarm off. Getting therapy multiple times a day hurt his sensitive ribs and skin—though less so when done by his favorite therapist Toni—but it was necessary. Then he caught a nasty new infection, MRSA, which was especially resistant to antibiotics. We joked that MRSA (pronounced "mursa") was "merciless," but it was serious. The infectious disease specialist told me they didn't have many options with which to fight it, since they had to save some antibiotics for the post-transplant period. With no expertise and much anxiety, I wondered if it might be better to use them all to save his life right then. Bob was so ill they were contemplating taking him off the transplant list, which also terrified me. Although in general he was confident he would survive long enough to get a transplant, one night Bob was distraught enough that he called the transplant coordinator and begged her to speed things up, something we knew was not in her control.

Just in time, Bob got his double-lung transplant. Months of lying weakly in the hospital meant that his muscles were gone, however, so his rehab period was long and intense. When he first came home, he was so weak he slowly tipped over and fell into the snow before even making it to the front door. He got the post-transplant side effects that many people do, and took to signing his emails "Shaky Jake." After the initial period of adjustment to the immunosuppressive regimen, accompanied by much self-monitoring, some worry, frequent bronchoscopies, and a couple of bouts with rejection, life eventually became good. Things got back to "normal." He resumed college and graduated with a degree in psychology. He fell in love. He traveled to North Carolina to see me (figure E.1) and to Italy to visit a girlfriend studying there. He had begun earning money by substitute teaching and then took a job teaching full-time. He taught computer skills and literature, exposing his seventh- and eighth-grade students to works by diverse authors that spoke to their lives. He joked with his students, told them honestly about his lung transplant, and helped them write and perform plays. He began a part-time master's degree program in educational psychology with the hopes of becoming a school counselor. He held a big five-year anniversary celebration of his transplant, where he was serenaded by his relatives. His five nieces and

Figure E.1 The author and her brother Bob hiking in 1997, a little more than a year after his double lung transplant.

nephews looked forward to his playful visits, and his chatty phone calls continued to be one of the highlights of my life. Among many things, we talked about the book I'd started on the history of lung transplantation, for which he made up ridiculous titles, proposed playing a prominent role, and cooked up plans to get Oprah's endorsement. He seemed to be such a normal guy that people who met him couldn't believe he'd had a lung transplant. Words can't describe how great it was to see him take advantage of his new lease on life.

But Bob's story also reflects the national trend; he eventually developed chronic rejection. His doctors tried the latest experimental treatments, but they made no apparent difference. Eventually he was back on oxygen and avoiding stairs and distant parking places. He reassured his students that he was going to be all right, and given all that he'd been through, he felt he would find a way to survive again. Still, we worried and began exploring the options. Loyola agreed to consider him for another transplant, but they weren't optimistic. In what felt like the blink of an eye, Bob was back in the hospital, gasping for air, and floating in and out of consciousness. He died at age 27, five and a half years after his lung transplant.

I sometimes feel it is cruel to give someone new life only to have it quickly snatched away again. I often feel no one should have to die that young and go through all he went through. In my more rational moments, however, I am appreciative of Bob's second chance at life. I realize that despite his misfortune at having CF, he was fortunate to have been born seven years later than John. During those seven years, the field of lung transplantation made significant strides and the procedure became far more available, which meant transplant was an option for him when it had not been realistic for John. It meant Bob gained a few bonus years that John didn't, and those years gave him the opportunity to be an adult: to graduate, fall in love, begin a career, and make a difference in the lives of kids. At his wake and funeral, it was apparent how much his students loved him and how bereft they were by his death. We grieved his loss even more intensely. It sounds trite to say that a light was extinguished from my life, but that is exactly how it felt.

One of my regrets is that Bob never wrote to his donor family. He wanted to, kept saying that he was going to do it and that he felt bad about not having done so, and yet somehow didn't bring himself to actually do it. Nor could he articulate exactly why it was so difficult for him. Having heard from other recipients, I suspect it was related to having to reflect on other people's losses and his own mortality. I hope that in some way this book will serve as a public expression of my deep appreciation for his donor family's willingness to think of others during their tragedy, and that other families who have done the same will know how much their actions have meant to people who received organ transplants.

I've only met a handful of the many people (physicians, nurses, surgeons, coordinators, respiratory therapists, dieticians, and lab techs) who skillfully and

sympathetically cared for my brothers during their many hospital stays and medical procedures. Most of them will probably never read this book, but I appreciate the chance to publicly thank them for helping John and Bob tolerate the many unpleasant aspects of illness. People like Toni, the respiratory therapist who traded laughs, listened, cared, and came down on her breaks to wash Bob's hair, showed a dedication that reflects wonderfully on their profession. Thrilled about his transplant, Toni stayed in touch with Bob and attended his anniversary party, and surgeon Edward Garrity came to his funeral. They admirably and compassionately have carried out the vision imagined by James Hardy, Joel Cooper, and other pioneers who labored to make lung transplantation a reality that improved people's lives.

I wrote this book for my brothers, my family, myself, and the other people and their loved ones who have experienced the struggles of lung disease and the euphoria and ordeal of lung transplantation. In the process of illustrating the patterns in candidates' and recipients' experiences, I quoted many interviewees but did not relate each person's whole story. Readers might well be curious about what ultimately happened in their transplant-related undertakings. Though disappointing, it is worth knowing that although Brett Pearce received his transplant and fulfilled his dream of attending medical school, while doing so he contracted an infection that killed him; and it might be gratifying to know that Paula Huffman didn't have to wait long after her interview to receive a transplant and that she later managed Virginia's team for the Transplant Games. Even if this book had enough space to report the fuller details of everyone's stories, many of their stories are still evolving, and printing them here would imply they were frozen in the moment in time when *Second Wind* was prepared for publication. To address this problem, I have created a website containing information about the transplant results and postinterview lives of our interviewees: http://festlesecondwind.wordpress.com. I welcome hearing from people who can share more about them. The history of lung transplantation is composed of many dramatic individual stories, all profoundly important to those most closely involved. Obviously I believe their stories are worth hearing; and I hope that sharing them increases understanding and support for those involved in the endeavor.

Notes

Introduction

1. Telephone interview with Danelle DiCiantis, conducted by Annie Evans, November 19, 2000; Laura Rothenberg, "My So-Called Lungs," in Sayantani DasGupta and Marsha Hurst (eds.), *Stories of Illness and Healing; Women Write Their Bodies* (Kent, OH: Kent State University Press, 2007), 44. The number of lung transplants in 1990 cited in "Report of the ATS Workshop on Lung Transplantation," *American Review of Respiratory Disease* 147 (1993): 772–776; 2010 waiting list data cited in "Waiting List Additions 2000-2010 U.S.," OPTN/UNOS 2011 Data Spring Regional Meetings, http://www.unos.org/docs/DataSlides_Spring_2011.pdf, accessed June 8, 2011.
2. For a critique of the assumptions and practices of modern medicine, see John D. Engel et al., *Narrative in Health Care; Healing Patients, Practitioners, Profession, and Community* (Oxford and New York: Radcliffe Publishing, 2008), 25–31; and Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (University of Chicago Press, 1995), 54–56, 81–85, and 172.
3. These cost estimates were for first-year billed charges for a transplant; costs for immunosuppression drugs and other treatment continued well beyond the first year. Millman Research Report, "2008 U.S. Organ and Tissue Transplant Cost Estimates and Discussion," http://publications.milliman.com/research/health-rr/pdfs/2008-us-organ-tisse-RR4-1-08.pdf, accessed June 8, 2011.
4. Rhonda Bodfield, "Appeal for Transplant Patient," *Arizona Daily Star*, December 17, 2010; Jane E. Allen, "Arizona Budget Cuts Put Some Organ Transplants Out of Reach," *ABC News/Health*, November 18, 2010, http://abcnews.go.com/Health/Health_Care/medicaid-cuts-make-organ-transplants-unaffordable/story?id=12177059, accessed June 8, 2011.
5. Frank, *Wounded Storyteller*, 53–54; Engel et al., *Narrative in Health Care*, 43.
6. Engel et al., *Narrative in Health Care*, 1, 6–7, 43, 219–229; Rita Charon, *Narrative Medicine; Honoring the Stories of Illness* (Oxford: Oxford University Press, 2006), vii, 192. Arthur Frank sees listening to stories of illness and responding to them with empathy as an important moral act. Listening communicates that a speaker has value. See Frank, *Wounded Storyteller*, 25, 53–54; and David B. Morris, *Illness and Culture in the Postmodern Age* (Berkeley: University of California Press, 1998), 257–263.
7. Engel et al., *Narrative in Health Care*, 1, 43, 220–229; Frank, *Wounded Storyteller*, xi–xii, 17–18, 24–25, 35–40, 54–59; DasGupta and Hurst, *Stories of Illness and*

Healing, 1, 28, 197, 210; Marsha Hunt and Sayantani DasGupta, "Narratives and Advocacy: A Gendered Construction," in *Stories of Illness and Healing*, 271–277; Paul K. Longmore and Lauri Umansky, "Disability History: From the Margins to the Mainstream," in Longmore and Umansky (eds.), *The New Disability History; American Perspectives* (New York: New York University Press, 2001), 6–7.

8. Some writers have contrasted "disease," by which they mean disordered biological processes, from "illness," which is more about a person's experience of suffering. See Valerie Raoul et al., *Unfitting Stories: Narrative Approaches to Disease, Disability, and Trauma* (Waterloo, Ontario: Wilfrid Laurier University Press, 2007), 5; Engel et al., *Narrative in Health Care*, 29. Judy Segal notes that pain may be a medical matter, but suffering is a personal and social one. Judy Z. Segal, "Interdisciplinary and Postdisciplinarity in Health Research in Canada," in *Unfitting Stories*, 12.
9. Transcribing always requires editorial decisions about how to punctuate and deal with pauses, repeated phrases, and incomplete phrases/sentences. It is probably fair to characterize our practice as "light editing," which can include deletion of false starts, constantly repeated phrases such as "you know," or fillers such as "like" or "um."
10. Arthur Frank has described the challenge in interpreting others' stories as "to avoid reducing any one voice to its terms of connection with others. In the ideal commentary, individual stories are empowered by their association with other narratives, but they are not subsumed within that association." The format of this book makes it difficult to show the full detail of each individual narrative; still, I hope to approach Frank's ideal of enlarging, or giving each story greater scope by connecting it to other stories. Arthur Frank, "The Negative Privilege of Women's Illness Narratives," in DasGupta and Hurst, *Stories of Illness and Healing*, 67.
11. We would probably ask more questions about community, identity, feelings about donors, makeup of the waiting list, sexuality, gender, and finances. I would also be more careful to train students to be aware of the possibility of subtly pushing interviewees into the more socially acceptable "traditional narratives" of restitution, which celebrate a comfortable message of the "resiliency of the human spirit." See Lawrence Langer, *Holocaust Testimonies: The Ruins of Memory* (New Haven: Yale University Press, 1991), 58–64; and Frank, *Wounded Storyteller,* 105–109.
12. Book-length autobiographies include Isabel Stenzel Byrnes and Anabel Stenzel, *The Power of Two; A Twin Triumph over Cystic Fibrosis* (Columbia and London: University of Missouri Press, 2007); Shirley E. Jewett, *I Call My New Lung Tina; Inspiration from a Transplant Survivor*, 2nd ed. (Victoria, British Columbia: Water Signs Publishing/Trafford Publishing, 2002); Laura J. Scott Ferris, *For Love of Life* (Flol Publisher, 2001); Randy Sims, *Living a Miracle; Turning Your Obstacles into Opportunities* (Livermore, CA: Wing Span Press, 2006); Laura Rothenberg, *Breathing for a Living; A Memoir* (New York: Hyperion, 2003); Charlie Tolchin, *Blow the House Down: The Story of My Double Lung Transplant* (Lincoln, NE: Writers Club Press, 2000); Tiffany Christensen, *Sick Girl Speaks! Lessons and Ponderings Along the Road to Acceptance* (New York: iUniverse, 2007). For a collection of many short personal accounts of transplant, see Joanne M. Schum, compiler, *Taking Flight; Inspirational Stories of Lung Transplantation* (Victoria, British Columbia: Trafford Publishing, 2002).
13. In *A Shared Authority: Essays on the Craft and Meaning of Oral and Public History* (Albany: State University of New York Press, 1990), Michael Frisch described how

the interviewer and interviewee/narrator are both shapers of an interview who share "author-ity" over it. This influential concept expanded into an ideal for the democratic practice of oral history in which collaboration between the scholar/interviewer and narrators is extended beyond the interview to the ways the interviews are used. Cognizant of some extraordinary examples of oral historians who approach this ideal in their projects (such as Alicia Rouverol, Wendy Rickard, Daniel Kerr, and Lorraine Sitza who described them in a 2003 volume of *The Oral History Review*), I must take responsibility for the fact that after the initial stages of interviewing, sharing transcripts with narrators, and depositing them in the archives, I undertook the process of analyzing the interviews and publishing my analysis of them without such collaboration and have, in a sense, "gotten the last word." See all the essays, including those by Linda Shopes and Michael Frisch on "Sharing Authority," *The Oral History Review* 30, no.1 (2003): 103–113. All narrators make decisions about what to reveal and not reveal, but writing a book using quotations involves a great deal of selection of the words of others.

14. Susan Lederer demonstrated that there is an early twentieth-century "prehistory" to organ transplantation, which people commonly think of as starting in the 1960s in the United States. It included the transfer of skin, testis, glands, bone, and blood and societal grappling with supply problems, the meaning of donation and commodification, and incorporation of a "foreign" body part into a new one. Susan E. Lederer, *Flesh and Blood; Organ Transplantation and Blood Transfusion in Twentieth-Century America* (Oxford: Oxford University Press, 2008). A fine treatment of early heart transplantation is seen in Donald McRae, *Every Second Counts; The Race to Transplant the Human Heart* (G. P. Putnam's Sons, 2006). Steven J. Peitzman has written a history of kidney disease that includes transplantation, *Dropsy, Dialysis, Transplant: A Short History of Failing Kidneys* (Baltimore: Johns Hopkins, 2007). The notes to chapter two include medical journal articles that summarize key moments in the history of lung transplantation, and important books by scholars from many fields other than history on the social, political, ethical aspects of organ transfer and donation. Keith Wailoo, Julie Livingston, and Peter Guarnaccia, *A Death Retold: Jesica Santillan, The Bungled Transplant, and Paradoxes of Medical Citizenship* (Chapel Hill: University of North Carolina Press, 2006) is an interdisciplinary collection of essays on the implications of Santillan's failed heart-lung transplant.

1 End-stage Lung Disease

1. Interview with Jan Travioli, conducted by Erin Witmer, Waxhaw, NC, November 2, 2000.
2. Case history included in Martin Bodian, *Fibrocystic Disease of the Pancreas* (New York: Grune and Stratton, 1953), 167.
3. Various researchers around the world were observing the symptoms of the disease, so it is difficult to know who to credit for its "discovery." Charles May calls the phenomenon "a revealing example of the gradual accumulation of observations from a variety of independent sources which may be required to attain a clear conception of a disease." Charles D. May, *Cystic Fibrosis of the Pancreas in Infants and Children* (Springfield, IL: Charles C. Thomas, 1954), 6–9; Ann Harris and

Maurice Super, *Cystic Fibrosis: The Facts* (Oxford: Oxford University Press, 1995), 9–10; Paul A. di Sant-Agnese, "The General Picture of the Disease," in Rustin McIntosh (ed.), *Research on Cystic Fibrosis* (Minneapolis: University of Minnesota Press, 1960), 3–7.

4. *Guide to the Diagnosis and Management of Cystic Fibrosis* (National Cystic Fibrosis Research Foundation, revised edition, 1971), vii; David M. Orenstein (ed.), *Cystic Fibrosis; A Guide for Patient and Family*, 2nd ed. (Philadelphia: Lippincott-Raven, 1997), xii, 78–79; Burton L. Shapiro and Ralph C. Heussner, *A Parent's Guide to Cystic Fibrosis* (Minneapolis: University of Minnesota Press, 1991), 17.
5. Keith Wailoo and Stephen Pemberton observed that although at certain moments in UnitedStates history (when it was useful to get research funding) its pan-ethnic nature was emphasized, CF was frequently described as "the most common fatal inherited disease . . . among Caucasians." The disease has a high prevalence in Europe and is less common in Asian Americans, African Americans, and Native Americans than in European Americans. There is greater incidence in Denmark than in Finland and more in parts of Central America than in others. Despite this complexity, some have portrayed it as a particularly "European" disease or treated it as a proxy for European identity. Keith Wailoo and Stephen Pemberton, *The Troubled Dream of Genetic Medicine; Ethnicity and Innovation in Tay-Sachs, Cystic Fibrosis, and Sickle Cell Disease* (Baltimore: The Johns Hopkins Press, 2006), 62–67, 110; Jane C. Davies et al., "Clinical Review: Cystic Fibrosis," *British Medical Journal* 335 (December 15, 2007): 1255–1257; Orenstein, *Cystic Fibrosis; A Guide*, xii; "Living with CF—Teacher's Guide," Cystic Fibrosis Foundation website, http://www.cff.org/living_with_cf/teachers-guide.cfm, accessed July 22, 2002.
6. Shapiro and Heussner, *Parent's Guide to CF*, 18–21; Orenstein, *Cystic Fibrosis; A Guide*, xi–xii, 1–7, 29–31, 93–97.
7. In one study of CF patients, the most prevalent symptoms were cough, shortness of breath, lack of energy, worrying, sinus discharge, lack of energy, feeling drowsy, feeling irritable, and having difficulty sleeping. Gregory S. Sawicki et al., "Self-Reported Physical and Psychological Symptom Burden in Adults with Cystic Fibrosis," *Journal of Pain and Symptom Management* 35, no. 4 (April 2008), 372–380. See also Orenstein, *Cystic Fibrosis; A Guide*, xi–xii, 1–7, 29–31, 84–85, 91–97.
8. Orenstein, *Cystic Fibrosis; A Guide*, 343; John D. Lloyd-Still, *Textbook of Cystic Fibrosis* (Boston: PSG Inc., 1983), xii.
9. Interview with Matt Byrd, conducted by Genienne Taormina, Chapel Hill, North Carolina, September 20, 2000. A "culture of hype and promise" regarding gene therapy for CF grew in the 1980s and 1990s. Wailoo and Pemberton, *The Troubled Dream of Genetic Medicine*, 109.
10. Lloyd-Still, *Textbook of Cystic Fibrosis*, xvii.
11. Interview with Brett Pearce, conducted by Mary Jo Festle, Chapel Hill, North Carolina, July 10, 1997; Interview with Kimmy Pearce, conducted by Melissa Pace, Chapel Hill, North Carolina, July 10, 1997. See also Joyce Clark Hicks, "Breathing easier," *Raleigh News and Observer*, December 22, 1997.
12. Interviews with Brett Pearce and Kimmy Pearce.
13. Interview with Tim Choquette, conducted by Lindsey Clarke, Durham, North Carolina, November 7, 1998; Telephone interview with Rosalie Gallogly, conducted by Melissa Pace, July 7, 1997; Carlene E. Weber, "College Education Prepares Her

for the Long Run," *CF Roundtable*, Winter 1991, 7; Philip Wenrich, "Attitude About CF Influences His Life," *CF Roundtable*, Fall 1992, 7.

14. Interview with Howell Graham, conducted by Melissa Pace, Wilmington, North Carolina, July 16, 1997; Laura J. Scott Ferris, *For Love of Life* (Flol Publisher, 2001), 35; David's mother quoted in Harris and Super, *Cystic Fibrosis: The Facts*, 3–4. Referring to all it entailed for her child, another mother said, "What is it like? Agonizing, frustrating, expensive, time-consuming, heartbreaking." Mary E. Carlsen, "A Mother's Perspective," *CF Roundtable*, Fall 1993, 5.
15. Janie Tate, "CF Often Influenced Her in College," *CF Roundtable*, Winter 1991, 9–10; Kristie Willis, "Hometown College is Stepping Stone to University," *CF Roundtable*, Winter 1991, 11.
16. Interview with Tim Choquette. Isabel Stenzel Byrnes and her twin sister were very aware of how CF made them different and also recognized the relative nature of their better years. Isabel thought that it was because their disease had not yet progressed beyond the stage where it was manageable. "Our 'healthy' high school years were a mere illusion created by the mask of heavy antibiotic use." Isabel Stenzel Byrnes and Anabel Stenzel, *The Power of Two; A Twin Triumph over Cystic Fibrosis* (Columbia and London: University of Missouri Press, 2007), 90.
17. Byrnes and Stenzel, *The Power of Two*, 54, 80–82, 148; Interview with Tim Choquette. See also Lisa Malia McDonough, "Tune-ups, With Some Creativity, Can Be Handled," *CF Roundtable*, Summer 1992, 6–7. Perri Klass, an adolescent medical specialist, described how savvy teens with CF were regarding IVs and negotiating hospital personnel. Quoted in Wailoo and Pemberton, *The Troubled Dream of Genetic Medicine*, note 79, p. 204.
18. Mike Williams, "Keep Death in Perspective When Dealing With It," *CF Roundtable*, Fall 1992, 3. Janice Kessinger also had a sibling who died of CF. "In having to face CF myself I've gained a lot of strength and courage in learning how to roll with the punches. The more adversity I go through in dealing with CF, the stronger I become. I'm not saying it's been easy, because it hasn't, but you can choose to either sink or swim, and I choose to swim." Janice Kessinger, "A Sister's Perspective," *CF Roundtable*, Fall 1993, 6.
19. Interview with Frank Avila, conducted by Andrew Oak, Burlington, North Carolina, November 4, 2002; Telephone interview with Bob Festle, conducted by Julie Gill, November 24, 1998; Ferris, *For Love of Life*, vii. See also Brenda L. P. Shepherd, "Living with CF—A Wife's Perspective," *CF Roundtable*, Fall 1993, 1; Pammie Post, "Vestibular Dysfunction," *CF Roundtable*, Summer 1993, 11; Dana Jarrett, "No Age is a Good Age to be Diagnosed with CF," *CF Roundtable*, Autumn 1995, 1, 16. Similarly, at a CF summer camp, when asked whether they would take a pill that would take away CF and everything associated with it, only 1 of the 40 young people present said they would. Byrnes and Stenzel, *The Power of Two*, 148.
20. Tinker Ready, "To Be Set Free," *Raleigh News and Observer*, (1994), http://www.nando.net/sproject/shelby/story.html, accessed June 27, 1997; Weber, "College Education Prepares Her for the Long Run"; Telephone interview with Danelle DeCiantis, conducted by Annie Evans, November 19, 2000.
21. Ferris, *For Love of Life*, 54–55; Interview with Matt Byrd; Interview with Rosalie Gallogly; "Amy's Story," Second Wind website, http://www.arthouse.com/secondwind/amysstory.htm, accessed August 26, 1997.

22. Interview with Howell Graham.
23. Interview with Tom Fereday, conducted by Jennifer Bradshaw, Sterling Virginia, November 25, 1998. At age six, twins Isabel and Ana Stenzel learned that a 10-year-old girl with CF they met at the hospital died. When she was 13, Isabel read Frank DeFord's account of his daughter's life and death with CF, and she found the details "morbidly fascinating," leading to frequent crying, worrying, and panic attacks. Byrnes and Stenzel, *The Power of Two*, 61.
24. Interview with Danelle DeCiantis; Laura Rothenberg, *Breathing for a Living; A Memoir* (New York: Hyperion, 2003), 2. At 13, in a "screw-you" to the disease, Tiffany Christensen dressed in black, drank and smoked, and wrote somber poetry about the meaninglessness of life. Tiffany Christensen, *Sick Girl Speaks! Lessons and Ponderings Along the Road to Acceptance* (New York: iUniverse, 2007), 172.
25. Interview with Matt Byrd; Balsam, "Two Years Later, His Pre-transplant Memories of CF are Fading Away," Spring 1992, 9; Interview with Howell Graham; Rosina Ferranti-Mehal, "She Exits CF Valley for a New Peak in Life," *CF Roundtable*, Summer 1992, 4.
26. Ready, "To Be Set Free." For more symptoms, see Sawicki et al., "Self-Reported Physical and Psychological Symptom Burden," 372; "Living with CF," Cystic Fibrosis Foundation website, http://www.cff.org/living_with_cf/, accessed July 12, 2002; Roland Merullo, "Of Young Life and Breath," *Philadelphia Inquirer*, April 7, 2002, accessed through Cystic Fibrosis Foundation website, http://www.cff.org/images/customcontent/4_7_02_Philadelphia_Inquirer.pdf, July 12, 2002.
27. Joni Murphy, "My Life—The Way I Live It!" *CF Roundtable*, Fall 93, 14; Ready, "To Be Set Free"; Interview with Howell Graham.
28. Mary Gohlke, *I'll Take Tomorrow: The Story of a Courageous Woman Who Dared to Subject Herself to a Medical Experiment—The First Successful Heart-Lung Transplant* (New York: M. Evans and Company, 1985), 20–21.
29. Ibid., 28–29, 40.
30. Interview with Jan Travioli, conducted by Erin Witmer, Waxhaw, North Carolina, November 2, 2000; Mickey Moran patient diary, entries February 23, 2001, and April 6, 2001, PH Central website, http://www.phcentral.org/emotional/diary/mickeym.html, accessed July 9, 2002.
31. Louise Pennewell, Patient Diary, April 22, 2001, PH Central website, http://www.phcentral.org/emotional/diary/louise.html, accessed July 23, 2002.
32. Gail Boyer Hayes, *Pulmonary Hypertension: A Patient's Survival Guide* (Ambler, PA: Pulmonary Hypertension Association, 1998), 3–8.
33. Sean P. Gaine and Lewis J. Rubin, "Seminar: Primary Pulmonary Hypertension," *Lancet* 352 (August 29, 1998): 719–725.
34. Interview with Jan Travioli; Alix Flipse, Patient Diary, March 15, 2000, PH Central website, http://www.phcentral.org/emotional/diary/louise.html, accessed July 23, 2002; Shirley E. Jewett, *I Call My New Lung Tina; Inspiration from a Transplant Survivor*, 2nd ed. (Victoria, British Columbia: Trafford Publishing, 2002), 29–30.
35. Other things that could trigger secondary pulmonary hypertension include emphysema, HIV infection, drug abuse, pregnancy, obesity, and pneumoconiosis from inhaling dust particles on the job. Pulmonary Hypertension, *A Patient's Survival Guide*, 19–25; Gaine and Rubin, "Primary Pulmonary Hypertension"; General

Frequently Asked Questions, Pulmonary Hypertension Association website, http://www.phassociation.org/learn/FAQs/General_AFQ.asp, accessed July 23, 2002.

36. Interview with Melanie Greene, conducted by Courtney Wells, Cornelius, North Carolina, October 27, 2000; Interview with Randall Benifield, conducted by Kristen Nastasia, Durham, North Carolina, November 13, 1998; Bob DelCimmuto, "Jessica's Story," Second Wind website, http://www.arthouse.com/secondwind/jessicas.htm, accessed August 26, 1997.
37. Lewis J. Rubin, "Primary Pulmonary Hypertension," *New England Journal of Medicine* 336, no. 2 (January 9, 1997): 111–117; Ronald J. Oudiz, "Pulmonary Hypertension, Primary," eMedicine, August 29, 2007, http://emedicine.medscape.com/article/301450-overview, accessed January 13, 2009; "Primary or Unexplained Hypertension," American Heart Association, http://www.americanheart.org/presenter.jhtml?identifier=4752, accessed January 13, 2009; Pulmonary Hypertension, *A Patient's Survival Guide*, 27–53; Interview with Jan Travioli.
38. Gaine and Rubin, "Primary Pulmonary Hypertension"; General Frequently Asked Questions, Pulmonary Hypertension Association website, http://www.phassociation.org/learn/FAQs/General_AFQ.asp, accessed July 23, 2002. The disease is also known (especially in Britain) as "cryptogenic fibrosingalveolitis."
39. Jeffrey R. Gavin and Michael P. D'Alessandro, "Idiopathic Pulmonary Fibrosis" (peer reviewed), Virtual Hospital website, University of Iowa Health Care, http://www.vh.org/Providers/Textbooks/DiffuseLung/Text/IPF.html, accessed July 24, 2002; "Idiopathic Pulmonary Fibrosis," NIH Publication No. 95–2997, September 1995, cited on "What is Idiopathic Pulmonary Fibrosis?" from the Pulmonary Fibrosis website, http://www.pulmonaryfibrosis.org/ipf.htm, accessed July 17, 2002; "What is Pulmonary Fibrosis?" Duke University familial pulmonary fibrosis website, http://www.fpf.duke.edu/disease.html, accessed July 17, 2002. Gavin and D'Alessandro speculate that thickening of the alveolar walls may not be attributed to scarring, citing a number of investigators who have shown that thickened alveolar walls are composed of numerous alveoli that have collapsed together after their epithelium was destroyed. Thus the fibrosis may be a later occurrence after "alveolar collapse."
40. Quoted in Cory Servaas, M.D., "Let's Hear It For Lungs," *Saturday Evening Post*, May/June 1985, 66.
41. Telephone interview with Kelly Helms, conducted by Elizabeth Harper, November 10, 1998. Health care workers who have conducted quality of life interviews with people with IPF have noted their main concerns being shortness of breath, exhaustion, sleeping problems, unhappiness with the treatments, significant changes to their daily activities, worries about finances, dependence, and being a burden on their families, decreased libido and social interactions, sadness about their lives being turned upside down and end-of-life issues. Jeffrey J. Swigris, "Patients' Perspectives on How Idiopathic Pulmonary Fibrosis Affects the Quality of Their Lives." *Heath and Quality of Life Outcomes* 3 (October 2005): 61–69.
42. American Thoracic Society, "Idiopathic Pulmonary Fibrosis: Diagnosis and Treatment (International Consensus Statement)," *American Journal of Respiratory Critical Care* 161, no. 2 (February 2000): 646–664; Thomas J. Gross and Gary Hunninghake, "Idiopathic Pulmonary Fibrosis," *New England Journal of Medicine* 345, no. 7 (August 16, 2001): 517–525; "Some Basic Facts," Coalition for Pulmonary Fibrosis website, http://www.coalitionforpf.org/default.asp, accessed July 24, 2002; "What is

Pulmonary Fibrosis?" Duke University familial pulmonary fibrosis website, http://www.fpf.duke.edu/disease.html, accessed July 17, 2002; "What is Interstitial Lung Disease?" American Lung Association website, http://www.lungusa.org/diseases/pulmfibrosis.html#what, accessed July 24, 2002.

43. Quoted in American Thoracic Society, "Idiopathic Pulmonary Fibrosis: diagnosis and treatment." According to one study, the mean survival was approximately four years. See Gavin and D'Alessandro, "Idiopathic Pulmonary Fibrosis. See also "What is Idiopathic Pulmonary Fibrosis?" from the IPF website, http://www.pulmonaryfibrosis.org/ipf.htm, accessed July 17, 2002; "What is Pulmonary Fibrosis?" Duke University familial pulmonary fibrosis website, http://www.fpf.duke.edu/disease.html, accessed July 17, 2002. The conclusion that no effective therapy exists was stated on the Coalition for Pulmonary Fibrosis website, http://www.coalitionforpf.org.
44. Cooper quoted in "Cooper Broke Lung Transplant Barrier," *Washington University Record*, August 17, 1995, http://record.wustl.edu/archive/1995/08-17-95/6595.html, accessed January 15, 2009; Robert Berkow (ed.), *Merck Manual of Medical Information* (Whitehouse Station, NJ: Merck Research Laboratories, 1997), 177–180; Thomas L. Petty, "COPD in Perspective," *Chest* 121, no. 5 (May 2002 supplement): 116S; "Fact Sheet: COPD" American Lung Association website,http://www.lungusa.org/diseases/copd_factsheet.html, accessed July 25, 2002; Joel D. Cooper, "The History of Surgical Procedures for Emphysema," *Annals of Thoracic Surgery* 63 (1997), 312–319.
45. Allan M. Brandt, *The Cigarette Century; The Rise, Fall, and Deadly Persistence of the Product that Defined America* (New York: Basic books, 2007), 5, 19–32, 56–67, 106; "History of the 1964 Surgeon General's Report on Smoking and Health," Center for Disease Control website, http://www.cdc.gov/tobacco/30yrsgen.htm, accessed July 24, 2002.
46. Brandt, *The Cigarette Century*, 4–5, 105–122, 153–159; Eric Burns, *The Smoke of the Gods; A Social History of Tobacco* (Philadelphia: Temple University Press, 2007), 195–202; Iain Gately, *Tobacco—The Story of How Tobacco Seduced the World* (New York: Grove Press, 2001), 245, 257–268; Jordan Goodman (ed.), *Tobacco in History and Culture; An Encyclopedia* (Detroit: Thomas Gale, 2005), 16, 609; Arlene B. Hirschfelder, *Encyclopedia of Smoking and Tobacco* (Phoenix: Oryx Press, 1999), 121; "Brief History of Tobacco Use and Abuse," Walter Reed Army Medical Center Online Patient Education, http://www.wramc.amedd.army.mil/education/tobaccohistory.htm, accessed July 27, 2002. In 1948, the *Journal of the American Medical Association* concluded, "more can be said in behalf of smoking as a form of escape from tension than against it…There does not seem to be any preponderance of evidence that would indicate the abolishment of the use of tobacco as a substance contrary to public health." Quoted in Gene Borio, "Tobacco Timeline," Tobacco.org website, http://www.tobacco.org/historytobacco_History.html, accessed July 27, 2002.
47. Glenda Jones, "Waiting and Writing," Living with COPD website, http://papaoo.com/copd-glenda.html, February 1, 2000.
48. Interview with Wayne Foster, conducted by Karen Mullis, Burlington, North Carolina, November 9, 1998.
49. Interview with Cheryl Maxham, conducted by Emily Linz, Manassas, Virginia, October 31, 1998.

50. Donna Wall, "That 'Other Lady' is Gone Forever," Living with COPD website, http://papapoo.com/copd-donna.html, accessed February 1, 2000. See also Telephone interview with Carol Stimmel, conducted by Tony Vasquez, November 17, 1998.
51. *Merck Manual of Medical Information*, 178; Jack Lieberman, "Alpha-$_1$-antitrypsin Deficiency—A Simplified Description," Alpha-$_1$ Association website, http://www.alpha1.org/what/geninfo_faq.htm, accessed July 24, 2002.
52. Telephone interview with Karen Fitch, conducted by Zach Smith, November 19, 1988.
53. Quoted in John Ritter, "To Breathe, to Live," *The Washingtonian* March 27, 1992, 52–59, 136.
54. Interview with Laura Richards, conducted by Amy Clayton, Durham, North Carolina, November 2, 1998.
55. Interview with Mary Peters, conducted by Claire Baker, Ferndale, Maryland, November 26, 2002; Interview with May Parker, conducted by John Rockefeller, Durham, North Carolina, November 13, 1998.
56. Quoted in Milton B. Rosenblatt, "Emphysema: Historical Perspective," *Bulletin of New York Academy of Medicine* 48, no. 6 (July 1972): 833–834; Andreas P. Naef, "History of Emphysema Surgery," *Annals of Thoracic Surgery* 64 (1997): 1506–1508.
57. Cooper, "History of Surgical Procedures for Emphysema," 312–319.
58. Petty, "COPD in Perspective," 118S–119S; *Merck Manual of Medical Information*, 179–180.
59. Interview with Kathryn Flynn, conducted by Glenn Long, Hillsborough, North Carolina, November 6, 1998; Interview with Kelly Helms.
60. Interview with Bill Poplett, conducted by Zack Harrison, Virginia Beach, Virginia, November 12, 2000; Hoilman, "COPD Like a Fish Out of Water"; Christensen, *Sick Girl Speaks!*, 123.
61. Interview with Frank Spears, conducted by John Asmussen, Oxford, North Carolina, November 1, 2000; Wall, "That 'Other Lady' is Gone Forever"; Swigris, "Patients' Perspectives on How Idiopathic Pulmonary Fibrosis Affects the Quality of Their Lives," 66.
62. Interview with Harold Blaise, conducted by Sondra Van Essen, Mebane, North Carolina, November 19, 1998; Karen Couture, "Listed for Life," Second Wind Lung Transplant Association website, http://www.2ndwind.org/Stories/Karen%20Couture's%20story.htm, accessed July 27, 2002.
63. Carolyn Ellis, *Final Negotiations; A Story of Love, Loss, and Chronic Illness* (Philadelphia: Temple University Press, 1995), 24–25, 62, 76.
64. Interview with Cheryl Maxham; Charles McNeill, "Waiting Was Hard But Worth It," *CF Roundtable*, Winter 1996, 8. Scholarly studies confirmed many shared this self-consciousness about being on oxygen. Christopher R. Gilbert and Cecilia M. Smith, "Advanced Parenchymal Lung Disease: Quality of Life and Palliative Care," *Mount Sinai Journal of Medicine* 76, no. 1 (February 2009): 66.
65. Interview with Thomas Bullard, conducted by Larry McSwain, Elon College, North Carolina, October 24, 2000. See also Interview with Laura Richards; Hoilman, "COPD Like a Fish Out of Water."
66. Interview with Laura Richards; Interview with Sharolyn Converse, conducted by Dena Gregory, Raleigh, North Carolina, November 7, 1998; Telephone interview

with May Parker, conducted by Amity Lutes, November 28, 2000; Interview with Sharolyn Converse.

67. Kane quoted in Ritter, "To Breathe, to Live."
68. Interview with Randall Benifield; Interview with Paula Huffman, conducted by Anna Story, Norfolk, Virginia, October 31, 1998; Sylvia Edwards, "Up Up and Away…Shooing COPD Blues Away," Living with COPD website, http://www.papapoo.com/copd-sylvia.htm, accessed February 1, 2000.
69. Roger Stevens, "My IPF Story," Roger Stevens's Idiopathic Pulmonary Fibrosis homepage, http://home.netcarrier.com/~rstevens/frames.html, accessed July 27, 2002.
70. Interview with Laura Richards; Edwards, "Up Up and Away"; Stevens, "My IPF Story"; Interview with Kelly Helms; Christensen, *Sick Girl Speaks!*, 140.
71. D. L. Dudley, "Psychological Concomitants to Rehabilitation in Chronic Obstructive Pulmonary Disease: I. Psychosocial and Psychological Considerations," *Chest* 77 (1980): 413–420.
72. Bates was referring to advanced emphysema in particular. Quoted in Cooper, "History of Surgical Procedures for Emphysema."

2 Sociomedical History of Lung Transplantation, 1963–2000

1. Mary Gohlke, *I'll Take Tomorrow* (New York: M. Evans and Company, 1985), 20, 29, 40, 67, 79–81; Max Jennings, "I Had a Heart and Lung Transplant," *The Ladies' Home Journal* 98 (October 1981): 39–47.
2. Roy Calne, *A Gift of Life; Observations in Organ Transplantation* (New York: Basic Books, 1970), 17–31; James D. Hardy, "Organ Transplantation," in Richard H. Meade (ed.), *An Introduction to the History of General Surgery* (Philadelphia: W.B. Saunders, 1968), 366.
3. Tony Stark, *Knife to the Heart; The Story of Transplant Surgery* (London: Macmillan, 1996), 19, 27–28, 34; Donald McRae, *Every Second Counts; The Race to Transplant the Human Heart* (G. P. Putnam's Sons, 2006), 85–86; Joseph E. Murray, "Human Organ Transplantation: Background and Consequences," *Science* 256 (June 5, 1992): 1413; Calne, *Gift of Life*, 31; Flye, "History of Transplantation," in M. Wayne Flye (ed.), *Principles of Organ Transplantation* (Philadelphia: W.B. Saunders, 1989), 8–10; Hardy, "Organ Transplantation," 367.
4. Quoted in Linda Herskowitz, "Heart-lung Transplant at Temple," *Philadelphia Inquirer*, March 12, 1987, B6; and William A. Cook, "Transplantation of the Lung: A Symposium; Rejection Lung Syndrome," *Vascular Surgery* 8, no. 5 (November–December 1974): 320–328. See also David A. Blumenstock and Carol Lewis, "The First Transplantation of the Lung in a Human Revisited," *Annals of Thoracic Surgery* 56 (1993): 1424; Calne, *Gift of Life*, 49, 57, 78–79.
5. Harris B. Shumaker, "A Surgeon to Remember: Notes About Vladimir Demickhov," *Annals of Thoracic Surgery* 58 (1994): 1196–1197; Igor E. Konstantinov, "A Mystery of Vladimir P. Demikhov: The 50th Anniversary of the First Intrathoracic Transplantation," *Annals of Thoracic Surgery* 65, no. 4 (April 1998): 1171–1176. Rather than doing difficult reconnections of individual pulmonary veins, Metras

used an "atrial cuff" connecting atrium to atrium, and he decided to connect the left bronchial artery to the subclavian artery. D. Metras, "Henri Metras: A Pioneer in Lung Transplantation," *Journal of Heart and Lung Transplantation* 11, no. 6 (November/December 1992): 1213–1216; Michael A. Maddaus, "The History of Lung Transplantation," in Sara J. and Norman E. Shumway (eds.), *Thoracic Transplantation* (Cambridge, MA: Blackwell Science, 1995), 16–17.

6. In the early 1950s, W. B. Neptune in Philadelphia developed similar surgical methods as Metras. A. A. Juvenelle in Buffalo performed autotransplantation to study whether the nerves would function properly. In Kansas in 1954, Creighton Hardin and Frederick Kittle achieved longer survival times by treating their dogs with the steroid cortisone. Maddaus, "History of Lung Transplantation," 16–19; Hardy, "Organ Transplantation," 368; Frank J. Veith and David A. Blumenstock, "Current Research Review," *Journal of Surgical Research* 11, no. 1 (January 1971): 33–34.
7. Stark, *Knife to the Heart*, 45; Hardy, "Organ Transplantation," 364–365; Flye, "History of Transplantation," 11. On survival rates, see Murray, "Human Organ Transplantation," 1414; Stark, *Knife to the Heart*, 47.
8. Maddaus, "History of Lung Transplantation," 19.
9. James D. Hardy, *The World of Surgery, 1945–1985; Memoirs of One Participant* (Philadelphia: University of Pennsylvania Press, 1986), 17–18, 118, 190, 120–123, 159–164, 240; Jurgen Thorwald, *The Patients*, trans. Richard and Clara Winston (New York: Harcourt Brace Jovanovich, 1972), 219.
10. James D. Hardy, "Lung Homotransplantation in Man," *Journal of the American Medical Association* 186, no. 12 (December 21, 1963): 99; Thorwald, *The Patients*, 220–223; Blumenstock and Lewis, "The First Transplantation of the Lung in a Human Revisited," 1423.
11. James D. Hardy, "Re-implantation and Homotransplantation of the Lung: Laboratory Studies and Clinical Potential," *Annals of Surgery* 157, no. 5 (May 1963): 707–718; Thorwald, *The Patients*, 221–223; James D. Hardy, "The First Lung Transplant in Man (1963) and the First Heart Transplant in Man (1964)," *Transplantation Proceedings* 31, nos. 1–2 (February–March 1999): 25–29; "Lung Transplantation—Experimental Background and Early Clinical Experience," in D. K. C. Cooper et al. (eds.), *The Transplantation and Replacement of Thoracic Organs*, 2nd ed. (Kluwer Academic Publishers, 1996), 429–432; Maddaus, "History of Lung Transplantation," 18.
12. Hardy, "Re-implantation and Homotransplantation of the Lung," 713–714.
13. At a 1963 meeting of British and Irish surgeons, Hardy announced, "Gentlemen, these transplantations will be performed in man in the very near future." Hardy, "Re-implantation and Homotransplantation of the Lung," 716. See also Blumenstock, "The First Transplantation of the Lung Revisited," 1425; Hardy, "Lung Homotransplantation in Man," 1065; Hardy, *The World of Surgery*, 249.
14. Thowald, *The Patients*, 218–219.
15. Hardy, "Lung Homotransplantation in Man," 1066; "First Lung Transplant in Man and the First Heart Transplant in Man," 25; Maddaus, "History of Lung Transplantation," 15–16; Hardy, "Lung Transplantation—Experimental Background and Early Clinical Experience," 431; Thorwald, *The Patients*, 224.
16. Thorwald, *The Patients*, 223–226.

17. Martin L. Dalton, "The First Lung Transplantation," *Annals of Thoracic Surgery* 60, no. 5 (November 1995): 1437–1438; Blumenstock, "The First Transplantation of the Lung Revisited," 1423; Hardy, *The World of Surgery*, 265.
18. Hardy, *The World of Surgery*, 265; Interview with James Hardy, conducted by Mary Jo Festle, Jackson, Mississippi, March 17, 2001.
19. Dalton, "The First Lung Transplantation," 1437–1438; "University Medical Team Transplants Human Lung," *Jackson Clarion-Ledger*, June 13, 1963, 1.
20. Quoted in Thorwald, *The Patients*, 227–231; Maddaus, "The History of Lung Transplantation," 16; Hardy, "Lung Transplantation—Experimental Background and Early Clinical Experience," 431; "Lung Homotransplantation in Man," 1071; "Lung Patient Doing Well at Hospital," *Jackson Clarion-Ledger*, June 15, 1963, 1.
21. Hardy, "First Lung Transplant in Man and the First Heart Transplant in Man," 25–26; "Lung Homotransplantation in Man," 1074; Blumenstock, "The First Transplantation of the Lung Revisited," 1423; Maddaus, "History of Lung Transplantation," 20.
22. George J. Magovern and Adolph J. Yates, "Human Homotransplantation of Left Lung: Report of a Case," *Annals of the New York Academy of Science* 120, article 1, 710–714; Alix Kerr, "A Noble Failure; Loses a Life but Advances Surgery," *Life* 55, no. 4 (July 26, 1963): 32–34.
23. Magovern and Yates, "Human Homotransplantation," 716, 720–725.
24. Quoted in "Lung Transplant Patient is Granted Commutation," *Jackson Clarion-Ledger*, June 26, 1963, 1, 14.
25. James D. Hardy to Harold M. Schmeck, July 10, 1963, "Lung Transplantation" binder, James Hardy Library, Department of Surgery, University of Mississippi Medical Center.
26. Quoted in Kerr, "A Noble Failure," 34. See also "Year of the Transplant," *Newsweek*, February 10, 1964, 50–52; "Patient Doing Well in Lung Transplant," *New York Times*, June 20, 1963, 33; "2d Lung Transplant Patient Dies in Pittsburgh Hospital," *New York Times*, July 16, 1963, 7. *Time* magazine mentioned it but in a story on research on prisoners. "Volunteers Behind Bars," *Time*, July 12, 1963, 72.
27. "Lung Transplantation," *JAMA*, December 21, 1963, 122. The editor of *JAMA* wrote to Hardy that he was "pleased to acknowledge the receipt of your editorial that will accompany your communication on Lung Transplantation. The manuscript department may find a few changes indicated; the message, however, will not be altered." John H. Talbott to Hardy, October 1, 1963, James Hardy collection, Rowland Medical Library archive, University of Mississippi Medical Center.
28. Interview with James Hardy. Letters in the Hardy library confirm that he got congratulations and support from other surgeons interested in transplantation.
29. Irvine H. Page, "Unwise Publicity," *Review of Modern Medicine,* January–June 1964, 5; Hardy, *The World of Surgery*, 282–283; J. Russell Elkinton, "Moral Problems in the Use of Borrowed Organs, Artificial and Transplanted," *Annals of Internal Medicine* 60, no. 2 (February 1964): 309–313; "Prolongation of Life in Affluent Society," *Review of Modern Medicine*, July–December 1963, 20–22.
30. At the conference liver transplanter Thomas Starzl told Hardy that they both were "absolute pariahs in American surgery." Hardy, *The World of Surgery*, 278–279. On numbers of transplants, see Frank J. Veith and David A. Blumenstock, "Current Research Review," *Journal of Surgical Research* 11, no. 1 (January 1971): 43–45.

31. A few months earlier, Hardy had visited New Orleans, where Keith Reemstma had transplanted a number of chimpanzee kidneys into human beings, one of whom was doing well. Hardy, *The World of Surgery*, 248; Thorwald, *The Patients*, 246. Rush's half-sister signed an operative permit with the word "suitable" heart, which was intentionally vague so that Hardy could use either a human or chimpanzee heart if his heart stopped. See Hardy, "First Lung Transplant in Man and the First Heart Transplant in Man." On a sheet titled "Operative Permit on Boyd Rush, Additional Discussion," Hardy explained that they believed Rush had never been married but subsequently learned he had been married twice. His first wife had died, and Rush's half-sister said the second had been gone for a long time and that they may have divorced. They concluded it would be futile to try to find her. "Rush, Boyd" file, Box labeled "Dr. Hardy's Files," Department of Surgery, University of Mississippi Medical Center.
32. Hardy, *The World of Surgery*, 271–280; emphasis in the original. See also Interview with James Hardy; William S. Stoney, "James D. Hardy, MD," in *Pioneers of Surgery* (Nashville: Vanderbilt University Press, 2008), 456; McRae, *Every Second Counts*, 126. For other accounts of the heart transplant, see Thorwald, *The Patients*, 248; Stark, *Knife to the Heart*, 158–162.
33. The Nuremberg war crimes tribunal drafted a set of ten principles for medical experimentation. Though not expressly condemning the use of prisoners, the code emphasized the voluntary consent of human subjects and the avoidance of unnecessary suffering and risk. Arthur L. Caplan (ed.), *When Medicine Went Mad; Bioethics and the Holocaust* (Totowa, NJ: Humana Press, 1992), 53–92; Jeff Lyon, "Experimenting with Humans, Part I, History and Context," *Second Opinion*, Vol. 6, 79–80; Gerson B. Grunfeld, "Modern Medicine and the Emergence of Biomedical Ethics," *Caduceus* 8, no. 1 (Spring 1992), 1–7. In 1966 the American Medical Association adopted the Ethical Guidelines for Clinical Investigation and the NIH adopted a new policy as well. George J. Annas and Michael A. Grodin, *The Nazi Doctors and the Nuremberg Code; Human Rights in Human Experimentation* (New York: Oxford University Press, 1992), 186.
34. Jeff Lyon, "Experimenting with Humans, Part I, History and Context," 82–85; James F. Childress, *Priorities in Biomedical Ethics* (Philadelphia: Westminster Press, 1981), 55–66; Annas and Grodin, *The Nazi Doctors*, 227–239, 331–333, 183–199.
35. Interview with James Hardy; Thorwald, *The Patients*, 224–226; M. H. Pappworth, *Human Guinea Pigs: Experiments on Man* (Boston: Beacon Press, 1967), 65; "Research: Volunteers Behind Bars," *Time*, July 12, 1963, 72; Lyon, "Experimenting with Humans," 79–80.
36. F. D. Moore, "Three Ethical Revolutions: Ancient Assumptions Remodeled Under Pressure of Transplantation," *Transplantation Proceedings* XX, no. 1, Supplement 1 (February 1988): 1065.
37. Arthur J. Snider, "Doctor Says Transplanted Lung is Functioning Well," *Chicago Daily News*, June 17, 1963.
38. Hardy, *The World of Surgery*, 233. Hardy said that in some ways the Mississippi medical field was "a wasteland" when he arrived. Interview with James Hardy.
39. Hardy quoted in Stark, *Knife to the Heart*, 161; Interview with James Hardy; Kenneth N. Morris, "Compassion, Caution, and Courage," *The Medical Journal of*

Australia 1, no. 26 (June 29, 1968), 1111; Hardy, *The World of Surgery*, 247; Gerald Leinwald, *Transplants; Today's Medical Miracles* (New York: Franklin Watts, 1985), 41–42; James Daniel Hardy, *The Academic Surgeon—An Autobiography* (Magnolia Mansions Press, 2002), 268, 286; Hardy, *The World of Surgery*, 246–247. See also Mary Jo Festle, "First Try at a Second Chance: The Pioneering Lung Transplant," *Journal of Mississippi History* 64, no. 2 (Summer 2002): 81–106.

40. Quotations are from letters from L. Londer, July 22, 1963; A. Smith, June 3, 1963; and E. Gatho, March 29, 1965. Similar letters are in "Miscellaneous Prospective Lung Transplant Patients" file, Hardy library.
41. In the mid-1960s, bioethicists started spelling out preconditions for performing "therapeutic innovation." They agreed doctors must explain to patients the potential problems and benefits of the new therapy in a clear, unhurried fashion; patients must understand the risks and possible alternative treatments and, unhindered by coercion or influence, be free to decline or consent. Before any patient could be approached, a hospital and its personnel must have the appropriate scientific background, meaning extensive research performed successfully in the laboratory, and extensive experience in the treatment of the relevant organs or diseases (in the case of transplantation, a team capable of handling rejection and infection). In addition, motives such as profit, institutional reputation, fame, a surgeon's ego, or municipal pride must not enter into the decision. Transplantation teams should have had their experimental plan approved by their hospital's institutional review board. Publicity about the procedures should be minimal and impersonal; the preferred manner of reporting should be from doctors to their medical colleagues at professional meetings and in medical journals. Herman L. Blumgart, "The Medical Framework for Viewing the Problem of Medical Experimentation," in *Ethical Aspects of Experimentation with Human Subjects*, published by *Daedalus* vol. 98, no. 2 (Spring 1969): 270. See also Moore, "Three Ethical Revolutions," 1063–1067; Lyon, "Experimenting with Humans," 85–87; Arnold G. Diethelm, "Ethical Decisions in the History of Organ Transplantation," *Annals of Surgery* 211, no. 5 (May 1990): 505–507; J. C. Hutzler, "When is a Procedure Ready for Clinical Application?" *Transplantation Proceedings* 18, Supplement 2 (1986): 78–79; Grunfeld, "Modern Medicine and the Emergence of Biomedical Ethics," 1–22. Hardy did not speak to the press after the transplant but left those tasks to a hospital spokesperson. The *Jackson Clarion-Ledger* did not mention Hardy's name until its third article, six days after the transplant, due to Mississippi State Medical Association policy. "Lung Graft Patient is Responding," *Jackson Clarion-Ledger*, June 19, 1963, 3; Janis Quinn, *Promises Kept; The University of Mississippi Medical Center* (University of Mississippi Medical Center, 2005), 46–51; Hardy, *The Academic Surgeon,* 214–216.
42. Hardy did approach the governor to ask for a pardon for Russell, but said he never made the possibility part of his discussions with Russell. Hardy used donor kidneys from prisoner volunteers on a number of occasions, having actively requested support from the governor to do so. By November 1964, Hardy had stopped using prisoners for a number of reasons, many of them practical (not ethical). Hardy letter to Ross R. Barnett, June 27, 1963, in "Lung Transplant Letters and Cases" box; Hardy letter to Delford L. Stickel, November 2, 1964; and Hardy to Ross R. Barnett, "Dr. Hardy's Files Transplant Related" box, all in Hardy library, Department of Surgery, University of Mississippi Medical Center. Hardy to Ross R. Barnett, June 21,

1963, James Hardy collection, Rowland Medical Library Archives, University of Mississippi Medical Center.

43. Blumgart, "The Medical Framework for Viewing the Problem of Medical Experimentation," 270.
44. Charles R. H. Wildevuur and John R. Benfield, "A Review of 23 Human Lung Transplantations by 20 Surgeons," *Annals of Thoracic Surgery* 9, no. 6 (June 1970): 497–498.
45. Lyon, "Experimenting with Humans," 82–83; Grunfeld, "Modern Medicine and the Emergence of Biomedical Ethics," 3.
46. Hardy, *The World of Surgery*, 280, 285, 279; Thorwald, *The Patients*, 250.
47. "Transplants: An Anniversary Review," *Time*, December 6, 1969, 60; "Surgical Show Biz," *The Nation*, January 22, 1968, 100; "Saving New Hearts," *Newsweek*, January 7, 1980, 39. References to Barnard are in McRae, *Every Second Counts*, 211; and Thorward, *The Patients*, 269, 287–288. See also Raymond Hoffenberg, "Christiaan Barnard: His First Transplants and Their Impact on Concepts of Death," *British Medical Journal* 323 (December 22–29, 2001): 1178; "We Climbed Everest," *Newsweek*, January 1, 1968, 52; "Surgery and Show Biz," *Newsweek*, January 15, 1968, 49; Irving H. Page, "A Realistic Look at Heart Transplants," *Saturday Review*, February 3, 1968, 54–60; George W. Miller, *Moral and Ethical Implications of Human Organ Transplants* (Springfield, IL: Charles C. Thomas, 1971), 8; "Transplants: Guarded Outlook," *Newsweek*, July 21, 1969, 110; William Bradley, "Christiaan Barnard: South Africa's Premier Surgeon," *Saturday Evening Post* 249, March 1977, 63; "Heart-Transplant Revival," *Newsweek*, November 1, 1976, 12; "Transplanted Hearts Will be Short-lived," *Science News* 94, no. 14 (September 1968): 260; *National Commission on Health Science and Society*, Hearings before the Subcommittee on Government Research of the Committee on Government Operations, U.S. Senate, 90th Congress, 2nd session, March 7, 8, 21, 22, 27, 28, April 2, 1968 (U.S. Government Printing Office, 1968).
48. "Surgical Show Biz," *Nation*, January 22, 1968, 100; "The State of Many Arts," *Science News*, March 2, 1968, 233; "Transplants: An Anniversary Review," 59; "Hasty Hearts?" *Newsweek*, January 22, 1968, 60; "Reassessing Transplants," *Newsweek*, September 1, 1969, 73; "Heart Surgery: Were Transplants Premature?" *Time*, March 15, 1968, 66; "Transplant Slump," *Newsweek*, May 17, 1971, 69; Edwin Diamond, "Are We Ready to Leave Our Bodies to the Next Generation?" *New York Times*, April 21, 1968; "A Plea for a Transplant Moratorium," *Science News*, March 16, 1968, 256.
49. Two sociologists who closely followed the world of organ transplantation referred to a "quasi moratorium" in heart transplantation beginning in 1970 through the early 1980s. Renee C. Fox and Judith P. Swazey, *Spare Parts; Organ Replacement in American Society* (New York: Oxford University Press, 1992), 7. See also Fox and Swazey, *The Courage to Fail; A Social View of Organ Transplants and Dialysis* (Chicago: University of Chicago Press, 1974), 123–148; Harry Schwartz, "A World Moratorium on Heart Transplants," *New York Times,* August 22, 1971, E7; Thorwald, *The Patients*, 323; "Heart Transplant Revival," 12; "Transplants: Guarded Outlook," 110. Ayesha Nathoo argued that although poor results, costs, donor supply, and divisions within the medical community contributed, "unprecedented media exposure of the medical controversy" played a crucial role in halting

heart transplants in Britain, which can probably be said about the United States too. Nathoo, *Hearts Exposed: Transplants and the Media in 1960s Britain* (Basingstoke, Hampshire: Palgrave Macmillan, 2009), 182–185.

50. Murray, "Human Organ Transplantation," 1414; Shumway quoted in "Saving New Hearts," *Newsweek*, January 7, 1980, 35–39; Leinwald, *Transplants Today's Medical Miracles*, 42–44; Thorwald, *The Patients*, 257–258; Kantrowitz, "America's First Human Heart Transplantation: The Concept, the Planning, and the Furor," *ASAIO Journal* 44, no. 4 (July–August 1998): 251; and McRae, *Every Second Counts*.
51. Kantrowitz quoted in *National Commission on Health Science and Society*, Hearings before the Subcommittee on Government Research, 36; Interview with James Hardy.
52. The *South African Medical Journal* said Barnard's first transplant could be called successful "because it made medical history, regardless of how short the patient might survive." Quoted in "Xenotransplantation: Risks, Clinical Potential, and Future Prospects," *Emerging Infectious Diseases* 2, no.1 (January–March 1996): 66. On Kantrowitz's views, see McRae, *Every Second Counts*, 219; and Kantrowitz, "America's First Human Heart Transplantation," 251. Barnard said the issue was one for patients to decide, while in 1968 kidney transplanter John Najarian told senators that he considered 75 percent survival at five years to be great success. *National Commission on Health Science and Society*, 20. Catherine Lyons asserted, "Medical science must . . . judge success by the quality of life it gives a patient and not merely by the fact that it prolongs the patient's life." Lyons, *Organ Transplants: The Moral Issues* (Philadelphia: The Westminster Press, 1970), 44–45. Journalist Craig McInnis pointed out, "Success in pioneering surgery is a relative term: success is 'going farther than anyone went before.' At the beginning, this might simply be getting out of the operating room alive, but a few years later success for the same operation might be defined as living three or five years." McInnes, "The Beat Goes On," *The Globe and Mail*, November 28, 1987.
53. Benfield comments included in Larry R. Kaiser, "The Evolution of Single Lung Transplantation for Emphysema," *Journal of Thoracic and Cardiovascular Surgery* 102, no. 3 (September 1991): 333–341; Charles R. H. Wildevuur and John R. Benfield, "A Review of 23 Human Lung Transplantations by 20 Surgeons," *Annals of Thoracic Surgery* 9, no. 6 (June 1970): 494; Fritz Derom et al., "Ten-month Survival after Lung Homotransplantation in Man," *Journal of Thoracic and Cardiovascular Surgery* 61, no. 6 (June 1971): 835–846.
54. Steering Committee, "A Report of the Lung Transplantation Workshop—1970," *Annals of Thoracic Surgery* 12, no. 4 (October 1971): 351; Kingo Shinoi et al., "Pulmonary Lobe Homotransplantation in Human Subjects," *American Journal of Surgery* 111 (May 1966): 617–628; Frank J. Veith and David A. Blumenstock, "Current Research Review: Lung Transplantation," *Journal of Surgical Research* 11, no. 1 (January 1971): 46. Given the difficulty achieving long-term survival in dogs, Frank Veith asserted that further attempts in humans were justified only in selected cases, and "should be approached with extreme caution." See comments after Wildevuur and Benfield, "Review of 23 Lung Transplantations," 514.
55. Wildevuur and Benfield, "Review of 23 Lung Transplantations," 489–496.
56. "A Report of the Lung Transplantation Workshop—1970," 351, 354–356; Veith and Blumenstock, "Current Research Review," 49–50; Wildevuur and Benfield,

"Review of 23 Lung Transplantations," 496; P. Michael McFadden and W. Brooks Emory, "Lung Transplantation," *The Surgical Clinics of North America* 78, no. 5 (October 1998): 749; Thomas Egan et al., "Lung Transplantation," *Current Problems in Surgery* 26, no. 10 (October 1989): 679–751; Interview with Joel Cooper, conducted by Mary Jo Festle, Philadelphia, Pennsylvania, February 16, 2009.

57. Michael A. Maddaus, "The History of Lung Transplantation," in Shumway and Shumway, *Thoracic Transplantation*, 21–22; Interview with Joel Cooper.
58. When Denis Gustar's transplant was attempted, the Toronto General lung transplant group was headed by Bill Nelems, who was "very discouraged" by the result. Interview with Joel Cooper.
59. There are conflicting reports about which year this unsuccessful attempt took place (1978 or 1977). Joel D. Cooper et al., "Technique of Successful Lung Transplantation in Humans," *Journal of Thoracic Surgery* 93, no. 2 (February 1987): 173–181; John Cruickshank, "Recipient of Lung is Rallying Strong," *The Globe and Mail*, August 30, 1982; Larry Doyle, "Canadian Doctors Pioneer Single-lung Transplants," United Press International wire service, April 14, 1988; J. M. Bill Nelems et al., "Human Lung Transplantation," *Chest* 78, no. 4 (October 1980): 569–573.
60. Thomas R. J. Todd, *Breathless; A Transplant Surgeon's Journal* (Renfrew, Ontario: General Store Publishing House, 2007), 23, 18; John R. Benifield, "A 1980 Perspective of Lung Transplantation," *Chest* 78, no. 4 (October 1980): 548–549; Interview with Joel Cooper.
61. "A New Immunosuppressant Hits the Market," *Chemical Week*, November 23, 1983, 9; "FDA Okays a Transplant-Rejection Drug," *Chemical Week*, September 14, 1983, 56; Pam Harrison, "A Guarded Breath of Hope," *Maclean's* 95, no. 50 (September 1982), 50; "Heart-Lung Transplant May Herald New Era," *JAMA* 245, no. 14 (April 10, 1981): 1397; Paul Lieberman, "Franzen Progress Raises Medical Hopes," *Atlanta Journal*, October 17, 1982; Stephen Strauss, "Scientist Braved Stumbling Blocks," *The Globe and Mail*, March 22, 1984; Royston M. Roberts, *Serendipity: Accidental Discoveries in Science* (John Wiley and Sons, Inc, 1989), 206–208. There was confusion about whether Stanford's approval to use cyclosporine for heart transplants included heart-lung transplants.
62. Lawrence K. Altman, "Transplants are Surging as Rates Improve," *New York Times*, October 5, 1982, C1-2; Harrison, "A Guarded Breath of Hope," 50; Sharon Begley, "Cyclosporine: The Breakthrough Drug," *Newsweek*, August 29, 1983; Stephen Strauss, "Cyclosporine: Drug from Fungus Called Penicillin of Transplants," *The Globe and Mail*, March 22, 1984.
63. Phil Gunby, "1981: A Milestone for Heart-Lung Transplants," *JAMA* 246 (22), December 4, 1981, 2537–2543.
64. Bruce Reitz et al., "Heart-Lung Transplantation: Successful Therapy for Patients with Pulmonary Vascular Disease," *New England Journal of Medicine* 306, no. 10 (March 11, 1982): 557–564; Gunby, "1981: A Milestone for Heart-Lung Transplants"; "Barnard's Bullet," *Time*, August 9, 1971, 3; "The Spectacular That Failed," *Time*, August 30, 1971, 46; "The Barnard Touch," *Newsweek*, August 9, 1971, 62–63. Stanford leaders criticized the premature clinical trials in Shumway and Shumway, *Thoracic Transplantation*, 37.
65. Bruce A. Reitz et al., "Heart and Lung Transplantation; Autotransplantation and Allotransplantation in Primates with Extended Survival," *Journal of Thoracic*

Cardiovascular Surgery 80, no. 3 (September 1980): 360–372; Reitz et al., "Heart-Lung Transplantation: Successful Therapy for Patients with Pulmonary Vascular Disease," 557–564.

66. Gohlke, *I'll Take Tomorrow*, 77, 100, 108; Jennings, "I Had a Heart and Lung Transplant," 39–47.
67. Richard Saltus, "A Look Ahead At Heart-Lung Transplants," *San Francisco Examiner*, March 14, 1982, B9–10.
68. Gohlke, *I'll Take Tomorrow*, 136–139, 146–156,162–169, 180–185, 200; Reitz, "Heart-Lung Transplantation"; Saltus, "A Look Ahead At Heart-Lung Transplants"; Jean Seligman, "Transplanting Heart and Lungs," *Newsweek*, March 30, 1981.
69. Reitz quoted in Saltus, "A Look Ahead At Heart-Lung Transplants"; Reitz et al., "Heart-Lung Transplantation," 557–564.
70. Norman Shumway, foreword, in Gohlke, *I'll Take Tomorrow*, 12; Gunby, "1981: A Milestone for Heart-Lung Transplants," 2537–2543.
71. Veith quoted in Paul Lieberman, "Franzen Progress Raises Medical Hopes," *Atlanta Journal*, October 17, 1982; Cooper quoted in Cory SerVaas, "Let's Hear It for the Lungs," *Saturday Evening Post*, May/June 1985, 97.
72. Interview with Joel Cooper.
73. E. Morgan et al., "Successful Revascularization of Totally Ischemic Bronchial Autografts with Omental Pedicle Flaps in Dogs," *Journal of Thoracic Cardiovascular Surgery* 84, no. 2 (August 1982): 204–210; Cooper et al., "Technique of Successful Lung Transplantation in Humans," 173–181; Todd, *Breathless*, 25–26; Maddaus, "The History of Lung Transplantation," 26; Frank J. Veith et al., "Lung Transplantation 1983," *Transplantation* 35, no. 4 (April 1983): 271–278; Interview with Joel Cooper.
74. Paul Lieberman, "Lung Transplant Doctors Get a Breath of New Life," *Atlanta Journal*, February 15, 1984, D14; Interview with Joel Cooper.
75. Quoted in *Breathless*, 42, 52–56, 67; Michael Tenszen and Robert Stephens, "Lung Recipient's Life Depends on Second Transplant Miracle," *The Globe and Mail*, September 16, 1982.
76. F. Griffith Pearson, "Lung Transplantation—Samuel Jason Mixter Lecture," *Archives of Surgery* 124 (May 1989): 535; "Muscle Damaged, Received 2 Lungs, Stroke Kills Patient," *The Globe and Mail*, December 1, 1982; Charles Campbell, "Case Raises Hope for Future Lung Transplants," Associated Press wire, December 1, 1982; Joan Hollobon, "MD Pessimistic About Future of Transplant Over Paraquat," *The Globe and Mail*, December 2, 1982; SerVaas, "Let's Hear It for the Lungs," 97; Lieberman, "Lung Transplant Doctors Get a Breath of New Life."
77. "A Life-Saving Lung," *Time*, October 11, 1982; "Recipient Dies 7 Weeks after Lung Transplant," *New York Times*, November 14, 1982; Joyce Wadler, "For Rare Lung Transplant Patient, Success is Measured in Weeks," *Washington Post*, October 12, 1982, A2.
78. Morton Shulman quoted in Pam Harrison, "A Second Reprieve," *Maclean's* 95, no. 60 (1982), emphasis in the original; Paul Lieberman, "Franzen Progress Raises Medical Hopes"; Todd, *Breathless*, 84; Interview with Joel Cooper; discussion following Cooper, "Technique of Successful Lung Transplantation in Humans," 173–181.
79. Veith, "Lung Transplantation 1983," 271–278; see also discussion following Cooper, "Technique of Successful Lung Transplantation in Humans," 179–181; Todd, *Breathless*, 37.

80. Quoted in Dorothy Lipovenko, "'A Wonderful Christmas Present,'" *The Globe and Mail*, December 20, 1983; and "On 20th Anniversary, Surgeon Reflects on First Lung Transplant," Associated Press State and Local Wire, November 7, 2003. See also Hollobon, "MD Pessimistic about Future of Transplants over Paraquat"; SerVaas, Let's Hear It for the Lungs," 67; Lieberman, "Lung Transplant Doctors Get a Breath of New Life."
81. SerVaas, "Let's Hear It for the Lungs," 98; Interview with Joel Cooper.
82. Todd, *Breathless*, 109–115; Interview with Joel Cooper; O'Malley, *Hospital*, 171–172; Denys Horgan, "Lung Transplant Patient Celebrates One-Year Mark," *The Globe and Mail*, November 14, 1984; Jim Lewis, "Salesman Tom Hall, 64, set lung transplant mark," *The Toronto Star*, February 21, 1990; Dorothy Lipovenko, "'A Wonderful Christmas Present,'" *The Globe and Mail*, December 20, 1983; Martin O'Malley, *Hospital; Life and Death in a Major Medical Centre* (Macmillan of Canada, 1986), 62–65, 171–172; Lieberman, "Lung Transplant Doctors Get a Breath of New Life"; SerVaas, "Let's Hear It for the Lungs," 69; Todd, *Breathless*, 105, 108; Interview with Joel Cooper; Caroline Decker, "Cooper Broke Lung Transplant Barrier," *Washington University Record*, August 17, 1995, http://wupa.wustl.edu/record/archive/1995/08-17-95/6595.html, accessed July 1, 1998. There was some inconsistency in surgeons' reports of how many lung transplants had been attempted. Frank Veith referred to his transplant in September 1982 as the fiftieth. See Robert D. McFadden, "Paraquat Victim is Given a Rare Lung Transplant," *New York Times*, September 26, 1982, 47; Altman, "Transplants are Surging As Survival Rates Improve"; "A Life Saving Lung," *Time*, October 11, 1982, 76.
83. Quoted in SerVaas, "Let's Hear It for the Lungs," 70. See also Lipovenko, "'A Wonderful Christmas Present.'"
84. Toronto Lung Transplantation Group, "Unilateral Lung Transplant for Pulmonary Fibrosis," *New England Journal of Medicine* 314, no. 18 (May 1, 1986): 1140–1145; O'Malley, *Hospital*, 178–179; Decker, "Cooper Broke Lung Transplant Barrier."
85. Quoted in Todd, *Breathless*, 124–126. Two and a half weeks post-transplant, Hall had developed a pneumothorax. Suspecting it meant his airway had torn, a devastated Cooper thought Hall would die. Interview with Joel Cooper.
86. Hall quoted in Lieberman, "Lung Transplant Doctors Get a Breath of New Life." Elaine Carey, "Lung Transplants Pioneered in T.O.," *Toronto Star*, September 11, 2003. Hall eventually died of renal failure; he had opted not to have a kidney transplant or go on dialysis. Interview with Joel Cooper. Cooper quoted in SerVaas, "Let's Hear It for the Lungs," 70.
87. Cooper and Hall quoted in SerVaas, "Let's Hear It for the Lungs," 70, 98. The hospital's PR spokesman wanted to announce the operation, but Cooper resisted the idea of calling press conferences hours after the operation, which he called the "Christiaan Barnard syndrome," because it was far too early to know if it was successful. See also O'Malley, *Hospital*, 67.
88. The Toronto Lung Transplant Group, "Experience with Single-Lung Transplantation for Pulmonary Fibrosis," *JAMA* 259, no. 15 (April 15, 1988): 2258–2262; Horgan, "Lung Transplant Patient Celebrates One-Year Mark." Cooper wouldn't permit photos of himself in newspapers and urged reporters not to single out any particular team members by name. Interview with Joel Cooper. For examples of Cooper deflecting praise, see "Technique of Successful Lung Transplantation in Humans";

and Joan Hollobon, "Heart-Lung Transplants Expand; Toronto Surgeons Use Procedure to Give Man Another Chance," *The Globe and Mail*, July 9, 1984.

89. Assenheimer quoted in SerVaas, "Let's Hear It for the Lungs," 71–73. Assenheimer described in Toronto Lung Transplant Group, "Unilateral Lung Transplant for Pulmonary Fibrosis," *New England Journal of Medicine* 314, no. 18 (May 1, 1986): 1141; Todd, *Breathless*, 130–131, 141.
90. SerVaas, "Let's Hear It for the Lungs," 68; Toronto Lung Transplant Group, "Experience with Single-Lung Transplantation for Pulmonary Fibrosis"; Todd, *Breathless*, 108–109, 126.
91. Interview with Joel Cooper.
92. John C. Baldwin, "Editorial—Lung Transplantation," *JAMA* 259, no. 15 (April 15, 1998); Toronto Lung Transplant Group, "Experience with Single-Lung Transplantation for Pulmonary Fibrosis."
93. Quoted in Lieberman, "Lung Transplant Doctors Get a Breath of New Life"; Todd, *Breathless*, 142.
94. Proud of the fact that he got people together to work as a team, Cooper compared himself to the conductor of an orchestra, noting that the others played the instruments. Interview with Joel Cooper.
95. Gohlke, *I'll Take Tomorrow*, 69, 79–83, 202–203; Todd, *Breathless*, viii, 37; Linda Ohler, "Courage and Character, Leaders and Legends: An Interview with Joel Cooper, MD, FACS, FRCPS," *Progress in Transplantation* 18, no. 4 (December 2004): 29–30.
96. The contrast could be seen in the number of cases performed, the way they were prepared for, and publicity surrounding them.
97. Cooper termed the coming together of his interests and that of his well-suited colleagues in Toronto as "fortuitous conversion of circumstances." He said it was "just the right time" at "the right place" with the right people, all willing to cooperate and take on roles necessary for the group's success. Interview with Joel Cooper.
98. Todd, *Breathless*, 127.
99. Ibid., 170; The Toronto Lung Transplant Group, "Experience with Single-Lung Transplantation for Pulmonary Fibrosis"; Frank J. Veith, "Lung Transplantation in Perspective," *New England Journal of Medicine* 314, no. 18 (May 1, 1986): 1186–1187; Rob Stein, "Doctors Succeed in Transplanting Single Lungs," United Press International wire service, May 1, 1986; Bartley P. Griffith, "Heart-Lung Transplantation: Lessons Learned and Future Hopes," *Annals of Thoracic Surgery* 43, no. 1 (July 1987): 6–16.
100. The first blood transfusions spurred an outpouring of news stories and fictional accounts in the first half of the twentieth century exploring themes of altruism by donors and identity for these "composite" recipients. Susan E. Lederer, *Flesh and Blood; Organ Transplantation and Blood Transfusion in Twentieth-Century America* (Oxford: Oxford University Press, 2008), 54–55, 110–111, 210–212. For positive reactions about the early heart transplants, see McRae, *Every Second Counts*, 122, 209, 85. Gallup poll cited in Gerald Leinwald, *Transplants Today's Medical Miracles* (New York: Franklin Watts, 1985), 61.
101. In 1968, the National Conference of Commissioners of Uniform State Laws passed the Uniform Anatomical Gift Act, which recognized the right of an individual to donate his/her organs for use after death, spelled out who else might make the

decision to donate, and designated to whom organs could be given. Sam Crowe and Eric Cohen, "Organ Transplantation Policies and Policy Reforms," staff discussion paper, President's Council on Bioethics, http://www.bioethics.gov/background/organ_donation.html, accessed October 29, 2008; Randal Bollinger, "The Role of UNOS in Thoracic Organ Transplantation," in Cooper et al., *The Transplantation and Replacement of Thoracic Organs*; Jeffrey Prottas, *The Most Useful Gift; Altruism and the Public Policy of Organ Transplants* (Jossey-Bass, 1994), 12; National Funeral Directors Association of the United States, *Organ and Tissue Transplantation and Body Donation* (University of Minnesota College of Medical Sciences, 1970), 7.

102. Quoted in Thorwald, *The Patients*, 269; and George W. Miller, *Moral and Ethical Implications of Human Organ Transplants* (Charles C. Thomas, 1971), x. See also Irving Ladimer, *The Challenge of Transplantation* (New York: Public Affairs Committee, Inc., 1970), 11–12; Harold M. Schmeck, Jr., *The Semi-Artificial Man; A Dawning Revolution in Medicine* (New York: Walker and Company, 1965), 154–155; Fred Warshofsky, in *The Rebuilt Man: The Story of Spare-Parts Surgery* (New York: Thomas Y. Crowell Company, 1965), 6. Funeral directors said donation would rarely result in delays or disfigurement. National Funeral Directors Association, *Organ and Tissue Transplantation*, 14.
103. On religions' stances on transplantation, see Robert M. Veatch, *Transplantation Ethics* (Washington, D.C.: Georgetown University Press, 2000), 6–13; Warshofsky, *The Rebuilt Man*, 168–171. In movies like *The Amazing Transplant* (1971), recipients assume the talents or evil characteristics of their donors. Lederer, *Flesh and Blood*, 53–56.
104. The Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death proposed criteria about unreceptivity and unresponsiveness, no movements or spontaneous breathing, and no reflexes. It suggested that tests should be repeated over the course of 24 hours, and added that a flat EEG would be of great confirmatory value. Margaret Lock, *Twice Dead; Organ Transplants and the Reinvention of Death* (University of California Press, 2002), 89; Veatch, *Transplantation Ethics*, 58; Robert Reinhold, "Harvard Panel Asks Definition of Death Be Based on Brain," *New York Times*, August 5, 1968, 1.
105. See Frank J. Vieth et al., "Brain Death I. A Status Report of Medical and Ethical Considerations," *JAMA* 238, no. 15 (October 10, 1977): 1651–1655; Frank Veith et al., "Brain Death II. A Status Report of Legal Considerations," *JAMA* 238, no. 16 (October 17, 1977): 1744–1748; Frank J. Veith, "Define Brain Death," *New York Times*, December 17, 1983; President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Defining Death; A Report on the Medical, Legal and Ethical Issues in the Determination of Death* (Washington, D.C.: President's Commission, 1981), 24.
106. Ethicist Paul Ramsey quoted in Albert R. Jonsen, *The Birth of Bioethics* (New York: Oxford University Press, 1998), 238–243. "Vulture" and vampire allusions in Craig McInnes, "The Beat Goes On," *The Globe and Mail*, November 28, 1987; Warshofsky, *The Rebuilt Man*, 163; Roy Calne, *A Gift of Life* (New York: Basic Books, 1970), 78. A few transplant surgeons—notably heart surgeons who had seemed less concerned about the ethics of the early heart transplants as well—seemed callous regarding donor rights. See Raymond Hoffenberg, "Christiaan Barnard: His First Transplants and Their Impact on Concepts of Death," *British Medical Journal*

323 (December 22–29, 2001): 1478; Lock, *Twice Dead*, 87–88. But other transplant surgeons were far more concerned about absolute certainty that donors were dead and the need for public understanding of their endeavors. See discussion at an international conference in 1966 and at the Second International Congress of the Transplant Society. Gordon Wolstenholme and Maeve O'Connor (eds.), *Law and Ethics of Transplantation*; a Ciba Foundation Blueprint (London: J. and A. Churchill, Ltd., 1968), 67, 72–73; Harold M. Schmeck, "Symposium Hears Transplant Plea," *New York Times*, September 9, 1968, 23.

107. Eman Quotah, "Organ Donation: The Feds, Film, and Family," *Harvard Public Health Review*, Winter 2002, http://www.hsph.harvard.edu/review/review_winter_02/alumorgan.html, accessed August 5, 2008; Robin Cook, *Coma* (Little, Brown and Company, 1977).
108. Some of the cases occurred before the Harvard criteria were published, but most afterward. See R. Converse, "But *When* Did He Die? Tucker v. Lower and the Brain-Death Concept," *San Diego Law Review* 12, no. 2 (March 1975), 424–435; "Controversy on Coast," *New York Times*, August 25, 1968, 50; "Heart Operation Key Issue in Trial," *New York Times*, October 29, 1973, 5; "How to Define Death is the Issue in Murder Trial," *New York Times*, May 20, 1974, 23; "Shooting That Led to an Implant Produces Manslaughter Verdict," *New York Times*, May 24, 1974, 20; Harold A. Schmeck, "Brain Death: When Does Life Cease?" *New York Times*, June 4, 1972, E7; Veatch, *Transplantation Ethics*, 43–52; Lederer, *Flesh and Blood*, 170–177. The Tucker v. Lower case has been remembered as a legal precedent in which a judge and jury apparently accepted the notion of brain death, but it was also significant as an example of the way African Americans were poorly treated by the medical system. Susan E. Lederer, "Tucker's Heart: Racial Politics and Heart Transplantation in America," in Keith Wailoo et al. (eds.), *A Death Retold: Jesica Santillan, the Bungled Transplant, and Paradoxes of Medical Citizenship* (Chapel Hill: University of North Carolina Press, 2006).
109. According to Norm Shumway in California uncertainty about the legal definition had "scared [the] hell out of doctors." Alexander M. Capron, "To Decide What Dead Means," *New York Times*, February 24, 1974, 168; Veith, "Brain Death II," 1744–1748.
110. M. K. Gaedeke Norris and Mary Anne House, *Organ and Tissue Transplantation: Nursing Care from Procurement through Rehabilitation* (Philadelphia: F.A. Davis Company, 1991), 12–13; President's Commission, *Defining Death*, 83–84.
111. The model statute read: "An individual who has sustained either (1) irreversible cessation of circulation and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made with accepted medical standards." President's Commission, *Defining Death*, 73, 1–12, and 24–30. There has never been absolute consensus on the whole brain standard in the United States, with some arguing for a less stringent "higher brain" standard and a few maintaining we should return to solely the cardiopulmonary standard. See, e.g., Veatch, *Transplantation Ethics*, chapter 4; Stuart Youngner in "Some Must Die," in Youngner, Fox, and O'Connell, *Organ Transplantation: Meanings and Realities* (University of Wisconsin Press, 1996), 50; Lock, *Twice Dead*, 125.
112. *National Organ Transplant Act: Hearings before the Subcommittee on Health and the Environment of the Committee on Energy and Commerce*, House of Representatives,

98th Congress, first session, on H.R. 4080, a bill to amend the Public Health Service Act to authorize financial assistance for organ procurement organizations, and for other purposes, July 29, October 17 and 31, 1983 (Washington, D.C.: U.S. Government Printing Office, 1984), 351; Task Force on Organ Transplantation, *Organ Transplantation: Issues and Recommendations; Report of the Task Force on Organ Transplantation* (Washington, D.C.: U.S. Department of Health and Human Services, 1986), 23.

113. Anthony Monaco testimony, *Organ Transplantation, Hearing before the Committee on Labor and Human Resources*, U.S. Senate, 98th Congress, 1st session, on Examination of the Problems Involved in Obtaining Organs for Transplant Surgery," October 20, 1983 (Washington, D.C.: U.S. Government Printing Office, 1984), 194; Prottas, *The Most Useful Gift*, 33, 17, 44; Monte Lorell, "The Organ Network," *Science Digest*, September 1982, 27; Paul Terasaki testimony, *National Organ Transplant Act* (House hearings 1983), 311–312; Matt Clark, "Interchangeable Parts," *Newsweek*, September 12, 1988, 61; Statement of Gene Pierce, *National Organ Transplant Act* (House hearings 1983), 211–215; "U.S. Establishes National Organ Donor Network in Virginia," *New York Times*, October 1, 1986, A24.
114. The largest transplant center in San Francisco did not "import" or "export" any organs, while Philadelphia exported 80 percent of its kidneys. Prottas, *The Most Useful Gift*, 118.
115. Ibid., 115–118; Tom Koch, *Scarce Goods; Justice, Fairness, and Organ Transplantation* (Westport, CT: Praeger, 2002), 54.
116. Statement of Charles and Marilyn Fiske, *Organ Transplantation* (Senate hearings 1983), 142–149; William Fox, "Tearful Talk between First Lady and Jamie's Mother," United Press International wire service, October 29, 1982; Karen Mills, "Parents Say Good-Bye to Brain-Dead Son Before Donating His Liver," Associated Press wire service, November 6, 1982.
117. Barbara L. Harris, "Transplant Too Costly? Try Politics—Friend in White House Crucial to Saving Many," *Oakland Tribune*, February 2, 1984, in *National Organ Transplant Act* (House 1984 Hearings), 93–100. See also Matt Clark et al., "The New Era of Transplants," *Newsweek*, August 29, 1983, 38; Fox Butterfield, "Plea for Liver Raises Question About Donor System in Nation," *New York Times*, May 10, 1986, A6; "A Workable Organ-Donor System," *New York Times*, September 23, 1986, A24.
118. Waxman, *National Organ Transplant Act* (House hearings 1983), 1–2.
119. Gore testimony, *National Organ Transplant Act* ("House Hearings 1984"), 8–9, 19, 23–25. Public law 92–603, section 299I, extended Medicare coverage to all victims of end-stage renal disease regardless of age or ability to pay. Intended to subsidize the costs of dialysis and transplantation, it paid 100 percent of the costs of organ procurement and had cost much more than Congress had anticipated. Gene A. Pierce, "Legislative Perspectives on the Development of the End-Stage Renal Disease Network and the National Organ Procurement and Transplantation Network," in Flye, ed. *Principles of Organ Transplantation*, 652–663.
120. Reagan asked his surgeon general to encourage *private* organizations to step up and gave one such organization, the American Council on Transplantation, start-up money, offices, and legal advice. Edward Brandt testimony, *National Organ Transplant Act* (House Hearings 1983), 14, 6; C. Everett Koop, Address, Presented

at the Organizational Meeting of the American Council on Transplantation, January 23, 1984, C. Everett Koop papers, National Library of Medicine Profiles in Science collection, http://profiles.nlm.nih.gov/QQ/Views/AlphaChron/series/019121/016596/018201/, accessed October 29, 2008.

121. Jeffrey Prottas argued, "The price of federal legislation was public involvement, and both the heart and liver communities were willing to pay the price—although they probably did not fully recognize the longer-range implications." Prottas, *The Most Useful Gift,* 131; Harris, "Transplant Too Costly? Try Politics"; *National Organ Transplant Act* (House Hearings 1984), 88–92; 109–110. See also *National Organ Transplant Act* (House Hearings 1983), 187–197, 228–229, 301–304, 329–330. Gore said the legislation had the support of the transplant surgeons, transplant coordinators, OPOs, Kidney Foundation, and many others, and committee hearings confirmed that support. The American Medical Association, however, said the bill was unnecessary and set a bad precedent for government intervention in medicine. *National Organ Transplant Act* (House Hearings 1984), 19–23, 113–117. The overwhelming House vote was cited by Henry Waxman in *National Organ Transplantation Act*, Hearing before the Subcommittee on Health and the Environment of the Committee on Energy and Commerce, House of Representatives, 101st Congress, 2nd session, on H.R. 3968, a bill to amend the Organ Transplant Amendments Act of 1988 to Change an effective date, April 20, 1990, 1.
122. Public Law 98–507, 98th Congress.98 Stat. 2339, October 19, 1984.
123. The task force was appointed by the HHS secretary and its makeup and charge were established by the National Organ Transplant Act. On discussion of rationing health care, see Matt Clark et al., "The New Era of Transplants," *Newsweek*, August 29, 1983, 38; Spencer Rich, "Organ Transplants: Rationing by Wallet?" *Washington Post*, September 1, 1991, A1.
124. The committee concluded that while the allocation system had generally been fair, there had been some exceptions and some serious allegations of instances where non-medical factors had been used to decide who should get a particular organ. It recommended transplant centers be approved by a formal process that applied well-defined criteria related to facilities, staff, training requirements, volume of transplants to be performed, and minimum survival rates, which should be monitored by HHS. OPOs should be run by boards made up of people other than simply transplant surgeons, be more efficient, not compete within the same region, make annual reports, and be evaluated by their outcomes. Task Force on Organ Transplantation, *Organ Transplantation: Issues and Recommendations*, 22–24, 31, 85–89.
125. HHS did not award the contract to UNOS until the final hours of the budget year. Then funding for the network was eliminated from the administration's proposed budget for fiscal 1988. HHS delayed allocating some of the grant money that Congress appropriated for OPOs and neglected to issue the reports it was supposed to submit annually. Margaret Engel, "Organ Network Dies in Reagan Plan," *The Washington Post*, January 11, 1987, A11; Don Colburn, "Transplants: Who Lives? Who Decides? Doctors Can Make Them Work – But Can Society Make Them Fair?" *Washington Post*, January 20, 1987, Z1; "Backers of Organ Gifts Criticize Reagan Cuts," *The New York Times*, January 13, 1987, C9; *National Organ Transplant Act* (House Hearing 1990), 35; Gore testimony, *National Organ Transplants*, Hearing before the Subcommittee on the Health and the Environment of the Committee

on Energy and Commerce, House of Representatives, 100th Congress, 1st session, April 2, 1987, 2–5.

126. The Omnibus Budget Reconciliation Acts of 1986 and 1987 gave the HHS secretary responsibility for monitoring each OPO's performance. In November 1987, with the enactment of section 1138 of the Social Security Act, transplant hospitals and OPOs were required to abide by the rules of UNOS in order to receive Medicare and Medicaid reimbursement. Because of this requirement, HHS determined that binding OPTN policies must be subject to review and approval by the Secretary and go through the Federal rule-making process. The HHS secretary was given authority to review all membership requirements and cancel UNOS' contract if it adopted any policy that adversely affected Medicare or Medicaid patients, was not scientifically supported, or was not in the public interest. Prottas, *The Most Useful Gift*, 14–19, 44–5; Engel, "Organ Network Dies in Reagan Plan"; Oscar Salvatierra testimony, *National Organ Transplant Act* (House Hearing 1990); "HRSA Contracts Unify Organ donor and Transplant Information Networks," *Public Health Reports* 102, no. 4 (July–August 1987): 452. Discussion of the Omnibus Budget Reconciliation Act of 1986 can be found in *National Organ Transplants* (House Hearing 1987).
127. Prottas, *The Most Useful Gift*, 43–48. During the Bush administration, there was further delay, inconsistency, and infighting within the executive branch. *National Organ Transplant Act* (House Hearing 1990), 12–14. See also Walter Graham, "The 'Yin and Yang' of UNOS; A Personal Retrospective on UNOS' First Two Decades," *UNOS Update*, May–June 2008, 4–5, http://www.unos.org/SharedContentDocuments/08_MayJune_YinYang.pdf, accessed October 29, 2008; Bollinger, "The Role of UNOS in Thoracic Organ Transplantation."
128. Prottas, *The Most Useful Gift*, 138–139. Despite being the only logical candidate for the job, UNOS was turned down at first because it had neglected to make its board of directors as representative as the national task force had wanted. It received the federal contract on September 30, 1986. Statement of John C. McDonald, *National Organ Transplants* (House Hearing 1987), 43–50.
129. "Computers to Set Transplant Priorities," *Washington Post*, June 12, 1987, A4; "Organ Match Gets High-Tech Help," *The Advertiser*, September 19, 1987. UNOS Committees were made up of transplant surgeons, transplant physicians, immunologists, organ procurement specialists, nurse coordinators, representatives of voluntary health organizations (like the kidney and heart associations), and the general public, a category that might include recipient or donor families and people interested in medical law and ethics. Statement of John C. McDonald, *National Organ Transplants* (House Hearing 1987), 78; Robert G. Harmon testimony, *National Organ Transplant Act* (House Hearing 1990), 18–21; Pierce, "Legislative Perspectives," 652–663.
130. Ronald Sullivan, "Doctors' Quandary: Picking Who Gets a Heart," *New York Times*, December 16, 1987, B1.
131. Oscar Salviatierra testimony, *National Organ Transplant Act* (House Hearing 1990), 40–47, 73, 77–8; Prottas, *The Most Useful Gift*, 141–142; Arthur Caplan testimony, *National Organ Transplant Act* (House Hearing 1990), 206; Graham, "The 'Yin and Yang' of UNOS"; Starzl, *The Puzzle People*, 278.
132. Todd, *Breathless*, 170.
133. Ibid., 171–176.

134. "Hopkins Finds Way to Preserve Lung Tissue," Associated Press news service, September 6, 1984; Bartley P. Griffith, "Heart-Lung Transplantation: Lessons Learned and Future Hopes"; Todd, *Breathless*, 178–180.
135. Craig McInnes, "Group Effort behind Toronto operation," *The Globe and Mail*, November 29, 1986.
136. Joel D. Cooper, "The History of Surgical Procedures for Emphysema," *Annals of Thoracic Surgery* 63 (1997): 312–319; Richard Severo, "First Cystic Fibrosis Heart-Lung Transplant Done," *New York Times*, November 6, 1983, A46; M. H. Yacoub, "Heart-Lung Transplantation for Cystic Fibrosis and Subsequent Domino Heart Transplantation," *Journal of Heart Transplantation* 9, no. 5 (September–October 1990): 459–467.
137. New conditions included Eisenmenger's syndrome, bronchiectasis, sarcoidosis, lymphangioleiomyomatosis, and eosinophilic granuloma. Elbert P. Trulock, "State of the Art: Lung Transplantation," *American Journal of Respiratory Critical Care Medicine* 155, no. 3 (March 1997): 789–818; H. Mal et. al., "Unilateral Lung Transplantation in End-Stage Pulmonary Emphysema," *American Review of Respiratory Disease* 40 (1989): 797–802; Douglas E. Wood and Genesh Raghu, "Lung Transplantation—Part I, Indications and Operative Management," *The Western Journal of Medicine* 165 (December 1996): 355–363; Elbert P. Trulock, "Lung Transplantation for COPD," *Chest* 3, no. 4 (April 1998 Supplement): 269–S276S; Frederick Glover et al., "The Past, Present, and Future of Lung Transplantation," *American Journal of Surgery* 173 (June 1997): 523–533.
138. "Youngest Heart-Lung Recipient Reported in London," The Associated Press news service, September 22, 1986.
139. Todd, *Breathless*, 159–160.
140. Ibid., 199; Thomas Egan et al., "Lung Transplantation," *Current Problems in Surgery* 26, no. 10 (October 1989): 679–751; J. D. Cooper et al., "Double-Lung Transplant for Advanced Chronic Obstructive Lung Disease," *American Review of Respiratory Disease* 139, no. 2 (February 1989): 303–307.
141. Cooper, "Double-Lung Transplant for Advanced Chronic Obstructive Lung Disease"; G. A. Patterson et al., "Technique of Successful Clinical Double-Lung Transplantation," *Annals of Thoracic Surgery* 45, no. 6 (June 1988): 626–633.
142. Yacoub's doing the first double lung transplant when others had carefully laid the groundwork was similar to Christiaan Barnard's performing the world's first heart transplant when Norm Shumway and others had done the research, an act much of the medical field disapproved of. Michael Babad, "North America's First Double-Lung Transplant Complete," United Press International wire service, November 27, 1986; "Double Lung Transplants," *The Guardian*, November 17, 1986; Interview with Joel Cooper.
143. Patterson, "Technique of Successful Clinical Double-Lung Transplantation"; Pearson, "Lung Transplantation," 535–538. Toronto's first three patients who underwent the double lung transplant all lived at least nine years. Cooper, "The History of Surgical Procedures for Emphysema"; Michael K. Pasque et al., "Improved Technique for Bilateral Lung Transplantation: Rationale and Initial Clinical Experience," *Annals of Thoracic Surgery* 49, no. 5 (May 1990): 785–791; Wood and Raghu, "Lung Transplantation—Part I"; Kaiser, "The Evolution of Single Lung Transplantation for Emphysema," 333–341. Harrison quoted in Craig McInnes, "A Celebration of

Life; Woman Breathes Freely after Lungs Replaced," *The Globe and Mail*, January 7, 1987.

144. "Man Who Received a Heart-Lung Transplant Became the Donor," Business Wire, April 7, 1988.
145. Quoted in "Baylor Surgeons Perform 'Domino' Transplant," United Press International wire service, March 10, 1989; Lawrence K. Altman, "In 3-Way Transplant, Living Patient Donates Heart," *New York Times*, May 13, 1987, A1; Thomas Ginsberg, "Families Thrilled with Living Heart, Doctors Ponder Ethics," Associated Press wire service, May 13, 1987; "Man Who Received a Heart-Lung Transplant Became the Donor."
146. "Lungs from One Donor Transplanted Into Two Patients at Stanford," Business Wire news service, December 11, 1989. One article said Toronto General was the only place performing single lung transplants in April 1988; Lawrence Surtees, "Toronto MDs Gain Praise for Lung Work," *The Globe and Mail*, April 25, 1988. In June 1990, Starnes said that for patients with emphysema Stanford still preferred heart-lung or double-lung. See discussion after Kaiser, "The Evolution of Single Lung Transplantation for Emphysema," 333–341.
147. Conventional wisdom for IPF later changed back to doing double lung transplants. P. Michael McFadden and W. Brooks Emory, "Lung Transplantation," *The Surgical Clinics of North America* 78, no. 5 (October 1998), 749; Trulock, "State of the Art: Lung Transplantation"; James R. Yankaskas et al., "Lung Transplantation in Cystic Fibrosis; Consensus Conference Statement," *Chest* 113, no. 1 (January 1998): 217–226. Stephanie M. Levine et al., "Single Lung Transplantation for Primary Pulmonary Hypertension," *Chest* 98, no. 5 (November 1990): 1107–1115; Kathy A. Fackelmann, "Single-lung Transplant Saves Failing Hearts," *Science News*, January 19, 1991; Wood and Raghu, "Lung Transplantation—Part I." Some centers, especially in Europe, continued to do heart-lung transplants for cystic fibrosis or PPH patients through the early 2000s. See Nicholas R. Banner, Julia M. Polak, and Magdi H. Yacoub (eds.), *Lung Transplantation* (Cambridge University Press, 2003), 114–117.
148. Harry Handelsman, *Single and Double Lung Transplantation*, U.S. Department of Health and Human Services, Health Technology Assessment Reports, 1991, Number 5, Public Health Service Agency for Health Care Policy and Research; Trulock, "State of the Art: Lung Transplantation"; Glover, "The Past, Present, and Future of Lung Transplantation"; Pasque, "Improved Technique for Bilateral Lung Transplantation: Rationale and Initial Clinical Experience."
149. Wood and Raghu, "Lung Transplantation—Part I"; The U.S. Organ Procurement and Transplantation Network [OPTN] and the Scientific Registry of Transplant Recipients [SRTR], "2007 POTN/SRTR Annual Report: Transplant Data 1997–2006," OPTN website, http://optn.org/AR2007/default.htm, accessed October 7, 2008; Todd, *Breathless*, vi–x. Cooper quoted in John Ritter, "To Breathe, To Live," *The Washingtonian* 27 (March 1992), 136.
150. Handelsman, *Single and Double Lung Transplantation*; "Medicare Covers Lung Transplants," press release, February 21, 1995, http://www.os.dhhs.gov/news/press/1995pres/950221.html, accessed June 26, 1998; "Lung Transplants Covered by Medicare, Agency Says," *Greensboro News and Record*, Feburary 22, 1995, A4. Hospitals had to demonstrate at least a 69 percent one-year survival rate and

62 percent two-year survival rate and perform at least ten lung transplants annually. At that time, Medicare already covered kidney, heart, and liver transplants.

151. R. B. Fallstrom, "Cystic Fibrosis Patients Find Hope in Lung Transplants," Associated Press wire service, January 28, 1991.
152. Quoted in Fallstrom, "Cystic Fibrosis Patients Find Hope in Lung Transplants."
153. Stephanie M. Levine and Charles L. Bryan, "Bronchiolitis Obliterans in Lung Transplant Recipients," *Chest* 107, no. 4 (April 1995): 894–897; James Theodore and Norman Lewiston, "Lung Transplantation Comes of Age," *New England Journal of Medicine* 322, no. 11 (March 15, 1990): 772–774; Trulock, "State of the Art: Lung Transplantation"; OPTN and SRTR, "2007 OPTN/SRTR Annual Report: Transplant Data 1997–2006"; Glover, "The Past, Present, and Future of Lung Transplantation"; Kaiser, "The Evolution of Single Lung Transplantation for Emphysema."
154. Quoted in "On 20th Anniversary, Surgeon Reflects on First Lung Transplant," Associated Press State and Local Wire, November 7, 2003.

3 Making the Decision and Being Evaluated for Transplant

1. Laura Rothenberg, *Breathing for a Living; A Memoir* (New York: Hyperion, 2003), 18–19.
2. Interview with Pauline DeLuca, conducted by Stacy Morin, Cary, NC, November 1, 2002.
3. Rothenberg, *Breathing for a Living*, 7–9, 19–27, 32–33.
4. Telephone interview with Steven Bunsen, conducted by Kristin Nagy, November 5, 2002.
5. Interview with Frank Avila, conducted by Andrew Oak, Burlington, NC, November 4, 2002; Telephone interview with Bob Festle, conducted by Julie Gill, November 24, 1998; Telephone interview with Kathleen Feeney, conducted by Sarah Starkey, October 29, 2002. See also Bessie Reberry, "Just Breathe," in Joanne Schum (ed.), *Taking Flight; Inspirational Stories of Lung Transplantation* (Victoria, B.C.: Trafford Publishing, 2002), 249.
6. Marilyn Hom, "Marilyn's Bi-Lateral Lung Transplant Story," in Schum, *Taking Flight*, 138; Lynn Coleman, "Waiting to Inhale," in Schum, *Taking Flight*, 61.
7. Kathryn Flynn, "My Transplant Story," *AirWays* 10, no. 2 (March 2002): 14; Don Hawkins, "Experiencing the Decision," *AirWays* 7, no. 6 (November 1999): 1–3; Mary Peters, "My Successful Transplant: Who Knew I was a Hero?" in Schum, *Taking Flight*, 236; Joe Prianti, "I am Back," and Lorrie Krebs, "Secrets of My Success," in Schum, *Taking Flight*, 246–247, 170; Charles Tolchin, *Blow the House Down; The Story of My Double Lung Transplant* (Writers Club Press, an imprint of iUniverse.com, 2000), 3.
8. Scott Collien, "Cheating Death," in Schum, *Taking Flight*, 63; Telephone interview with Mary Ellen Smith, conducted by Justin Lee Herman, October 31, 2002; Interview with Sharolyn Converse, conducted by Dena Gregory, Raleigh, NC, November 7, 1998.
9. Carolyn Boyd, "The Most Precious Gift," in Schum, *Taking Flight*, 35; Telephone interview with Mary Peters, conducted by Claire Baker, November 17, 2002; Mike

Yurkiw, "The Unlikely Story of How I'm Still Here," in Schum, *Taking Flight*, 341; Interview with Kathleen Feeney.

10. Interview with Dana Schmidt, conducted by Kelly Foster, Durham, NC, November 19, 2002.
11. Charles McNeill, "Waiting was Hard but Worth It," *CF Roundtable*, Winter 1996, 8; Telephone interview with Jimmy Carroll, conducted by Daniel Jackson, November 10, 2002; Sheila Lynn Millikan, "Gifted with New Life," in Schum, *Taking Flight,* 216.
12. As one patient guide put it, "It is very difficult to predict precisely when an individual should have a transplant. In general decisions about the need for transplantation need to be addressed at least 2 years before the operation is likely to be essential. The physician needs to allow sufficient waiting time for both transplant assessment and the local availability of donor lungs that are in short supply." A. G. De Soyza and P. A. Corris, "When Should a Patient Be Referred for Transplantation?" Cystic Fibrosis Medicine (online), November 2002, http://www.cysticfibrosismedicine.com/htmldocs/CFText/transwhen.htm, accessed July 31, 2003.
13. Interview with "Lynn" (who preferred anonymity), conducted by Inga Bajalyte, Durham, NC, October 19, 2002.
14. Annabel Law, "Playing with the Cards We're Dealt," in Schum, *Taking Flight*, 175.
15. Interview with Jimmy Carroll.
16. Interview with "Lynn."
17. Telephone Interview with David Courtney, conducted by Morgan Kelso, November 13, 2000; Interview with Kathryn Flynn, conducted by Glenn Long, Hillsborough, NC, November 6, 1998.
18. Interview with Tiffany Vancannon, conducted by Kelly Poisson, Cary, NC, October 31, 2002; Shirley Stock, "Needalung," in Schum, *Taking Flight*, 301; Interview with Tim Choquette, conducted by Lindsey Clarke, Durham, NC, November 7, 1998; Interview with Randall Benifield, conducted by Kristen Nastasia, Durham, NC, November 13, 1998.
19. Laura J. Scott Ferris, *For Love of Life* (Flol Publisher, 2001), 181; Telephone interview with Mary Peters, conducted by Claire Baker, November 17, 2002; Interview with Paula Huffman, conducted by Anna Maria Story, Norfolk, VA, October 31, 1998.
20. Interview with Carol White, conducted by Gretchen Buskirk, Louisburg, NC, November 1, 2002; Interviews with Kathryn Flynn, David Courtney, Steve Bunsen, and Tim Choquette; Boyd, "The Most Precious Gift," 35.
21. Stock, "Needalung," 301; Interviews with Dana Schmidt, Jimmy Carroll, and Frank Avila.
22. Interview with Dare Reitz, conducted by Stephen Bloodworth, Burgaw, NC, November 3, 1998; Daniel Ensign, "Life is So Much Easier," in Schum, *Taking Flight*, 85.
23. Boyd, "The Most Precious Gift," 35; Telephone interview with May Parker, conducted by Amity Lutes, November 28, 2000; Interview with Carol White; McNeil, "Waiting was Hard But Worth It," 8; Shepard, "Second Breath," 282.
24. Interview with Jimmy Carroll.
25. Telephone interview with Laura Richards, conducted by Brielle Gould, November 8, 2002. Paula Huffman concurred. "What I discovered was that you have to be

pretty doggone healthy to be able to need a lung transplant. There can't be a whole lot else wrong with you." Interview with Paula Huffman.

26. United Network for Organ Sharing website, "Transplant 101—Getting on the List," http://www.transplantliving.org/transplant101/gettingOnTheList.asp, accessed July 29, 2003; Karen A. Couture, *Information You Should Know About Lung Transplantation: Before, During, and After* (Second Wind Lung Transplant Association, Inc., 1997), 5–6.
27. Ed Pearlman, "It Can't Happen to Me," in Schum, *Taking Flight*, 233; Tolchin, *Blow the House Down*, 22; Interviews with Tim Choquette, Kathleen Feeney, Karen Couture, and Mary Peters.
28. Interviews with Paula Huffman and Karen Couture.
29. Ruth Donahue, "What a Roller Coaster Ride Life Can Deal You!" *AirWays* 10, no. 5 (September 2002): 1–5.
30. Telephone interview with May Parker, conducted by Amity Lutes, November 28, 2000. Tom Fereday's insurance saga was also complex because he was still on his father's insurance policy and his family had long since lost touch with his father. Interview with Tom Fereday, conducted by Jennifer Bradshaw, Sterling, Virginia, November 25, 1998.
31. UNOS website, "Transplant 101—Financing a Transplant," http://www.transplantliving.org/transplant101/financingATransplant.asp, accessed July 29, 2003.
32. Interview with Mary Peters; Tolchin, *Blow the House Down*, 28. The term "green screen" was used by surgeon Clive Callender in Yvonne J. Medley, "Minorities Needing Transplants Find Ally," *Washington Times*, August 8, 1996, C8.
33. Couture, *Information You Should Know about Lung Transplantation*, 6–9; Interviews with Lori Hughes and Mary Peters.
34. Interviews with Tiffany Vuncannon, Jimmy Carroll, Frank Avila, Bob Festle, Paula Huffman, and Pauline DeLuca; and Interview with Jasper Martin, conducted by Chris Champagne, Burlington, NC, October 30, 2002.
35. Interviews with Pauline DeLuca, "Lynn," and Steve Bunsen Tolchin, *Blow the House Down*, 44.
36. Ferris, *For Love of Life*, 190; Interviews with Sharolyn Converse and Bob Festle.
37. Interviews with Frank Avila, Bob Festle, Kathleen Feeney, and Mary Peters.
38. Interview with Mary Peters.
39. Interview with Pauline DeLuca.
40. Interview with Kathleen Feeney.
41. Interviews with Frank Avila, Sharolyn Converse, and Dana Schmidt. Some common reasons for being rejected included as ventilator-dependence; addiction to cigarettes, alcohol, or other mind-altering drugs; antibiotic-resistant infection; malignant disease in the last five years; incapacitating mental illness or psychosocial instability; abnormalities in liver, kidney, or cardiac functioning; weight outside a certain range; hepatitis B or C or HIV infection; high levels of prednisone use; and bone marrow failure. Couture, *Information You Should Know about Lung Transplantation*, 6–7.
42. Interview with Mary Peters; Donahue, "What a Roller Coaster Ride Life Can Deal You!"; Carol Macina, "No One Ever Prepared Me for this One," in Schum, *Taking Flight*, 184; Interview with Sharolyn Converse.
43. Don Hawkins, "Experiencing the Decision"; Interview with Harold Blaise, conducted by Sondra Van Essen, Mebane, NC, November 19, 1998; Interview with

Randall Benifield; Telephone interview with Laura Richards, conducted by Brielle Gould, November 8, 2002.
44. Interview with Mary Peters.
45. Interview with Richard Throlson, conducted by Jessica Lesko, Durham, NC, November 7, 2002. Russ Adair, "The Road to Skyline Drive," in Schum, *Taking Flight*, 16–18; Interview with Pauline DeLuca; Ferris, *For Love of Life, 191–3.*
46. Interviews with Sharolyn Converse and Karen Couture; Donahue, "What a Roller Coaster," 1–5.

4 Waiting and Coping

1. Interview with Howell Graham, conducted by Melissa Pace, Wilmington, NC, July 16, 1997.
2. Interview with May Parker, conducted by John Rockefeller, Durham, NC, November 13, 1998, and conducted by Amity Lutes, Lexington, SC, November 28, 2000; Interview with Charla Parker, conducted by Thom Cleary, Durham, NC, November 13, 1998.
3. Interview with Frank Avila, conducted by Andrew Oak, Burlington, NC, November 4, 2002.
4. The survival data cited are for graft survival rather than patient survival, which are very slightly different. "Adjusted Graft Survival by Year of Transplant at 3 months, 1 year, 3 years, 5 years, and 10 years, Deceased Donor Lung Transplants," Table 12.9a, 2007 OPTN/SRTR Annual Report, Organ Procurement and Transplantation Network, http://www.optn.org/AF2007/1209a_lu.htm, accessed March 11, 2009. The median waiting time for those listed in 1998 was 1,105 days, and in 2000 it was 1,663 days. Table 12.2, "Time to Transplant, 1997 to 2006, New Lung Waiting List Registrations," OPTN/SRTR 2007 Annual Report.
5. In matching lungs, sometimes transplant programs also considered the presence of a particularly dangerous virus (cytomegalovirus).
6. Interview with Ruth Hall, conducted by John Stephen Bolger, King, NC, November 7, 2002. Psychological studies found that lung transplant candidates reported recurring themes, including uncertainty, fear of the future, and a feeling of having one's life on hold during the waiting period. Kath Macdonald, "Living in Limbo—Patients with Cystic Fibrosis Waiting for Transplant," *British Journal of Nursing* 15, no. 10 (2006): 566–572. While there are only a handful of scholarly articles that analyze the wait for lung transplant candidates in the United States, international studies and those on patients waiting for other organs reinforce that of a Dutch study, which found that, apart from the physical limitations, the waiting period is a stressful and psychologically difficult period. Three of the more important stressors were the fear that the transplant would come too late, tension from carrying the beeper, and the worry that the transplant center would forget about them. Karin Vermeulen et al., "Stress, Psychological Distress, and Coping in Patients on the Waiting List for Lung Transplantation: An Exploratory Study," *Transplant International* 18 (2005): 954–959.
7. Reported Deaths and Annual Death Rates Per 1000 Patient-Years at Risk Waiting List, 1997 to 2006, Table 1.6, and One Year Adjusted Patient Survival by Organ

and Year of Transplant, Table 1.12a, 2007 OPTN/SRTR Annual Report, Organ Procurement and Transplantation Network, http://www.optn.org/AR2007/106_dh.htm, accessed March 11, 2009. Lynn Pollack, Letter to the editor, *AirWays* 9, no. 4 (July 2001): 4–6.

8. Quoted in Richard Merritt, "Depression Predicts Quality of Life for Patients Awaiting Lung Transplants, *AirWays* 10, no. 5 (September 2002): 6–8.
9. Telephone interview with Karen Couture, conducted by Derrick Krout, November 8, 2002; Telephone interview with Jimmy Carroll, conducted by Daniel Jackson, November 7, 2002.
10. Merritt, "Depression Predicts Quality of Life"; Christopher R. Gilbert and Cecilia M. Smith, "Advanced Parenchymal Lung Disease: Quality of Life and Palliative Care," *Mount Sinai Journal of Medicine* 76, no. 1 (February 2009): 63–70; Interview with Pauline DeLuca, conducted by Stacy Morin, Raleigh, NC, November 1, 2000; Interview with Jimmy Carroll; Eileen J. Burker, "Quality of Life in Patients Awaiting Lung Transplant: Cystic Fibrosis Versus Other End-Stage Lung Diseases," *Pediatric Pulmonology* 30 (2000): 453–460. In this study of 100 patients, 19 percent scored more than one standard deviation above the mean on the state anxiety measure. The majority did not have abnormally high levels of anxiety.
11. Interview with Lynn [who preferred her last name not be used], conducted by Inga Bajalyte, Durham, NC, October 19, 2002; Interview with Brett Pearce, conducted by Mary Jo Festle, Chapel Hill, NC, July 10, 1997.
12. Interview with Tiffany Vuncannon, conducted by Kelly Poisson, Cary, NC, October 31, 2002; Lori Holbert, "Perfect Lungs at the Perfect Time," *CF Roundtable*, Spring 2002, 1, 20–21.
13. Interview with Frank Avila.
14. Interview with Tiffany Vuncannon.
15. Randy Sims, *Living a Miracle: Turning Your Obstacles Into Opportunities* (Livermore, CA: WingSpan Press, 2006), 52–53; Telephone interview with Mary Peters, conducted by Claire Baker, Ferndale, Maryland, November 26, 2002; Joe G. Driskill, "My Transplant Story," in Schum, *Taking Flight*, 79.
16. Interview with Melodie Greene, conducted by Courtney Wells, Cornelius, NC, October 27, 2000; Sims, *Living a Miracle*, 54. See also Telephone interview with Danielle DeCiantis, conducted by Annie Evans, November 20, 2000; Telephone interview with Kathleen Feeney, conducted by Sarah Starkey, October 29, 2002.
17. Rothenberg, *Breathing for a Living*, 8–9; Interview with Dana Schmidt, conducted by Kelly Foster, Durham, NC, November 19, 2002; Ferris, *For Love of Life*, 200–203; Shirley Jewett, *I Call My New Lung Tina* (Victoria, British Columbia: Trafford Publishing, 2002), 126–127.
18. Larissa Myaskovsky et al., "Avoidant Coping With Health Problems"; Burker, "Quality of Life in Patients Awaiting Lung Transplant."
19. Sims, *Living a Miracle*, 64; Laura Scott Ferris, *For Love of Life* (Flol Publishing, 2001), 181–199.
20. Interview with Randall Benifield, conducted by Kristen Nastasia, Durham, NC, November 13, 1998; Interviews with Jimmy Carroll, Laura Richards, and Randall Benifield.
21. Interview with Dare Reitz, conducted by Stephen Bloodworth, Burgaw, NC, November 3, 1998; Interview with Pauline DeLuca. Frank Avila was being wheeled

into the operating room when the anesthesiologist told him they weren't going to proceed because the donor lungs were filling up with fluid. Interview with Frank Avila.

22. Interview with Richard Throlson, conducted by Jessica Lesko, Durham, NC, November 7, 2002; Interview with Carol White, conducted by Gretchen Buskirk, Louisburg, NC, November 1, 2002; Interview with Frank Avila; Telephone interview with Bob Festle, conducted by Julie Gill, November 24, 1998; Interview with Laura Richards.
23. Charles McNeill, "Waiting Was Hard But Worth It," *CF Roundtable*, Winter 1996, 8; Interview with Spears, conducted by John Asmussen, Oxford, NC, November 1, 2000; Telephone interview with M. L. Bryan, conducted by George Baker, Jr., November 20, 1998; Interviews with Jimmy Carroll and Mary Peters.
24. Interview with Pauline DeLuca; McNeill, "Waiting Was Hard But Worth It"; Christensen, *Sick Girl Speaks!*, 71; Interview with Tom Fereday, conducted by Jennifer Bradshaw, Sterling, Virginia, November 25, 1998.
25. Interview with Laura Richards; Ensign, "Life is so Much Easier," 85. Lung candidates rated their financial stress in as 2.59 on a scale where one represented no stress and five was extreme. Burker, "Quality of Life in Patients Awaiting Lung Transplant."
26. Interview with Kimberly Pearce, conducted by Melissa Pace, Chapel Hill, NC, July 10, 1997; Interview with Randall Benifield; McNeill, "Waiting Was Hard But Worth It."
27. Kathy Vanderford, "Miracles Still Happen," *AirWays* 9, no. 4 (July 2001): 8–18.
28. Interview with Tim Choquette, conducted by Lindsey Clarke, Durham, NC, November 7, 1998; Interview with Laura Richards, conducted by Amy Clayton, Durham, NC, November 2 and 8, 1998; Interview with Tiffany Vuncannon. The observation about isolation was made in Macdonald, "Living in Limbo." See example in Tabetha-Lyn Armalius, Letter to the editor, *CF Roundtable,* (Autumn 1995): 10.
29. Interview with Cheryl Maxham, conducted by Emily Linz, Manassas, Virginia, October 31, 1998; Ferris, *For Love of Life*, 199. See also Lon [no last name provided], "Waiting," *AirWays* 6, no. 6 (November 1998): 12–13.
30. Patients with advanced restrictive lung diseases appreciated the comfort they received from their family/loved ones, but they also were concerned about the physical, financial, and emotional burden being placed on them. Gilbert and Smith, "Advanced Parenchymal Lung Disease," 64. Shirley Jewett said pulmonary hypertension was "a WE disease…It's so systemic that the spouse is afflicted." Jewett, *I Call My New Lung Tina*, 183.
31. Telephone interview with Steve Bunsen, conducted by Kristen Nagy, November 5, 2000; Interview with Judy Ryan.
32. Interview with Lori Hughes, conducted by William York, Lawndale, NC, November 1, 2002; Sims, *Living a Miracle*, 130.
33. Vermeulen, "Stress, psychological distress, and coping in patients on the waiting list for lung transplantation."
34. Interview with Harold Blaise, conducted by Sondra Van Essen, Mebane, NC, November 19, 1998; Gilbert and Smith, Advanced Parenchymal Lung Disease."
35. Melody Masha Pierson, "Matchmaker, Matchmaker, Make Me a Match," *AirWays* 16, no. 4 (September 2008): 4; Interviews with Mary Peters and Cheryl Maxham; Michelle Jones, "Blowing Out the Candles," in Schum, *Taking Flight*, 164.

36. Interview with Rosalie Gallogly, conducted by Melissa Pace, July 7, 1997; Interview with Jack Snyder, conducted by Erin Alston, Durham, NC, November 9, 2000.
37. Interview with Barbara Stepp, conducted by Jamie Goebel, Durham, NC, October 27, 2000; Interview with Laura Richards; Telephone interview with Kelly Helms, conducted by Elizabeth Harper, November 10, 1998; Macdonald, "Living in Limbo." On appreciation yet tensions with caregivers, see also interview with Jan Travioli, conducted by Erin Witmer, Waxhaw, NC, November 2, 2000; Telephone interview with David Courtney, conducted by Morgan Kelso, November 13, 2000.
38. Interview with Joanne Schum. Brett Pearce agreed that it was "really hard" to watch his sister "get very sick and die." Interview with Brett Pearce. Scott Jemison, "How One Man Fought and Won," in Schum, *Taking Flight*, 157; Christensen, *Sick Girl Speaks!,* 163; Interview with Harold Blaise, conducted by Sondra Van Essen, Mebane, NC, November 19, 1998.
39. Second Wind Lung Transplant Association, Inc. website, http://www.2ndwind.org/, accessed March 14, 2011.
40. Telephone interview with Joanne Schum, conducted by Sarah Fitch, November 8, 2000; Interview with Dare Reitz; Interview with Sharolyn Converse, conducted by Dena Gregory, Raleigh, NC, November 7, 1998.
41. Interviews with Karen Couture and Carol White. Joanne Schum was too shy to send emails to the Second Wind group but still felt she benefitted from reading email messages from others in the community. "When you're waiting for transplant, you feel like you're the only one who has these thoughts go through your head, or feelings you have." Telephone interview with Joanne Schum.
42. Cheryl Keeler, "Peer Support Program," *AirWays* 15, no. 1 (March 2008): 2–3; Interviews with M. L. Bryan and Dana Schmidt.
43. Interviews with Pauline DeLuca and Harold Blaise.
44. Interviews with Joanne Schum and Steven Bunsen.
45. Some patients in this study did not read all the information provided them, sometimes because they did not want to hear about things that could go wrong. Sharon Moloney et al., "Deciding about Lung Transplantation: Informational Needs of Patients and Support Persons," *Progress in Transplantation* 17, no. 3 (September 2007): 183–192. Interview with Joanne Schum. Pauline DeLuca said that she stopped reading some of the personal accounts on Second Wind "because I don't want to be negative . . . I wanted to keep that fighter mindset and not be worried about what could go wrong. I just didn't want to know what could go wrong." Interview with Pauline DeLuca.
46. Interviews with Bob Festle and Brett Pearce. Isabel Stenzel Byrnes described a younger friend who felt a similar repugnance toward her illness being too much of her identity and disliked CF support groups. "CF, CF, CF . . . that's all everybody talks about. I mean, don't these people have a life?" Byrnes observed, "She had a point. CF camp had transformed us, restricting our identities, defining us as people with a disease. There was something liberating about not exploring that part of our lives so deeply." Byrnes and Anabel Stenzel, *The Power of Two; A Twin Triumph over Cystic Fibrosis* (Columbia and London: University of Missouri Press, 2007), 148.
47. Interview with Barbara Stepp; Don Hawkins, "Experiencing the Decision," *AirWays* 7, no. 6 (November 1999): 1–3; Interview with J. Wayne Foster, conducted by Karen Mullis, Burlington, NC, November 11, 1998. See also Interview with Carol White.

48. McNeill, "Waiting was Hard, but Worth It"; Interviews with Frank M. Spears, Charla Parker, and Barbara Stepp; Judy Ryan, "Each Day is a Gift," in Schum, *Taking Flight*, 265. UNC pulmonary therapist Connie Arnold believed community formed quickly for the same reason Parker cited. Cited in Tinker Ready, "For Those Who Cannot Take Breathing for Granted, the Chance of a Double Lung Transplant at UNC Hospitals Offers One Last Hope," *Raleigh News and Observer*, March 7, 1993.
49. Interviews with Harold Blaise and Dana Schmidt. One author asserted that a number of studies related to different medical procedures concluded that the Internet is not a dependable source of information for patients. Patients, however, report that medical information in Internet sites is useful and accurate, which she interpreted as suggesting that patients overrate the quality of the information provided. Maureen P. Flattery, "Living with pulmonary artery hypertension: Patients' experiences," *Heart and Lung* 34, no. 2 (March/April 2005): 99–107.
50. Jewett, *I Call My New Lung Tina*, 190; Interview with David Courtney.
51. Interviews with Rosalie Gallogly, May Parker, and Brett Pearce; Telephone interview with Tracy Raub, conducted by Greer Fenton, November 29, 2000. See also interview with David Courtney.
52. Many candidates participated in both disease-specific groups and the lung transplant community.
53. Interview with Karen Couture; Interview with Ruth Hall, conducted by John Stephen Bolger, King, NC, November 7, 2002.
54. Rothenberg, *Breathing for a Living*, 49.
55. Interviews with Laura Richards, Barbara Stepp, Jack Snyder, and Kelly Helms. Senior citizen Harold Blaise teared up as he described the plight of young girls he'd met at rehab who he wished could get transplanted sooner. Bill Poplett was asked if he felt any resentment toward people who received lungs while he was still waiting. He answered, "When you go through this, you feel so happy for those people." Interview with William Poplett, conducted by Zack Harrison, Virginia Beach, VA, November 12, 2000.
56. Interview with Melodie Greene.
57. Melody Masha Pierson, "Matchmaker, Matchmaker, Make Me a Match"; Jeremiah 29: 11–14, cited in Susan C. Burroughs, "Living While You Wait . . . Living after the Transplant," in Schum, *Taking Flight*, 48–49; See also interview with Matthew Byrd, conducted by Genienne Taormina, Chapel Hill, NC, October 23, 2000.
58. Katey Ballard, "My Transplant Journey and My Walk With God," *AirWays* 13, no. 4 (July 2006): 10–12; Jewett, *I Call My New Lung Tina*, 98, 127; Byrnes and Stenzel, *Power of Two*, 231. Joanne Schum and Barbara Borowski also mentioned people bargaining. Schum, "To My Surprise—I Have Been Part of Transplantation Numerous Times!!" *Airways* 10, no. 1 (January 2002): 5–11; Borowski, "My Three Caregivers," *Airways* 10, no. 3 (May 2002): 7–10; Interview with Laura Richards.
59. Cuenin decided the "quality of days alive are more important than quantity; that disease and death are not enemies, but something one can learn to 'heal into,' instead of 'heal from.'" Cathy Cuenin, "Moment to Moment," *AirWays* 13, no. 3 (May 2006): 7, 12; Christensen, *Sick Girl Speaks*!, 126.
60. Interview with Judy Ryan; Burker, "Quality of Life in Patients Awaiting Lung Transplant"; Byrnes and Stenzel, *Power of Two*, 259.

61. Interviews with William Poplett, Tracy Raub, and Tiffany Vuncannon; Telephone interview with Karen Fitchett, conducted by Zach Smith, November 1998.
62. Eileen J. Burker et al., "Religious and Non-Religious Coping in Lung Transplant Candidates: Does Adding God to the Picture Tell Us More?" *Journal of Behavioral Medicine* 28, no. 6 (December 2005): 513–526.
63. Interview with Paula Huffman, conducted by Anna Story, Norfolk, Virginia, October 31, 1998. For description of passive deferral, self-directed, and collaborative religious coping styles, see Eileen J. Burker, "Religious Coping, Psychological Distress and Disability Among Patients with End-stage Pulmonary Disease," *Journal of Clinical Psychology in Medical Settings* 11, no. 3 (September 2004): 179–193.
64. While "punishing reappraisal" was a predictor of distress and disability, the authors did not know if the relationship was causal. Burker, "Religious and Non-Religious Coping in Lung Transplant Candidates."
65. Larissa Myaskovsky et al., "Avoidant Coping with Health Problems"; Burker, "Quality of Life in Patients Awaiting Lung Transplant." Eileen J. Burker said denial was the least used coping strategy of lung transplant candidates. "The Psychosocial Aspects of Transplantation," 4th Annual Second Wind National Lung Transplant Conference (Durham, NC, October 2000).
66. Interview with Tommy Bullard, conducted by Larry McSwain, Elon, NC, October 24, 2000; Lon, "Waiting." Myaskovsky found that when a patient's health status was higher, the coping strategy of avoidance resulted in less difficulty functioning daily as a result of emotional problems. She said this observation may be consistent with Taylor and Aspinwail's conclusion that intermittent denial of disease may be an adaptive coping strategy especially when aspects of a disease are not amenable to active efforts. Myaskovsky et al., "Avoidant Coping with Health Problems." Macdonald cited other scholars as saying that although denial is normally regarded as a negative way of coping, it can be seen as a positive coping strategy in some chronic illnesses. Macdonald, "Living in Limbo."
67. Interview with Matt Byrd. It is possible that candidates may not have admitted alcohol or drug use since they feared being taken off the list if their transplant physicians found out. In addition, the candidates may well have been selected for eligibility for transplant precisely because of their ability to face their situation and care for themselves and that is why they so rarely exhibited denial and disengagement.
68. Kathryn J. Foss, "I'm Dancing Like Nobody's Watching!" in Schum, *Taking Flight*, 97; Interviews with Mary Peters, Laura Richards, M. L. Bryan, Sharolyn Converse, Karen Fitchett, and William Poplett.
69. Jemison, "How One Man Fought and Won"; Sims, *Living a Miracle*, 27; Interview with Karen Fitchett; Judy Ryan, "Each Day is a Gift," in Schum, *Taking Flight*, 265; Borowski, "My Three Caregivers"; Christensen, *Sick Girl Speaks*!, 45. Although lung transplant candidates tended to associate hope only with the possibility of receiving a transplant, it is possible for terminally ill patients to feel hope while accepting the fact that they are going to die. Kaye Herth, "Fostering Hope in Terminally-Ill People," *Journal of Advanced Nursing* 15, no. 11 (1990): 1250–1259.
70. Interviews with May Parker, Mary Peters, and Paula Huffman.
71. Jewett, *I Call My New Lung Tina*, 73; Pierson, "Matchmaker, Matchmaker, Make Me a Match"; Maureen P. Flattery, "Living with Pulmonary Artery Hypertension: Patients' Experiences." Sheila Millikan looked forward to monthly support group

meetings because they provided "funny tales of 'life in the Predni-zone' or the zany actions of doctors [which] helped turn our fears into relief and laughter." Sheila Lynn (Hudnall) Millikan, "Gifted with New Life," in Schum, *Taking Flight*, 216.

72. Interview with May Parker; Christensen, *Sick Girl Speaks*!, 93–95; Byrnes and Stenzel, *Power of Two*, 236.
73. This study also found that older patients (who often had COPD) rated highly in the area of accepting their disease. Burker, "Quality of Life in Patients Awaiting Lung Transplant." Another study found subtle differences between COPD and CF transplant candidates. Jessica L. Taylor et al., "Coping and quality of life in patients awaiting lung transplantation," *Journal of Psychosomatic Research* 65 (2008): 71–79.
74. "Dreams are like clouds . . . floating through a sky blue mind," *AirWays* 7, no. 4 (July 1999): 5–7. On making plans, see also Interviews with Lori Hughes, Howell Graham, and Rosalie Gallogly.
75. Interviews with Kimberly Pearce and Brett Pearce.
76. Byrnes and Stenzel, *Power of Two*, 258. While waiting for a second transplant, Tiffany Christensen observed, "I didn't know if I should continue to eat all the junk food I wanted—one of the best parts about dying—or go back to a healthier diet. My concerns ranged from serious spiritual dilemmas to the mundane." *Sick Girl Speaks*!, 169.
77. Kathy Vanderford, "Miracles Still Happen," *AirWays* 9, no. 4 (July 2001): 8, 13–18.
78. Patients listed for transplant tended to get more aggressive treatment, which included being intubated, an unpleasant option that many nontransplant patients chose to avoid. The author concluded, "Patients with CF have known, often for a large portion of their lives, that they have a life span-limiting disease, but there are many potential barriers to communication about end of life issues. For example, the hope offered by improved therapies and lengthening life span in patients with CF may affect the ability and desire of both patients and physicians to have such discussions. Aggressive management strategies such as lung transplant may seem inconsistent with discussion of end of life care." Elisabeth P. Dellon, "Effects of Lung Transplantation on Inpatient End of Life Care in Cystic Fibrosis," *Journal of Cystic Fibrosis* 6 (November 2007): 396–402. Another CF study suggested some disagreement or tension between CF pulmonary physicians and transplant physicians, and concluded "the overall quality of the dying experience has not been determined and remains an important unanswered question." Dee Ford and Patrick A. Flume, "Impact of lung transplantation on site of death in cystic fibrosis," *Journal of Cystic Fibrosis* 6 (November 2007): 391–395. In one non-CF situation, Kitty Adair, who was caring for her very ill cousin Debbie, was concerned that transplant candidate Debbie refused to think about making a will or arranging medical power of attorney. Telephone interview with Kitty Adair, conducted by Allison Riley, November 20, 1998.
79. Interview with Harold Blaise.
80. Macdonald, "Living in Limbo"; Interview with Karen Fitchett. Ana wrote asking for that encouragement and attitude for her sister, Isabel. Byrnes and Stenzel, *Power of Two*, 265–267.
81. Jemison, "How One Man Fought and Won." Barbara Stepp advised candidates, "Learn to enjoy whatever it is that you can do now with your life rather than sit back waiting." Interview with Barbara Stepp.

82. Christensen, *Sick Girl Speaks!*, 169–170; Burroughs, "Living While You Wait . . . Living after the Transplant"; Michael Pollack quoted in Letter to editor by Lynn Pollack, *AirWays* 9, no. 4 (July 2001): 4–6. During her waiting period, Shirley Jewett first took some actions in the event she was going to die and then prepared for a transplant. Jewett, *I Call My New Lung Tina*, 103.
83. Sims, *Living a Miracle*, 51; Interview with Jasper Martin, conducted by Chris Champagne, Madison, NC, October 30, 2000; Interview with Jan Travioli.

5 Getting "The Call"

1. Interview with Cheryl Maxham, conducted by Emily Linz, Manassas, VA, October 31, 1998.
2. Nancy Hulet, "Gary Makes a Miracle," in Joanne Schum (ed.), *Taking Flight; Inspirational Stories of Lung Transplantation* (Victoria, B.C.: Trafford Publishing, 2002), 148.
3. Laura J. Scott Ferris, *For Love of Life* (Flol Publisher, 2001), 205.
4. Scott Collien, "Cheating Death," in Schum, *Taking Flight*, 62–63; Interview with Lori Hughes, conducted by Chad York, Lawndale, NC, November 1, 2002; Telephone interview with Karen Couture, conducted by Derrick Krout, November 8, 2002; Francisco Avila, "Survivor: Transplants," in Schum, *Taking Flight*, 23.
5. [Lung] Transplants by Donor Type, January 1, 1988–April 30, 2003, Organ Procurement and Transplantation Network data, http://www.optn.org/latestData/rptData.asp, accessed July 9, 2003; "Living Lobar Lung Transplant: Donor Information," Duke Transplant Center.
6. "Understanding Donation," International Association for Organ Donation, http://www.iaod.org/understanding-organ-donation-braindeath.htm; "Brain Death," University of Missouri Health Care Family Guide Neuromedicine, http://www.muhealth.org/~neuromedicine/braindeath.shtml; National Donor Family Council; "Questions Regarding Brain Death," Association of Organ Procurement Organizations, http://www.aopo.org/aopo/html%20files/frequentlyAskedQuestions.html#Section%20C, accessed July 10, 2003; Ron Peterson and Kathryn Flynn, "Lung Transplant—The New Millennium," *Airways* 7, no. 6 (November 1999): 11; Colleen Krantz, "Giving Life a Second Chance," *Milwaukee Journal Sentinel*, July 12, 1998, 1.
7. Because the system preserves the anonymity of organ donors, the donor stories in this section come from people who have publicly acknowledged they made the decision to donate in newspaper and magazine stories and websites. Usually it was not possible to know if the donor's lungs were actually given to a lung transplant recipient. Mary Steenland, "A Donor Mother's Story," Multiple Organ Retrieval and Exchange Program of Ontario, Donor Stories, http://web.idirect.com/~more/donors_stories_1f.html, accessed July 10, 2003; Tim Barela, "One For All: A Captain's Tragic Death Saves Five," *Airman* 43, no. 5 (May 1999): 40–43; Zvika Krieger, "Lyric Benson, PC '02, Shot by Ex-Boyfriend," *Yale Herald*, April 25, 2003.
8. This was true until the last decade or so, when donation after cardiac death resumed, as discussed in chapter ten.
9. Peterson and Flynn, "Lung Transplant," 9; "4th International Congress on Lung Transplantation," *Airways* 9, no. 1, 16.

10. Quoted in Krantz, "Giving Life a Second Chance," 1. Anthropologist Lesley Sharp notes that the job of approaching families about donation was emotionally trying and has a high burnout rate. Lesley Sharp, *Strange Harvest; Organ Transplants, Denatured Bodies, and the Transformed Self* (Berkeley: University of California Press, 2006), 57. V. Lee Langley and Margaret Shaw, "A Day in the Life: The Donor and Her Family," *Urologic Nursing* 22, no. 1 (February 2002): 13–21; Avis Thomas-Lester, "A Helping Hand at the Hardest Moment," *Washington Post*, November 10, 1996.
11. Memorial to Jay Bullock, Transweb, http://www.med.umich.edu/trans/develop/testing/people/donors/memorial/donors/bullock_jay.html; Justin Catanoso, "Grateful Patient Thanks Parents of Donor," *Greensboro News and Record*, April 23, 1994, B1; Patricia Curtis, "Why I Had to Have This Baby," *Redbook* 199, no. 4 (October 2002): 104–109. "It Hurt to Breathe Without Her," said the Memory Quilt Story for Kayla Rack, New York Organ Donor Network, Donors and Their Families, http://www.nyodn.org/gift/memory_details2_14.html, accessed July 11, 2003.
12. Pat Ledbetter, "My Daughter's Heart," LifeGift Organ Donor Center Donor Stories, http://www.lifegift.org/do_sto.htm; Memorial to Lisa Smith, Transweb Memorials to Organ and Tissue Donors, http://www.med.umich.edu/trans/develop/testing/people/donors/memorial/donors/smith_lisa.html, accessed July 11, 2003.
13. Memorial for Lisa Cortese Davis, Transweb Memorials to Organ and Tissue Donors, http://www.med.umich.edu/trans/develop/testing/people/donors/memorial/donors/lisa_davis.html, accessed July 11, 2003; Steenland, "A Donor Mother's Story"; Krantz, "Giving Life a Second Chance"; Nagy, "Organ Donors Give Gift of Life," *Greensboro News and Record*, December 27, 1994, A1; Barela, "One for All."
14. Ledbetter, "My Daughter's Heart." Similarly, Mary Steenland said, "[Organ donation] provided an opportunity to cherish and reaffirm life, ironically offered in the pit of my own retching shock and turmoil in the face of my child's death. A taste of springtime in the bleak of winter, the option to donate was itself a gift." Steenland, "A Donor Mother's Story."
15. "Turning Tragedy into Triumph," Multiple Organ Retrieval and Exchange Program of Ontario, Donor Stories, http://web.idirect.com/~more/donors_stories_2f.html, accessed July 10, 2003; Krantz, "Giving Life a Second Chance." Some donor families considered this continuity of the loved one to be simply that of a body part, but for others, that body part constituted an important part of the donor's essence. Anthropologist Lesley Sharp notes that many donor kin have stories they interpret as evidence that donors can assert themselves beyond the grave. She sees these "ghost stories" as memory work, "an effort to pull what would otherwise be a lost or irretrievable part of the past into the here and now." Sharp, *Strange Harvest*, 146–156. See also Madeline Kochen, "Mother's Final Gift," *The Washington Post*, September 16, 2000, A19.
16. Sharp, *Strange Harvest*, 181, 138–139; Darrach and Murphy, "After a Child Dies." *Life* 18, no. 12 (October 1995): 42–47. According to one study, about one in five families had second thoughts about their decision to donate a loved one's organs. Cited in "Too Late For Organ Donor Families Who Change Their Minds," *Science a Go Go*, April 24, 1998, http://www.scienceagogo.com/news/19980324163707data_trunc_sys.shtml, accessed January 13, 2009.
17. Possible complications included pain, bleeding, fluid leakage, air leakage, infection, pneumonia, and irritation of the heart. Laura Pappano, "The Gift," *Boston Globe*

Magazine, November 17, 1996; "Living Lobar Lung Transplant: Donor Information," Duke Transplant Center, http://organtransplant.mc.duke.edu/transplant.nsf/webpages/LungDonor, accessed July 9, 2003. A total of 204 living lobar lung transplants had been performed by April 30, 2003. [Lung] Transplants by Donor Type, January 1, 1988–April 30, 2003, Organ Procurement and Transplantation Network data, http://www.optn.org/latestData/rptData.asp, accessed July 9, 2003.

18. Pappano, "The Gift"; Sheryl Stolberg, "Historic Lung Transplant Draws Mixed Reaction," *Los Angeles Times*, February 11, 1993, A1; Dean Lamanna, "The Breath of Life," *Ladies' Home Journal* 110 (November 1993): 120–124.
19. Collien, "Cheating Death"; Telephone interview with Kelly Helms, conducted by Elizabeth Harper, November 10, 1998.
20. Charles McNeill, "Waiting was Hard but Worth It," *CF Roundtable*, Winter 1996, 8; Daniel Martini, "An Alpha-$_1$ Transplant Success Story," in Schum, *Taking Flight*, 193.
21. Telephone interview with Karen Couture; Interview with Lori Hughes; Interview with Dare Reitz, conducted by Stephen Bloodworth, Burgaw, NC, November 3, 1998.
22. Hope Fennell, "A Life Lived Stubbornly," in Schum, *Taking Flight*, 92; Interview with Matt Byrd, conducted by Genienne Taormina, Chapel Hill, NC, October 23, 2000; Telephone interview with Steven Bunsen, conducted by Kristin Nagy, November 5, 2002.
23. Interview with Jasper Martin, conducted by Chris Champagne, Burlington, NC, October 30, 2002; Telephone interview with M. L. Bryan, conducted by George Baker, November 20, 1998.
24. Telephone interview with Mary Ellen Smith, conducted by Justin Lee Herman, October 31, 2002; Daniel Ensign, "Life is So Much Easier," in Schum, *Taking Flight*, 85–86; Interview with Judy Ryan, conducted by Melissa Meiskey, Garner, NC, November 9, 2002.
25. Karen Couture, *Information You Should Know About Lung Transplantation: Before, During and After* (Second Wind Lung Transplant Association, 1997), 25; Interview with Randy and Tammy Ellis, conducted by Amanda Wentzler, Cary, NC, October 24, 1998; Interview with "Lynn" (who requested anonymity), conducted by Inga Bajalyte, Durham, NC, October 19, 2002; Maureen Janik, "My Life…Act II," and Jennifer Russell, "My Lung Transplant Adventure," in Schum, *Take Flight*, 153 and 259. Kathleen Feeney described GoLytely: "The stuff was so bad—I had to suck an ice cube to numb my taste buds, then guzzle it, then suck an ice cube." Interview with Kathleen Feeney.
26. Interview with Dana Schmidt; Avila, "Survivor: Transplants."
27. Interview with Lori Hughes; McNeil, "Waiting was Hard, but Worth It"; Kathleen Feeney, "Kathleen—Version 2.0," in Schum, *Taking Flight*, 89; Telephone interview with Kelly Helms, conducted by Elizabeth Harper, November 10, 1998; Lee Starr, "Lucky Lee the Miracle Man," in Schum, *Taking Flight*, 291–293.
28. Lisa Mannheimer, "A Miracle Happened on March 3, 2001," and Richard Mannheimer, "Determination Conquers All," in Schum, *Taking Flight*, 189–190.
29. Interview with Pauline DeLuca.
30. Interview with Carol White, conducted by Gretchen Buskirk, Louisburg, NC, November 1, 2002.
31. Interview with Tom Fereday, conducted by Jennifer Bradshaw, Sterling, Virginia, November 25, 1998; Telephone interview with Bob Festle, conducted by Julie

Gill, November 24, 1998. Interview with Karen Couture. Like Fereday, Bill Poplett and his wife "talked about many things in our life and our love." Poplett, "My Best Friend I Never Knew," in Schum, *Taking Flight*, 242.

32. Interview with Ruth Hall, conducted by John Stephen Bolger III, King, NC, November 7, 2002. Cheryl Maxham used humor, too. "I was laughing and joking with them. I have false teeth and they had to take my teeth out and we were joking around about that." Interview with Cheryl Maxham. See also Linda Josefowicz, "My Story," in Schum, *Taking Flight*, 166; Interview with Kathleen Feeney.
33. Interview Jasper Martin; Vanderford, "Miracles Still Happen"; Ferris, *For Love of Life*, 211; Collien, Cheating Death"; Interview with William Poplett, conducted by Zack Harrison, Virginia Beach, Virginia, November 12, 2000. Lori Hughes had a similar response to the medical equipment, "two tables of instruments of all kinds, it was all metal stuff and blankets and gauze and things." She asked, "Is that all for me?" When they said they would use every single instrument, she responded, "Oh my goodness!" Interview with Lori Hughes.
34. Interviews with Dare Reitz and Mary Ellen Smith; Telephone interview with Jimmy Carroll, conducted by Daniel Jackson, November 10, 2002; David A. Lee, "The Inside Confidential Story," in Schum, *Taking Flight*, 178.
35. Interview with Dana Schmidt, conducted by Kelly Foster, Durham, NC, November 19, 2002; Interview with Frank Avila, conducted by Andrew Oak, Burlington, NC, November 4, 2002; Interview with Cheryl Maxham. See also Interview with Pauline DeLuca; Carolyn Boyd, "The Most Precious Gift," in Schum, *Taking Flight*, 35–37.
36. Hawkins, "Experiencing the Decision." *Airways* 7, no. 6 (November 1999).

6 Second Wind: Life after Transplant with a Donor Lung

1. Quotes from Joanne Schum and Carolyn Boyd in Karen A. Couture, *The Lung Transplantation Handbook*, 2nd ed. (Victoria, British Columbia: Trafford, 2001), 87, 64.
2. Interview with Howell Graham, conducted by Melissa Pace, Wilmington, NC, July 16, 1997.
3. The cited statistics are benchmark survival rates for transplant recipients reported worldwide between 1994 and 2005. The United States did about half the world's lung transplants. Elbert P. Trulock et al., "Registry of the International Society for Heart and Lung Transplantation: Twenty-fourth Official Adult Lung and Heart-Lung Transplantation Report—2007," *Journal of Heart and Lung Transplantation* 26, no. 8 (August 2007): 782–795.
4. Interview with Pauline DeLuca, conducted by Stacy Morin, Raleigh, NC, November 1, 2000; Interview with Tim Choquette, conducted by Lindsey Clarke, Durham, NC, November 7, 1998.
5. Telephone interview with Rosalie Gallogly, conducted by Melissa Pace, July 7, 1997; Telephone interview with Carol Stimmel, conducted by Tony Vasquez, November 17, 1998. For Bill Poplett, being removed from the ventilator "was the most emotional feeling, the first breath of air that I'd had since all them years."

Interview with William Poplett, conducted by Zack Harrison, Virginia Beach, VA, November 12, 2000.

6. Interview with Rosalie Gallogly; Interview with Frank Spears, conducted by John Asmussen, Oxford, NC, November 1, 2000.
7. Interview with Frank Spears; Daniel Ensign, "Life is so Much Easier," in Joanne Schum (ed.), *Taking Flight; Inspirational Stories of Lung Transplantation* (Victoria, B.C.: Trafford Publishing, 2002), 85–86; Laura Scott Ferris, "Celebrate & Cherish Life," in Schum, *Taking Flight*, 94–95.
8. Interview with William Poplett; Charles Tolchin, *Blow the House Down: The Story of My Double Lung Transplant* (San Jose: Writers Club Press, 2000), 191, 186; Telephone interview with Don Hawkins, conducted by Shannon Carpenter, October 28 and November 24, 2000.
9. Interview with Cheryl Maxham, conducted by Emily Linz, Manassa, VA, October 31, 1998; Telephone interview with Mary Ellen Smith, conducted by Justin Herman, October 31, 2002.
10. In one study, 73 percent of recipients experienced such mental syndromes. Claire N. Hallas and Jo Wray, "Psychology," in Nicholas Banner, Julia M. Polak, and Magdi Yacoub (eds.), *Lung Transplantation* (Cambridge, England: Cambridge University Press, 2003), 342–352; Mary Amanda Dew and Andrea F. DiMartini, "Psychological Disorders and Distress After Adult Cardiothoracic Transplantation," *Journal of Cardiovascular Nursing* 20, no. 5S (September–October 2005): S51–66. Laura J. Scott Ferris, *For Love of Life* (Flol Publisher, 2001), 216, 221; Isabel Stenzel Byrnes and Anabel Stenzel, *The Power of Two; A Twin Triumph over Cystic Fibrosis* (Columbia and London: University of Missouri Press, 2007), 245–247; Interview with Jan Travioli, conducted by Erin Witmer, Waxhaw, NC, November 2, 2000; Interview with Tiffany Vuncannon, conducted by Kelly Poisson, Cary, NC, October 31, 2002.
11. Interview with Jack Snyder, conducted by Erin Alston, Durham, NC, November 9, 2000; Interview with Kathryn Flynn, conducted by Glenn Long, Hillsborough, NC, November 16, 1998.
12. Ferris, *For Love of Life*, 219; Byrnes and Stenzel, *Power of Two*, 247; Interview with Pauline DeLuca. Mary Ellen Smith asked her coordinator, "What if I forget how to breathe?" Interview with Mary Ellen Smith.
13. Matthew G. Hartwig and R. Duane Davis, "Surgical Considerations in Lung Transplantation: Transplant Operation and Early Postoperative Management," *Respiratory Care Clinics of North America* 10, no. 4 (December 2004): 473–504; Interview with Tiffany Vuncannon, conducted by Kelly Poisson, Cary, NC, October 31, 2002; Interview with Darlene (Dare) Reitz, conducted by Stephen Bloodworth, Burgaw, NC, November 3, 1998; Interview with Matt Byrd, conducted by Genienne Taormina, Chapel Hill, NC, October 23, 2000.
14. Tiffany Christensen, *Sick Girl Speaks! Lessons and Ponderings Along the Road to Acceptance* (New York: iUniverse, 2007), 36–37, 47–48, 74–76.
15. Interview with Howell Graham; Interview with Carol White, conducted by Gretchen Buskirk, Louisburg, NC, November 1, 2002; Interview with Jasper Martin, conducted by Chris Champagne, Madison, NC, October 30, 2000; Interview with Lynn [prefers last name not be used], conducted by Inga Bajalyte, Durham, North Carolina, October 19, 2002.

16. Jonathan B. Orens and Edward R. Garrity, Jr., "General Overview of Lung Transplantation and Review of Organ Allocation," *Proceedings of the American Thoracic Society* 6 (2009): 13–19; Hartwig and Davis, "Surgical Considerations in Lung Transplantation"; Interview with Melodie Greene, conducted by Courtney Wells, Cornelius, NC, October 27, 2000.
17. Telephone interview with Karen Fitchett, conducted by Zach Smith, November 1998; Telephone interview with Kelly Helms, conducted by Elizabeth Harper, November 10, 1998; Interview with Lori Hughes, conducted by William York, Lawndale, NC, November 1, 2002.
18. Orens and Garrity, Jr., "General Overview of Lung Transplantation"; Hartwig and Davis, "Surgical Considerations in Lung Transplantation"; Interview with Kathleen Feeney; Interview with Barbara M. Stepp, conducted by Jamie Goebel, Durham, NC, October 27, 2000. Some recipients started off well and then had sudden downturns. See interviews with M. L. Bryan, Carol White, and Randy Sims, *Living a Miracle; Turning Your Obstacles into Opportunities* (Livermore, CA: WingSpan Press, 2006), 72–73.
19. Interviews with Tim Choquette and Jan Travioli and Barbara Stepp. Telephone interview with Steve Brunson, conducted by Melissa Pace, July 2, 1997.
20. Interview with Jasper Martin; Interview with Tom Fereday, conducted by Jennifer Bradshaw, Sterling, Virginia, November 25, 1998; Interview with Pauline DeLuca.
21. Telephone interview with M. L. Bryan, conducted by George Baker, Jr., November 20, 1998; Telephone interview with Jimmy Carroll, conducted by Daniel Jackson, November 7, 2002; Interview with Tom Fereday; Telephone interview with Kathleen Feeney, conducted by Sarah Starkey, October 29, 2002. Shirley Jewett said it was three months before she felt better. Jewett, *I Call My New Lung Tina; Inspiration from a Transplant Survivor*, 2nd ed. (Victoria, British Columbia: Trafford Publishing, 2002), 175.
22. Hartwig and Davis, "Surgical Considerations in Lung Transplantation"; Selim M. Arcasoy, "Medical Complications and Management of Lung Transplant Recipients," *Respiratory Care Clinics of North America* 10, no. 4 (December 2004): 505–529; Duke Transplant Center, *Lung Transplant Patient Guide* (Duke University Medical Center, 2007), http://www.dukehealth.org/HealthLibrary/CareGuides/Transplants/PatientGuides/LungTransplant, accessed May 1, 2009.
23. Orens and Garrity, "General Overview of Lung Transplantation and Review of Organ Allocation"; Arcasoy, "Medical Complications and Management of Lung Transplant Recipients"; Hartwig and Davis, "Surgical Considerations in Lung Transplantation"; R. M. Kotloff and V. N. Ahya, "Medical Complications of Lung Transplantation," *European Respiratory Journal* 23 (2004): 334–342. Recipients could also develop a wide range of other nonpulmonary medical problems, which proved more threatening to them than to members of the general public.
24. Interviews with Mary Ellen Smith and Tim Choquette; Telephone interview with Steven Bunsen, conducted by Kristen Nagy, November 5, 2002; Telephone interview with Bob Festle, conducted by Julie Gill, November 24, 1998.
25. Telephone interview with Joanne Schum, conducted by Sarah Fitch, November 8, 2000; Tolchin, *Blow the House Down*, 156–157, 196; Interviews with Carol White, M. L. Bryan, and Jimmy Carroll.

26. Interview with Carol Stimmel.
27. Kotloff and Ahya, "Medical Complications of Lung Transplantation"; Trulock et al., "Registry of the International Society for Heart and Lung Transplantation." Another study said that 4 percent of lung transplant recipients developed cancer within their first year and 12 percent in their first five years. Ramsey Hachem, "Post-Transplant Lymphoproliferative Disease," *AirWays* 17, no. 1 (March 2009): 3.
28. Interview with Richard Throlson, conducted by Jessica Lesko, Durham, NC, November 7, 2002; Interviews with Howell Graham and Cheryl Maxham.
29. Ana Stenzel, "Now That I Have Tasted Chocolate . . ." in Schum, *Taking Flight*, 296–298. Dew and DiMartini found that mood (depression) and anxiety disorders were the most common psychiatric disorders after cardiothoracic transplantation and that distress levels were higher in transplant recipients than in the general population. Mary Amanda Dew and Andrea F. DiMartini, "Psychological Disorders and Distress after Adult Cardiothoracic Transplantation," *Journal of Cardiovascular Nursing* 20, no. 5S (September–October 2005): S51–66. Hallas and Wray reported that a relatively large proportion of recipients had clinically meaningful depression. Hallas and Wray, "Psychology." Couture reported that people taking immunosuppressant medications were more susceptible to anxiety. Couture, *Lung Transplantation Handbook*, 91.
30. Interviews with Kathleen Feeney and Joanne Schum.
31. Telephone interview with Mary Peters, conducted by Claire Baker, November 26, 2002; Couture, *Lung Transplantation Handbook*, 118; Interviews with Rosalie Gallogly, Dare Reitz, and Steve Brunson.
32. Couture, *Lung Transplantation Handbook*, 110–140. The Cleveland Clinic patient guide listed side effects for prednisone and recommendations for how to deal with them. Lung Transplant Program at Cleveland Clinic, "Prednisone for Organ Transplantation," http://my.clevelandclinic.org/services/Lung_Transplantation/hic_Prednisone_for_Organ_Transplantation.aspx, accessed May 1, 2009.
33. Harrington quoted in Couture, *Lung Transplantation Handbook*, 118; Byrnes and Stenzel, *Power of Two*, 248.
34. Hartwig and Davis, "Surgical Considerations in Lung Transplantation."
35. Tolchin, *Blow the House Down*, 156–157, 196; Byrnes and Stenzel, *Power of Two*, 250; Interviews with Kathleen Feeney, Lynn, and Howell Graham. Tierney quoted in Couture, *Lung Transplantation Handbook*, 116.
36. Tolchin, *Blow the House Down*, 244–245.
37. Telephone interview with Karen Couture, conducted by Derrick Krout, November 8, 2002; Interviews with William Poplett and M. L. Bryan.
38. Interviews with Kathleen Feeney, Steven Brunson, Mary Ellen Smith, and Melodie Greene; Interview with Judy Ryan, conducted by Melissa Meiskey, Garner, NC, November 9, 2002.
39. Interviews with Mary Ellen Smith, Laura Richards, and Rosalie Gallogly.
40. Cleveland Clinic [Lung] "Transplant Medications Overview," http://my.clevelandclinic.org/services/Lung_Transplantation/hic_Lung_Transplant_Rejection.aspx, accessed May 1, 2009. Mary Peters reiterated the message she heard, "If I don't deal with the medicines and the schedule even when I don't feel like it and even when I want to run away from it, I'll lose my life." Interview with Mary Peters.

41. Interviews with Kathryn Flynn and Karen Couture.
42. Interview with Steve Brunson and Steven Bunsen; Interview with Brett Pearce, conducted by Mary Jo Festle, Chapel Hill, NC, July 10, 1997. Similarly, Bob Festle accepted that in his job as a teacher, he would be especially vulnerable to colds. Interview with Bob Festle. Likewise, although anti-rejection drugs put him at higher risk for skin cancers, for Matt Byrd, who was an irrigation spray technician for a golf course, it was essential to be outdoors all day. Interview with Matt Byrd. *Aspergillus fumigates* is a fungus that lives in soil, decaying leaves, and grass, and it can be inhaled. Couture, *Lung Transplantation Handbook*, 144.
43. Interviews with Carol White, Mary Ellen Smith, and Tom Fereday. Matt Byrd took more risks after transplant, just as he had before transplant. He admitted there were times he drank more than he was supposed to and the next day he couldn't keep anything in his stomach, including his anti-rejection pills. Interview with Matt Byrd.
44. Interviews with Joanne Schum, Kathryn Flynn, Carol White; Interview with Frank Avila, conducted by Andrew Oak, Burlington, NC, November 4, 2002. Similarly, two years after his transplant, Steven Bunsen admitted, "I may be getting a little more lax now the further out I get. I shouldn't, but I do."
45. This study from nurses in Pittsburgh was based on in-depth interviews with 14 lung recipients. They found patients tended to be in one of four psychosocial stages related to symptom experience and reporting to their transplant teams. The four stages were naiveté, vulnerability, discovery, and insight, though not all went through all the stages nor went through them in a linear fashion. Annette De Vito Dabbs et al, "Striving for Normalcy: Symptoms and the Threat of Rejection after Lung Transplantation," *Social Science and Medicine* 59, no. 7 (October 2004): 1473–1484. There aren't many studies about noncompliance among lung transplant recipients, but studies on heart transplant recipients suggest that nonadherence/noncompliance tends to increase with the passage of time. See Sandra Cupples et al., "Report of the Psychosocial Outcomes Workgroup of the Nursing and Social Sciences Council of the International Society for Heart and Lung Transplantation: Present Status of Research on Psychosocial Outcomes in Cardiothoracic Transplantation: Review and Recommendations for the Field," *Journal of Heart and Lung Transplantation* 25, no. 6 (June 2006): 716–725.
46. Quoted in Dabbs, "Striving for Normalcy." "Mr. Victor," "Mr. Gerrard," and "Mr. Barr" are pseudonyms used in this study.
47. Interviews with Judy Ryan and Tiffany Vuncannon. After Floridian Kelly Helms had some skin cancers removed, she got "real careful" going to the beach. Interview with Kelly Helms.
48. Quoted in Dabbs, "Striving for Normalcy."
49. Interviews with Lynn and Cheryl Maxham.
50. Interviews with Judy Ryan and Carol Stimmel; Interview with Laura Richards, conducted by Amy Clayton, Durham, NC, November 2 and 8, 1998.
51. Ana Stenzel, "Now That I Have Tasted Chocolate," in Schum, *Taking Flight*, 296–298; Interview with Jan Travioli; Claire N. Hallas and Jo Wray, "Psychology," in Banner, Polak, and Yacoub, *Lung Transplantation*, 342–352.
52. Interviews with Steve Brunson and Kathryn Flynn.
53. Renee C. Fox and Judith P. Swazey, *Spare Parts; Organ Replacement in American Society* (New York: Oxford University Press, 1992), 31–40.

54. Interviews with Judy Ryan and Dare Reitz; Telephone interview with Danielle DiCiantis, conducted by Annie Evans, November 20, 2000.
55. Stenzel, "Now That I Have Tasted Chocolate"; Interview with Cheryl Maxham; Ferris, *For Love of Life*, 234. Dare Reitz felt unworthy, too. "When Princess Diana got killed, I questioned God. Why would he save me and let her go, someone who has done so much for the world?" Interview with Dare Reitz.
56. Fox and Swazey, *Spare Parts*, 32–40.
57. Interview with Frank Spears; Rothenberg, *Breathing for a Living*, 103; Jewett, *I Call My New Lung Tina*, 179.
58. Damian Neuberger, "A Rose for Chad," *AirWays* 13, no. 6 (January 2007): 10–11; Mary Hardy, "Meeting My Amish Donor Family," *AirWays* 14, no. 3 (July 2007): 10–11. Isabel Byrnes, whose mother was Japanese and father was German and donor was Latino, said after the transplant that she was proud to be triracial. Byrnes and Stenzel, *Power of Two*, 278–280.
59. Ferris, *For Love of Life*, 230.
60. Some of Sharp's research participants spoke of "cell memory" as an explanation for why recipients could experience a donor's presence. As an immunological concept, cell memory refers to the body's ability to code and later respond to pathogens (e.g., the purpose of vaccinations is that T cells can learn to recognize and "remember" disease based on exposure through prior inoculation). Recipients with whom Sharp spoke literally asserted that cells retain memories of their origins. Although they inaccurately used language related to blood, genetics, and immunology, Sharp postulated that many who spoke about cell memory were not really discussing science, but were more metaphorically trying to explain radical transformations recipients experienced and make sense of the newly constructed bodies and sense of self in people who were now hybrids. Sharp, *Strange Harvest; Organ Transplants, Denatured Bodies, and the Transformed Self (Berkeley: University of California Press, 2006)*, 199–200; Lesley A. Sharp, "Organ Transplantation as a Transformative Experience: Anthropological Insights into the Restructuring of the Self," *Medical Anthropology Quarterly* 9, no. 3 (September 1995): 379–382.
61. Interviews with Jasper Martin and Jan Travioli. Some people were not curious about the details of their donors' lives or preferred not to know them. See Interview with Rosalie Gallogly.
62. Interviews with Kelly Helms, Frank Spears, and Steve Brunson; Ferris, "Celebrate & Cherish Life."
63. Kathryn J. Foss, "I'm Dancing like Nobody's Watching!" in Schum, *Taking Flight*, 97–98; Interviews with William Poplett and Judy Ryan.
64. Don Hawkins also made it a habit to speak publicly about the miracles that organ donation could create. Interview with Don Hawkins. Interview with Howell Graham; Ferris, "Celebrate & Cherish Life."
65. Interviews with Kathryn Flynn, Danielle DiCiantis, Dare Reitz, and Kelly Helms.
66. Interview with Pauline DeLuca.
67. Byrnes and Stenzel, *Power of Two*, 283; Interviews with Jimmy Carroll and Don Hawkins. For examples of close relationships, see Neuberger, "A Rose for Chad"; and Hardy, "Meeting My Amish Donor Family."
68. Sharp, *Strange Harvest*, 165–174, 196–198, 204.
69. Interviews with Howell Graham and Kathleen Feeney.

70. Interviews with Steven Bunsen, Mary Ellen Smith, Judy Ryan, and Tiffany Vuncannon. Barbara Stepp, who kept setting deadlines to write but not following through, said, "I wish I knew whether they wanted to hear from me . . . I keep thinking, 'they had to lose in order for me to live.'" Interview with Barbara Stepp.
71. Interviews with Rosalie Gallogly, Carol White, and Tom Fereday.
72. Rothenberg, *Breathing for a Living*, 96–99; Sims, *Living a Miracle*, 130; Ferris, *For Love of Life*, 230; Interviews with Karen Couture and Lynn. Ana Stenzel wrote that she was "humbled by feelings of gratitude, guilt, and a sense of responsibility to live for this man." Byrnes and Stenzel, *Power of Two*, 282.
73. Tolchin, *Blow the House Down*, 243–245.
74. With diseases like cystic fibrosis, transplant did not cure the disease for which it was performed or eliminate all its symptoms (many of which were unrelated to lungs), but it did address the lung problems that would have killed the person who had CF. Replacing the lungs did solve the fundamental problem of people who suffered from conditions such as idiopathic pulmonary fibrosis, however.
75. Interview with Mary Peters.

7 Quality of Life after Transplant

1. Telephone interview with Kathleen Feeney, conducted by Sarah Starkey, October 29, 2002.
2. Telephone interview with Karen Couture, conducted by Derrick Krout, November 8, 2002; Karen Couture, "A Life's Work," in Joanne Schum (ed.), *Taking Flight; Inspirational Stories of Lung Transplantation* (Victoria, B.C.: Trafford Publishing, 2002), 65–66; "The Real Heroes of Transplantation," Second Wind Lung Transplant Association, Inc., http://www.2ndwind.org/stories/The%20Real%20Heroes.html, accessed June 30, 2011.
3. On the increasing awareness that extending survival is not always a sufficient rationale for treatment, see Gordon Guyatt et al., "Users' Guides to the Medical Literature: XII. How to Use Articles about Health-Related Quality of Life," *Journal of the American Medical Association* (*JAMA)* 277, no. 15 (April 16, 1997): 1232–1237.
4. Elbert P. Trulock, et al., "Registry of the International Society for Heart and Lung Transplantation: Twenty-fourth Official Adult Lung and Heart-Lung Transplantation Report —2007," *Journal of Heart and Lung Transplantation* 26, no. 8 (August 2007): 782–795.
5. Lianne G. Singer, "Cost-effectiveness and Quality of Life: Benefits of Lung Transplantation," *Respiratory Care Clinics of North America* 10, no. 4 (December 2004): 449–457.
6. Scott D. Ramsey, "The Cost-effectiveness of Lung Transplantation," *Chest* 108 (December 1995): 1594–1601. See also Cliff K. Choong and Bryan F. Meyers, "Quality of Life after Lung Transplantation," *Thoracic Surgery Clinics* 14, no. 3 (August 2004): 385–407.
7. Thomas Gill et al., "A Critical Appraisal of the Quality of Quality-of-Life Measurements," *JAMA* 272, no. 8 (August 24, 1994): 624.

8. R. D. Levy et al., "Lung Transplant Outcomes: A Review of Survival, Graft Function, Physiology, Health Related Quality of Life, and Cost-effectiveness," *European Respiratory Journal* 24 (2004): 674–685. See also Kathleen L. Grady and Dorothy M. Lanuza, "Physical Functional Outcomes after Cardiothoracic Transplantation," *Journal of Cardiovascular Nursing* 20, no. 5S (Sep–Oct 2005): S43–50; Martin Schwaiblmair et al, "Cardiopulmonary Exercise Testing Before and After Lung and Heart-Lung Transplantation," *American Journal of Respiratory Critical Care Medicine* 159 (1999): 1277–1283.
9. For many years, clinicians used physiological or lab tests because they had no idea how to actually measure the phenomenon of feeling better. Guyatt et al., "Users' Guides to the Medical Literature."
10. Singer, "Cost-effectiveness and Quality of Life." WHO definitions in Roger D. Yusen, "Technology and Outcomes Assessment in Lung Transplantation," *Proceedings of the American Thoracic Society* 6 (2009): 128–136; and Cynthia R. Gross, "The Cost of Lung Transplantation and the Quality of Life Post-Transplant," *Clinics in Chest Medicine* 18, no. 2 (June 1997): 391–403.
11. Marcia A. Testa and Donald C. Simonson, "Assessment of Quality-of-Life Outcomes," *New England Journal of Medicine* 334, no. 13 (March 28, 1996): 835–840; Sandra Cupples et al., "Report of the Psychosocial Outcomes Workgroup of the Nursing and Social Sciences Council of the International Society for Heart and Lung Transplantation: Present Status of Research on Psychosocial Outcomes in Cardiothoracic Transplantation: Review and Recommendations for the Field," *Journal of Heart and Lung Transplantation* 25, no. 6 (June 2006): 716–725.
12. Some of the instruments were designed primarily with lung disease in mind, while others were more generic, allowing comparison across disease groups. Often in a study researchers used a couple of different survey instruments, most of which had been tested for reproducibility, internal consistency, validity, and reliability.
13. Sample question from the "Rand 36-item Health Survey 1.0 Questionnaire Items," Rand, http://www.rand.org/health/surveys/sf36item/question.html, accessed July 30, 2001. General health was often measured using the Sickness Impact Profile and the Medical Outcome Study Health Survey; instruments for or condition-specific conditions included the St. George's Respiratory Questionnaire and the Transplant Frequency Questionnaire. To get at more subtle psychological factors, a 2000 study included a Body Cathexis Scale, Derogatis Sexual Functioning Inventory, and Rosenberg Self Esteem Scale. Marjolaine M. Limbos, "Psychological Functioning and Quality of Life in Lung Transplant Candidates and Recipients," *Chest* 118, no. 2 (August 2000): 408–416. Good overviews of lung transplant QOL studies include Dorothy Lanuza, "Research on the Quality of Life of Lung Transplant Candidates and Recipients: An Integrative Review," *Heart and Lung* 29, no. 3 (May–June 2000): 180–195; Choong and Meyers, "Quality of life after lung transplantation"; Cynthia R. Gross, "The Cost of Lung Transplantation and the Quality of Life Post-Transplant."
14. While excluding these individuals made sense for ease of administering surveys, excluding those without telephones or fluency in English introduced class and ethnic bias.
15. This study used the Short-Form-36 (SF-36) Health Survey, which was commonly used and assessed patients' perceptions of health-related quality of life across eight

domains, and the Transplant Symptom Frequency Questionnaire, designed by researchers at the University of Florida to measure the frequency and severity of symptoms likely to be encountered. Recipients' $FEV\text{-}_1$ scores and six-minute walk scores more than doubled. James R. Rodrigue, "Does Lung Transplantation Improve Health-related Quality of Life? The University of Florida Experience," *Journal of Heart and Lung Transplantation* 24, no. 7 (June 2005): 755–763.

16. Quoted in Choong and Meyers, "Quality of Life after Lung Transplantation." See also Claire N. Hallas and Jo Wray, "Psychology," in Nicholas Banner, Julia M. Polak, and Magdi Yacoub (eds.), *Lung Transplantation* (Cambridge, England: Cambridge University Press, 2003), 342–352; Grady and Lanuza, "Physical Functional Outcomes after Cardiothoracic Transplantation."
17. Hallas and Wray, "Psychology"; Cupples et al., "Report of the Psychosocial Outcomes Workgroup"; Krista A. Barbour et al., "Psychosocial Issues in the Assessment and Management of Patients Undergoing Lung Transplantation," *Chest* 125, no. 5 (May 2006): 1367–1374; Mary Amanda Dew and Andrea F. DiMartini, "Psychological Disorders and Distress After Adult Cardiothoracic Transplantation," *Journal of Cardiovascular Nursing* 20, no. 5S (September–October 2005): S51–66.
18. Rodrigue, "Does Lung Transplantation Improve Health-related Quality of Life?"; Hans W. Kunsebeck et al., "Quality of Life and Bronchiolitis Obliterans Syndrome in Patients after Lung Transplantation," *Progress in Transplantation* 17, no. 2 (June 2007): 136–141.
19. The number of recipients followed in some recent US studies ranged from 10 to 54. See Table 2 in Choong and Meyers, "Quality of Life after Lung Transplantation."
20. Choong and Meyers, "Quality of Life after Lung Transplantation." With its 66 participants, the University of Florida study more than doubled the number of subjects (59) in all four of the other longitudinal studies. Rodrigue, "Does Lung Transplantation Improve Health-related Quality of Life?"
21. Critics also noted many studies did not account for patients' willingness to undergo risk. For criticism of QOL studies, see Yusen, "Technology and Outcomes Assessment in Lung Transplantation"; Choong and Meyers, "Quality of Life after Lung Transplantation"; Cupples et al., "Report of the Psychosocial Outcomes Workgroup"; Gross, "The Cost of Lung Transplantation and the Quality of Life Post-Transplant"; Jeffrey J. Swigris et al., "Patients' Perspectives on How Idiopathic Pulmonary Fibrosis Affects the Quality of Their Lives," *Heath and Quality of Life Outcomes* 3 (October 2005): 66–69.
22. "Missing data as a result of patients dying or poor health status do not occur at random. Therefore, excluding these patients from the analysis will result in clinically significant bias and result in a better overall HRQL [health-related quality of life] than it actually is in the total group of lung transplant recipients." Elisabeth TenVergert, "The Effect of Lung Transplant on Health-related Quality of Life: A Longitudinal Study," *Chest* 113, no. 2 (February 1998): 358–364. In one study, of 15 people who had completed pretransplant surveys and then underwent lung transplant, 3 died. The investigators revealed this, but didn't include them in the results. Dorothy Lanuza, "Prospective Study of Functional Status and Quality of Life Before and After Lung Transplantation," *Chest* 118, no. 1 (July 2000): 115–122. Investigators in another study excluded "those who were currently hospitalized or receiving IV medications for a medical illness or complication of their lung transplant." Limbos,

"Psychological Functioning and Quality of Life in Lung Transplant Candidates and Recipients."

23. Larissa Myaskovsky et al., "Trajectories of Change in Quality of Life in 12-Month Survivors of Lung or Heart Transplant," *American Journal of Transplantation* 6 (2006): 1939–1947. One study mentioned "the reported costs associated with the intensive follow-up care and expensive drugs regimen raise the question of whether this intervention is cost effective." Helen-Maria Vasiliadis, "A Cost-Effectiveness and Cost-Utility Study of Lung Transplantation," *Journal of Heart and Lung Transplantation* 24, no. 9 (September 2005): 1275–1283.
24. Jan Paul Ouwens et al., "The Cost Effectiveness of Lung Transplantation Compared with That of Heart and Liver Transplantation in the Netherlands," *Transplant International* 16, no. 2 (February 2003): 123–127; Singer, "Cost-Eeffectiveness and Quality of Life." Despite finding that lung transplants were more than twice as expensive per year of life gained as heart and liver transplants, the Dutch Insurance Board opted to continue offering lung transplants. The UK study was Ani C. Anyanwu et al., "An Economic Evaluation of Lung Transplantation," *Journal of Thoracic and Cardiovascular Surgery* 123 (March 2002): 411–420.
25. Ramsey, "The Cost-effectiveness of Lung Transplantation."
26. Thomas Egan, letter to the editor, *Chest* 110, no. 2 (August 1996): 577.
27. Thomas M. Egan, "QALYs or Quackery? The Quagmire of Quantifying the Cost of Breathing," *Journal of Thoracic and Cardiovascular Surgery* 123 (March 2002): 406–408.
28. Anyanwu, "An Economic Evaluation of Lung Transplantation."
29. Quoted in Rodrigue et al., "Does Lung Transplantation Improve Health-related Quality of Life?" On the formulas for estimating health-related quality of life, see Gross, "The Cost of Lung Transplantation and the Quality of Life Post-transplant"; Singer, "Cost-effectiveness and Quality of Life"; Yusen, "Technology and Outcomes Assessment in Lung Transplantation"; Ramsey, "The Cost-effectiveness of Lung Transplantation"; and Choong and Meyers, "Quality of Life after Lung Transplantation."
30. Cupples et al., "Report of the Psychosocial Outcomes Workgroup"; Singer, "Cost-effectiveness and Quality of Life."
31. Myaskovsky, "Trajectories of Change in Quality of Life." Many of the recently published QOL studies were done by staff in transplant centers, suggesting they have shrewdly opted to use the tools of their critics to defend the value of their programs.
32. Gross, "The Cost of Lung Transplantation and the Quality of Life Post-Transplant." The panel emphasized that this type of analysis should be an aid to decision-making, not a mechanical procedure for rationing health care resources.
33. Yusen said we still could not the answer the following question: Do the benefits of lung transplantation outweigh the harms? Yusen, "Technology and Outcomes Assessment in Lung Transplantation."
34. Choong and Meyers, "Quality of Life after Lung Transplantation."
35. I am aware of only a few studies that included an open-ended question. In two cases, I believe the investigators asked just one open-ended question. Lanuza, "Prospective Study of Functional Status and Quality of Life Before and After Lung Transplantation"; and Limbos, "Psychological Functioning and Quality of Life in

Lung Transplant Candidates and Recipients." An exception to the trend of relying on quantitative surveys is Annette De Vito Dabbs et al., "Striving for Normalcy: Symptoms and the Threat of Rejection after Lung Transplantation," *Social Science and Medicine* 59, no. 7 (October 2004): 1473–1484. This study undertaken by nurses in Pittsburgh was based on in-depth interviews with 14 lung recipients.

36. Things they heard that had not been measured included concerns about future health and life expectancy; the ability to continue work or education; personal growth; ongoing need for medication and medical care; overall outlook on life; and ability to contribute to society and give to others. Limbos, "Psychological Functioning and Quality of Life in Lung Transplant Candidates and Recipients."
37. Although newer instruments to measure quality of life were characterized by steps such as item selection, item reduction, pretesting, and quantitative evaluation for reproducibility and validity, Thomas Gill said most instruments had poor "face validity"—that anyone applying common sense and a bit of clinical reality could see that they don't actually measure what most people consider "quality of life." Gill, "A Critical Appraisal of the Quality of Quality-of-Life Measurements."
38. Mary Jo Festle, "Qualifying the Quantifying: Assessing the Quality of Life of Lung Transplant Recipients," *Oral History Review* 29, no. 1 (Winter–Spring 2002): 59–86.
39. Interview with Cheryl Maxham, conducted by Emily Linz, Manassa, Virginia, October 31, 1998; Interview with Howell Graham, conducted by Melissa Pace, Wilmington, NC, July 16, 1997.
40. Telephone interview with Joanne Schum, conducted by Sarah Fitch, November 8, 2000; Interview with Karen Couture.
41. Telephone interview with Danielle DiCiantis, conducted by Annie Evans, November 20, 2000; Telephone interview with Mary Ellen Smith, conducted by Justin Herman, October 31, 2002; Interview with Kathryn Flynn, conducted by Glenn Long, Hillsborough, NC, November 16, 1998; Interview with Pauline DeLuca, conducted by Stacy Morin, Raleigh, NC, November 1, 2000; Interviews with Howell Graham, Cheryl Maxham and Karen Couture; Interview with Tim Choquette, conducted by Lindsey Clarke, Durham, NC, November 7, 1998.
42. Interview with Richard Throlson, conducted by Jessica Lesko, Durham, NC, November 7, 2002.
43. Interview with Tiffany Vuncannon, conducted by Kelly Poisson, Cary, NC, October 31, 2002.
44. Interview with Ruth Hall, conducted by John Stephen Bolger, King, NC, November 7, 2002.
45. Telephone interview with Tracy Raub, conducted by Greer Fenton, November 29, 2000; Telephone interview with Mary Peters, conducted by Claire Baker, November 26, 2002.
46. Isabel Stenzel Byrnes and Anabel Stenzel, *The Power of Two; A Twin Triumph over Cystic Fibrosis* (Columbia and London: University of Missouri Press, 2007), 251–252; Shirley E. Jewett, *I Call My New Lung Tina* (Victoria, British Columbia: Water Signs Publishing/Trafford Publishing, 2002), 181; Interview with Kathryn Flynn.
47. Interview with Jasper Martin, conducted by Chris Champagne, Madison, NC, October 30, 2000; Interview with Joanne Schum; Telephone interview with Kelly Helms, conducted by Elizabeth Harper, November 10, 1998; Interview with Tom Fereday, conducted by Jennifer Bradshaw, Sterling, Virginia, November 25, 1998.

48. Telephone interview with Jimmy Carroll, conducted by Daniel Jackson, November 7, 2002; Interviews with Kelly Helms and Kathryn Flynn; Interview with Jack Snyder, conducted by Erin Alston, Durham, NC, November 9, 2000. Steven Bunsen admitted he couldn't walk or run indefinitely, but he could do things he hadn't done for years and had "the quality back." Telephone interview with Steven Bunsen, conducted by Kristen Nagy, November 5, 2002.
49. Interview with Jan Travioli, conducted by Erin Witmer, Waxhaw, NC, November 2, 2000.
50. Trulock, "Twenty-fourth Official Adult Lung and Heart-Lung Transplantation Report—2007."
51. Byrnes and Stenzel, *The Power of Two*, 251–252; Telephone interview with Don Hawkins, conducted by Shannon Carpenter, October 28 and November 24, 2000; Interview with Kelly Helms.
52. Interview with Carol White, conducted by Gretchen Buskirk, Louisburg, NC, November 1, 2002; Interview with Mary Peters; Telephone interview with Steve Brunson, conducted by Melissa Pace, July 2, 1997.
53. Trulock, "Twenty-fourth Official Adult Lung and Heart-Lung Transplantation Report—2007."
54. W. Paris et al., "Return to Work after Lung Transplantation," *Journal of Heart and Lung Transplantation* 17, no. 4 (April 1998): 430–436.
55. Interview with Barbara Stepp, conducted by Jamie Goebel, Durham, NC, October 27, 2000; Paris, "Return to Work after Lung Transplantation"; Interview with Melodie Greene, conducted by Courtney Wells, Cornelius, NC, October 27, 2000; Interview with Kathryn Flynn.
56. Paris, "Return to Work after Lung Transplantation"; Interviews with Danelle DeCiantis, Howell Graham, and Jack Snyder.
57. Christensen, *Sick Girl Speaks!*, 56.
58. Interviews with Mary Peters and Jack Snyder; Interview with Laura Richards, conducted by Amy Clayton, Durham, NC, November 2 and 8, 1998.
59. Neil Kauten, "One Lucky Father," in Schum, *Taking Flight*, 168–169; Interviews with Karen Couture, Kathleen Feeney, and Jan Travioli.
60. Randy Sims, *Living a Miracle; Turning Your Obstacles into Opportunities* (Livermore, CA: WingSpan Press, 2006), 76; Nancy Hulet, "Gary Makes a Miracle," in Schum, *Taking Flight*, 148; Interview with Carol White; Daniel Martini, "An Alpha-$_1$ Transplant Success Story," in Schum, *Taking Flight*, 193.
61. Interviews with Steven Bunsen, Jimmy Carroll, Mary Ellen Smith, Lori Hughes, and Rosalie Gallogly; Telephone interview with Carol Stimmel, conducted by Tony Vasquez, November 17, 1998.
62. Interviews with Steve Brunson, Jack Snyder, Pauline DeLuca, Carol White, Barbara Stepp, and Joanne Schum.
63. Interview with Kathryn Flynn.
64. Interviews with Jasper Martin and Melodie Greene.
65. Interview with Frank M. Spears, conducted by John Asmussen, Oxford, NC, November 1, 2000; Interviews with Joanne Schum and Steven Bunsen.
66. Peters quoted in Karen A. Couture, *The Lung Transplantation Handbook*, 2nd ed. (Victoria, BC: Trafford, 2001), 36. Interviews with Bob Festle, Jasper Martin, Karen Couture, and Don Hawkins.

67. Interviews with Frank Spears, Cheryl Maxham, and Tom Fereday.
68. Interviews with Karen Couture and Danelle DeCiantis.
69. Hans Kunsebeck et. al., "Quality of Life and Bronchiolitis Obliterans Syndrome."
70. Ramsey Hachem, "Photopheresis for the Management of Lung Transplant Rejection," *AirWays* 14, no. 6 (January 2008): 1–2; G. M. Verleden et al., "Is it Bronchiolotis Obliterans Syndrome or is it Chronic Rejection?" *European Respiratory Journal* 25, no. 2 (2005): 221–224.
71. Jonathan B. Orens and Edward R. Garrity, Jr., "General Overview of Lung Transplantation and Review of Organ Allocation," *Proceedings of the American Thoracic Society* 6 (2009): 13–19; Trulock, "Twenty-fourth Official Adult Lung and Heart-Lung Transplantation Report—2007"; University of Pittsburgh Medical Center Pulmonary Division, "Bronchiolitis Obliterans," http://path.upmc.edu/divisions/pulmpath/bron02.htm, accessed May 15, 2009; R. Morton Bolman, III, "Advantage-FK 506: Reduced Chronic Rejection for Lung Transplant Recipients," *Annals of Thoracic Surgery* 60 (1995): 495–496.
72. Kunsebeck, "Quality of Life and Bronchiolitis Obliterans Syndrome"; Mi-Kyung Song et al., "Course of Illness after the Onset of Chronic Rejection in Lung Transplant Recipients," *American Journal of Critical Care* 17 (2008): 246–253; Verleden, "Is it Bronchiolitis Obliterans Syndrome or is it Chronic Rejection?"
73. Bronciolitis obliterans has been associated with the frequency and intensity of acute rejection episodes, previous pulmonary infection, and ischemic damage during the donor harvest, and gastroesophageal reflux disease. Treatment efforts have included increased or changed immunosuppressive drugs, inhaling cyclosporine, taking macrolide antibiotics, surgery to correct reflux, and photopheresis. Ramsey Hachem, "Photopheresis for the Management of Lung Transplant Rejection"; Laurie Snyder, "What is Chronic Rejection—Part II," *AirWays* 13, no. 4 (July 2006): 1, 8–10.
74. One study suggested that a modern cohort of retransplantees had a one-year survival rate of 62 percent and three-year of 49 percent. Steven M. Kawut, "Outcomes after Lung Retransplantation in the Modern Era," *American Journal of Respiratory Critical Care Medicine* 177, no. 1 (2008): 114–120.
75. Marcia Roenigk, "One Day at a Time," in Schum, *Taking Flight*, 255–256; Christensen, *Sick Girl Speaks!*, xiv, 101, 77–79; Interviews with Ruth Hall, Richard Throlson, and Kelly Helms.
76. Interview with Kelly Helms.
77. Interview with Tiffany Vuncannon; Kathryn Foss, "I'm Dancing Like Nobody's Watching!" in Schum, *Taking Flight*, 97–98; Ana Stenzel, "Now That I Have Tasted Chocolate." Stenzel wrote of the irony of having one's hopes raised by new medical treatments. "People in our generation had a carrot dangling in their faces: a normal life, a chance to realize ambitions, the potential to excel academically and thrive vocationally, and the opportunity to fall in love, all because we were living longer with CF." It was as though a cruel universe tempted people with CF then pulled the rug out from under them. In *Power of Two*, 195.
78. Larry L. Schulman (Editorial), "Quality of Life after Lung Transplantation," *Chest* 108, no. 6 (December 1995): 1489–1490.
79. Cynthia R. Gross et al, "Long-term Health Status and Quality of Life Outcomes of Lung Transplant Recipients," *Chest* 108, no. 6 (December 1995): 1587–1593. One other study asked a similar question to ten recipients three months post-transplant

requiring them to respond with a "yes" or "no" to whether they would have undergone the lung transplant knowing what they now knew and also asking them to explain their response. Nine of the ten reported they were very satisfied with their decision to undergo the transplant and the tenth said it was too soon to tell. Lanuza, "Prospective Study of Functional Status and Quality of Life Before and After Lung Transplantation."

80. Interviews with Joanne Schum, Carol Stimmel, Tim Choquette, Mary Peters, Lynn, and Richard Throlson; Interview with Thomas Bullard, conducted by Larry McSwain, Elon, NC, October 24, 2000.
81. Rothenberg, *Breathing for a Living: A Memoir* (New York: Hyperion, 2003), 132–133, 98–99.
82. Christensen, *Sick Girl Speaks!*, 105, 168.
83. Interview with Kimberly Pearce, conducted by Melissa Pace, Chapel Hill, NC, July 10, 1997; Interview with Dare Reitz, conducted by Stephen Bloodworth, Burgaw, NC, November 3, 1998; Interviews with Jimmy Carroll and Mary Ellen Smith.
84. Interviews with Dare Reitz, Pauline DeLuca, Frank Spears, Jimmy Carroll, Cheryl Maxham, Carol Stimmel, and Frank Avila.
85. Interviews with Carol Stimmel, Laura Richards, Melodie Greene, Kathleen Feeney, and Steven Bunsen.
86. Interviews with Tom Fereday, Tim Choquette, and Rosalie Gallogly.
87. Interviews with Kathryn Flynn, Joanne Schum, Steve Brunson, Steven Bunsen, Mary Peters, and Richard Throlson.
88. Sharp also thought recipients might self-censor because they worried transplant teams might feel they aren't entitled to talk of problems since the surgery saved their lives. Sharp, *Strange Harvest*, 108, 122–123. Interviews with Lori Hughes and Mary Peters.
89. Lanuza, "Prospective Study of Functional Status and Quality of Life before and after Lung Transplantation"; Myaskovsky, "Trajectories of Change in Quality of Life."
90. For those transplanted in the United States in 1987, the ten-year patient survival rate was just 12 percent; by 1996 it was 24 percent. *Adjusted Patient Survival by Year of Transplant for Deceased Donor Lung Transplants*, Table 12.13a, OPTN/SRTR 2007 Annual Report, U.S. Department of Health and Human Services, HRSA, http://www.ustransplant.org/annual_reports/current/1213a_lu.htm, accessed May 22, 2009.
91. Interview with Pauline DeLuca.
92. Interviews with Ruth Hall and Pauline DeLuca; Tolchin, *Blow the House Down*, 243; Couture, *The Lung Transplantation Handbook*, 184.

8 Lung Transplants in the Twenty-First Century

1. Thomas Diflo, "The Transplant Surgeon's Perspective on the Bungled Transplant," in Keith Wailoo, Julie Livingston, and Peter Guarnaccia, *A Death Retold: Jesica Santillan, the Bungled Transplant, and Paradoxes of Medical Citizenship* (UNC Press, 2006), 73–74; Jerry Adler et al., "A Tragic Error," *Newsweek*, March 3, 2003.

2. Keith Wailoo et al., "Introduction: Chronicles of an Accidental Death," in Wailoo, Livingston, and Guarnaccia, *A Death Retold*, 1, 7; Rob Stein, "Girl Has Second Transplant After Error," *Washington Post*, February 21, 2003, A1; Keith Wailoo and Julie Livingston, "The Politics of Second Chances: Waste, Futility, and the Debate over Jesica's Second Transplant," in Wailoo, Livingston, and Guarnaccia, *A Death Retold*, 119–120; Sheryl Gay Stolberg and Lawrence K. Altman, "An Ethical Dilemma With Few Precedents," *New York Times*, February 21, 2003, A23.
3. HHS had been developing regulations near the end of the George H. Bush administration, but then Bush put a moratorium on new regulations, so they were not issued. In 1990, Congress asked the Government Accounting Office (GAO) to investigate the effectiveness of the nation's transplant system, and the GAO found some problems. *Organ Transplant and Bone Marrow Donor Reauthorization*, Hearings before the subcommittee on Health and the Environment of the Committee on Energy and Commerce, House of Representatives, 103rd Congress, 1st session, April 22 and May 19, 1993 (US Government Printing Office, 1994), 6–18, 39, 45. For more details on the HHS regulation controversy, see Mary Jo Festle, "Enemies or Allies? The Organ Transplant Medical Community, the Federal Government, and the Public in the U.S., 1967–2000," *Journal of the History of Medicine and Allied Sciences* 65 (January 2010): 48–80.
4. Frist comments, *Putting Patients First: Resolving Allocation of Transplant Organs*, Joint Hearing before the Subcommittee on Health and Environment of the Committee on Commerce, House of Representatives, and the Committee on Labor and Human Resources, US Senate, 105th Congress, 2nd session, June 18, 1998, 93. See also "Patient Advocacy Group Condemns UNOS Interference with Government Hearings," National Transplant Action Committee press release, PR Newswire, December 9, 1996; "Transplant Community Overwhelmingly Supports UNOS," UNOS press release, PR Newswire, December 6, 1996; Paul Recer, "Patients Say Transplants Should Go First to the Sickest," Associated Press, December 10, 1996; Rich Weiss, "A Searing Debate over a Life-and-Death Policy," *Philadelphia Inquirer*, December 15, 1996, E3; "Some Patients Object to Rule Change on Who Gets Scarce Livers, " *New York Times*, November 18, 1996, A15.
5. Shalala testimony, *Putting Patients First*, 69–86; "HHS Rule Calls for Organ Allocation Based on Medical Criteria, Not Geography," HRSA Press Release, March 26, 1998, archived at http://www.hhs.gov/news/press/1998pres/980326a.html, accessed November 12, 2008.
6. Anthony M. D'Alessandro, "Hostile Organ Takeover; Donna Shalala, Organ Donor Czar," *Washington Times*, March 16, 2000, A21. Already in 1996 UNOS had been referring to the possibility of regulations as an "unprecedented federal takeover." Rich Weiss, "Who Should Get Liver Transplants? As Demand Far Outpaces Donors, Federal Officials May Revamp Rules," *Washington Post*, December 9, 1996.
7. Shalala testimony, *Putting Patients First*, 110. The national board of patient advocacy group TRIO voted to support the regulations, yet some local chapters disagreed. A consortium of hospitals in the southeast wrote a collective letter opposing the regulations. A different consortium, The Campaign for Transplant Patient Fairness, supported the regulations. See, e.g., the Joint Statement on the Organ Allocation Provisions in the OPTN Rule, *Putting Patients First,* 17–26; "Campaign

for Transplant Patient Fairness Weighs in on UNOS Plan, Calls on HHS to Protect Patient Interests," U.S. Newswire, March 13, 2000.

8. Thomas Barrett testimony, *Putting Patients First,* 59; Sheryl Gay Stolberg, "Patients' Lives on the Line in Battle Over Transplants," *New York Times*, March 25, 1998; Weiss, "A Searing Debate"; "Liver Allocation Policies Should Serve Public's Interest Not Transplant Centers'," press release, University of Pittsburgh Medical Center, December 10, 1996. South Carolina, Oklahoma, Louisiana, and Tennessee passed or considered laws to keep donated organs within their state boundaries. "Fighting Over Organs: The War Over Transplants: States v. Washington," *Economist*, May 2, 1998, 26–31. In addition, some regions squabbled. Andrew Buchanan, "Illinois Excluded from Midwest organ-sharing Network," Associated Press wire, August 20, 1999.
9. Institute of Medicine, *Organ Procurement and Transplantation*, 2, 14; Childress testimony, *Putting Patients First,* 200; Meckler, "Transplant World in Nasty Fight over New Rules"; "Patient Advocates Reject Transplant Network's Proposal to Revise Pending Federal Regulations," U.S. Newswire, September 15, 1999; Letter from American Liver Foundation, *Putting Patients First,* 237.
10. Richard N. Pierson III et al., "Thoracic Organ Transplantation," *American Journal of Transplantation* 4, Supplement 9 (2004): 93–105; T. M. Egan et al., "Development of the New Lung Allocation System in the United States," *American Journal of Transplantation* 6 (2006): 1212–1227; K. R. McCurry et al., "Lung Transplantation in the United States, 1998–2007," *American Journal of Transplantation* 9, Part 2 (2009): 942.
11. Thomas Egan, "Ethical Issues in Thoracic Organ Distribution for Transplant," *American Journal of Transplantation* 3 (2003): 369; Ramsey Hachem, "The Lung Allocation Score—Three Years Later," *Second Wind AirWays* 15, no. 3 (July 2008): 3–4; Denise Grady, "Lung Patients See a New Era of Transplants," *New York Times*, September 24, 2006, 1.
12. Steven Q. Davis and Edward R. Garrity, Jr. "Organ Allocation in Lung Transplant," *Chest* 132, no. 5 (November 2007): 1646–1651; Thomas M. Egan and Robert M. Kotloff, "Pro/Con Debate: Lung Allocation Should Be Based on Medical Urgency and Transplant Survival and Not on Waiting Time," *Chest* 128, no. 1 (July 2005): 410–411; Grady, "Lung Patients See a New Era of Transplants." Over 40 percent of those on the waiting list actually were "inactive," meaning they would not have accepted a donor organ if it were offered to them.
13. Egan, "Development of the New Lung Allocation System," 1213–1214; Davis and Garrity, "Organ Allocation in Lung Transplant," 1647.
14. Egan, "Development of the New Lung Allocation System," 1215, 1219–1223; Hachem, "The Lung Allocation Score—Three Years Later," 3–4; UNOS,"Questions and Answers for Transplant Professionals about Lung Allocation Policy," brochure, http://www.unos.org/SharedContentDocuments/Lung_Patient(1).pdf, accessed January 18, 2009.
15. Concerns included the patient data not being current enough and not including some important diagnostic factors used to predict survival such as $FEV\text{-}_1$ in patients with CF and right heart function in those with PPH. In addition, "patient advocacy groups voiced concern that the use of separate survival models for major diagnoses drew prejudicial distinctions among candidates with different illnesses." There were

also concerns the new system didn't adequately address special needs among the pediatric population. Egan, "Development of the New Lung Allocation System," 1214.

16. Laurie Barclay, "New Lung Allocation Policy: A Newsmaker Interview With Joel D. Newman," *Medscape Medical News*, June 29, 2004.
17. Egan and Kotloff, "Pro/Con Debate."
18. Interim summary report, UNOS Thoracic Committee, October 2, 2007, March 10, 2008, and July 18, 2008; Dayle Kern, "Advocates at Work: Unique Team Responds to Transplant Inequities for PH Patients," *Pathlight* (A newsletter for the Pulmonary Hypertension Association) 16, no. 1 (Winter 2007): 7; Mitchel L. Zoler, "Lung Allocation Biased against PAH Patients," *Internal Medicine News*, August 1, 2006; McCurry, "Lung Transplantation in the United States, 1998–2007," 955.
19. Herrington quoted in Grady, "Lung Patients See a New Era of Transplants"; Hachem, "The Lung Allocation Score—Three Years Later"; McCurry, "Lung Transplantation in the United States, 1998–2007," 942–945, 949.
20. McCurry, "Lung Transplantation in the United States, 1998–2007," 949; Laurie Snyder, "The Lung Allocation Score and Implications for Lung Transplant," *AirWays* 14, no. 4 (September 2007): 1–2.
21. Quoted in Grady, "Lung Patients See a New Era of Transplants"; Barclay, "A Newsmaker Interview With Joel D. Newman."
22. McCurry, "Lung Transplantation in the United States, 1998–2007," 942–946. A few early studies suggested that survival rates may have decreased slightly as a result of transplanting sicker patients, and there were suggestions that perhaps the system would need to be adjusted to insure that patients who are too sick are taken off the list. Rabiya S. Tuma, "Lung Allocation Score Alters Patients and Outcomes," *Medscape Medical News*, May 3, 2007, http://www.medscape.com/viewarticle/555995, accessed August 15, 2008. The committee that designed the system thought some slight decrease in overall survival might well occur, but that it would be outweighed by other improvements. Davis and Garrity, Jr. "Organ Allocation in Lung Transplant," 1646–1651.
23. Orens quoted in Tuma, "Lung Allocation Score Alters Patients and Outcomes"; Egan, "Development of the New Lung Allocation System," 1226; Davis and Garrity, "Organ Allocation in Lung Transplant," 1650.
24. Clemens Aigner and Walter Klepetko asserted that "realistic application [of xenotransplantation] . . . is not currently on the horizon." "Lung Transplantation Using Donors after Cardiac Death," *Current Opinion in Organ Transplantation* 12, no. 5 (October 2007): 459. See also Jeffrey Platt et al., "Recommendations of the National Heart, Lung, and Blood Institute Heart and Lung Xenotransplantation Working Group," *Circulation* 106, no. 9 (August 27, 2002): 1043.
25. In 1986, the time limit a donor lung could be outside the body was about 4 hours, and by 2007 it had increased to 12. David Weill, "Donor Criteria in Lung Transplantation: An Issue Revisited," *Chest* 121, no. 6 (June 2002): 2029–2031; Laura Meckler, "Drugs Preserve Organs for Transplant," Associated Press Online, April 30, 2002.
26. In "controlled" donations after cardiac death, donors usually were on a ventilator due to irreversible brain injuries caused by trauma or intracranial bleeding. "Uncontrolled" donations involve sudden deaths and cause different ethical issues,

since families may not be readily available at the time a decision to donate has to be made. Robert Steinbrook, "Organ Donation after Cardiac Death," *New England Journal of Medicine* (July 19, 2007): 209–213. On medical organizations' positions, see Institute of Medicine Division of Health Care Services, *Non-Heart-Beating Organ Transplantation: Practice and Protocols* (Washington, D.C.: National Academy Press, 2000), 1–5; American Medical Association, "Opinion 2.157—Organ Donation After Cardiac Death," AMA Code of Medical Ethics, http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2157.shtml, accessed March 1, 2010; UNOS, "The Role of the OPTN/UNOS in the Evolving Practice of Donation after Cardiac Death," press release, February 27, 2007, http://www.unos.org/news/newsDetail.asp?id=814, accessed March 1, 2010; J. L. Bernat et al., "Report of a National Conference on Donation after Cardiac Death," *American Journal of Transplantation* 6 (2006): 281–291.

27. Some objected that the legal definition of death was not truly being met or that "irreversible" cardiac cessation was difficult to prove. Some health care providers were uncomfortable because there was such a short time between withdrawing care, pronouncing death, and recovering the organs. Rob Stein, "In the Emergency Room, An Ethics Dilemma," *Washington Post*, March 15, 2010, A1; Renee C. Fox, "An Ignoble Form of Cannibalism," *Kennedy Institute of Ethics Journal* 3, no. 2 (June 1993): 231–239; Robert M. Arnold et al., *Procuring Organs for Transplant; The Debate over Non-Heart-Beating Cadaver Protocols* (Baltimore and London: Johns Hopkins University Press, 1995); Steinbrook, "Organ Donation after Cardiac Death," 209–213; Leslie Whetstine et al., "Pro/Con Debate: When is Dead Really Dead?" *Critical Care* 9, no. 6 (December 2005): 538–542; Gary Greenberg, "As Good as Dead," *New Yorker*, August 13, 2001; Darshak Sanghavi, "The Last Decision," *New York Times*, December 20, 2009, MM38. On lungs in particular, see Aigner and Klepetko, "Lung Transplantation Using Donors after Cardiac Death," 459–463; David P. Mason, "Should Lung Transplantation Be Performed Using Donation after Cardiac Death? The United States Experience," *Journal of Thoracic and Cardiovascular Surgery* 136, no. 4 (2008): 1061–106; Jim Ritter, "Loyola Transplant Surgeon Pioneers New Way to Increase Supply of Organs," *AirWays* 15, no. 2 (May 2008): 4.
28. "Clinton Administration Launches National Organ and Tissue Donation Initiative," HRSA press release, December 15, 1997, http://www.hhs.gov/news/press/1997pres/971215a.html, accessed March 8, 2010; "Organ Donations Increase in 1998 Following National Initiative and New Regulations," Department of Health and Human Services, April 16, 1999, FDCH Federal Department and Agency Documents, accessed via Lexis-Nexis, March 8, 2010; Summary Notes from Advisory Committee on Organ Transplantation Meeting, Washington, D.C., May 6–7, 2004, http://www.organdonor.gov/research/acot_meeting_notes_archive.htm, accessed October 14, 2008; "HHS Announces 7 Pct Increase in Organ Donors in 2001," U.S. Newswire, April 22, 2002; "HRSA Administrator Duke Addresses Organ Donation Breakthrough Collaborative Meeting," US Fed News, December 9, 2004.
29. Wailoo and Livingston, "The Politics of Second Chances," 122; Susan E. Morgan et al., "America's Angel or Thieving Immigrant? Media Coverage, The Santillan Story, and Publicized Ambivalence Toward Donation and Transplantation," in Wailoo, Livingston, and Guarnaccia, *A Death Retold*, 30–31; Gross, "Playing With

Matches Without Getting Burned: Public Confidence in Organ Transplantation," in Wailoo, Livingston, and Guarnaccia, *A Death Retold*, 180; Rob Stein, "Teenage Girl in Botched Organ Transplant Dies," *Washington Post*, February 23, 2003. In 2001, about 1 percent of the total number of transplants in the United States were performed on undocumented immigrants, while about 2 percent of deceased organ donations came from undocumented immigrants. "About 1 Percent of Transplant Done for Undocumented Immigrants in 2001," Associated Press State and Local Wire, March 3, 2003; Shankar Vedantam, "U.S. Citizens Get More Organs Than They Give," *Washington Post*, March 3, 2003.

30. Diflo, "The Transplant Surgeon's Perspective on the Bungled Transplant," in Wailoo, Livingston, and Guarnaccia, *A Death Retold*, 78–79; "Organ Transplants: UNOS Adopts New Policies," American Health Line, July 1, 2003; Tracy Weber and Charles Ornstein, "Faults Found in Four More California Organ Transplant Centers," *LA Times*, November 14, 2006; Matt O'Connor, "Institutions Deny Waiting List for Livers Abused for Profit," *Chicago Tribune*, July 29, 2003; T.E. Hamilton, "Improving Organ Transplantation in the United States—A Regulatory Perspective," *American Journal of Transplantation* 8 (2008): 2503–2505; Weber and Ornstein, "Feds Tighten Transplant Rules, Jeopardizing Programs' Funding," *Los Angeles Times*, March 22, 2007; M. M. Abecassis et al., "Transplant Center Regulations—A Mixed Blessing? An ASTS Council Viewpoint," *American Journal of Transplantation* 8 (2008): 2496–2502.
31. Robert D. O'Neill, "'Frankenstein to Futurism': Representations of Organ Donation and Transplantation in Popular Culture," *Transplantation Reviews* 20, no. 4 (October 2006): 122–130; Susan E. Morgan, "Entertainment (Mis)Education: The Framing of Organ Donation in Entertainment Television," *Health Communication* 22 (2007): 143–151; "Weekly Program Rankings," ABC Television Network Press Release, May 16, 2006, http://abcmedianet.com/web/dnr/dispDNR.aspx?id=051606_06, accessed March 12, 2010; Susan E. Morgan et al., "Family Discussions about Organ Donation: How the Media Influences Opinions about Donation Decisions," *Clinical Transplantation* 19 (2005): 674–682; Victoria Rideout, "Television as a Health Educator: A Case Study of Grey's Anatomy," September 2008, http://abcmedianet.com/web/dnr/dispDNR.aspx?id=051606_06, accessed March 12, 2010; Lauren Movius et al., "Motivating Television Viewers to Become Organ Donors," *Cases in Public Health Communication and Marketing* 1 (June 2007): 3.
32. Thomas Hugh Feeley and Donald Vincent III, "How Organ Donation is Represented in Newspaper Articles in the United States," *Health Communication* 21, no. 2 (2007): 125–131; Tenaya Wallace and Tom Mone, "Television Can Save Your Life," *LA Daily News*, December 3, 2009; Morgan, Entertainment (Mis) Education"; Morgan, "Family Discussions about Organ Donation"; Brian L. Quick, "Coverage of the Organ Donation Process on Grey's Anatomy: The Story of Denny Duquette," *Clinical Transplantation* 23, no. 6 (November/December 2009): 788–793; Kevin B. O'Reilly, "Campaign Targets TV's Skewed View of Organ Donation," American Medical News, September 3, 2007, http://www.ama-assn.org/amednews/2007/09/03/prl20903.htm, accessed March 15, 2010.
33. "The History of Second Wind Lung Transplant Association, Inc.," *AirWays*, November 2005, 13–18; Kathryn Flynn, "Evelyn Heering, Executive Director, Resigns," *AirWays*, November 2005, 8–11.

34. U.S. Transplant Games Participant Testimonials, Press Room, National Kidney Foundation, http://www.kidney.org/news/tgames2010/PressRoom/Testimonials/index.cfm#athlete, accessed March 19, 2010; National Donor Memorial, Honoring America's Organ and Tissue Donors, http://www.donormemorial.org/, accessed March 29, 2010. National Donor Family Council, "Our History," http://www.kidney.org/transplantation/donorFamilies/aboutHistory.cfm, accessed June 10, 2010. Anthropologist Lesley Sharp observed that in the early years of the games the organizers, who feared emotional outbursts from donor kin, tended to invite them but not allow them to speak and tried to keep recipients and donor kin separate. It was health care professionals who worried about the impact of donor kin, not recipients, who were honored to meet them. At the games recipients and donor kin tended to have open, sensitive conversations that helped both parties. Sharp criticized the national donor memorial for being too general, anonymous, and sanitized. Sharp, *Strange Harvest*, 161–169, 177–179, 135, 144–146.
35. Selim M. Arcasoy, "Editorial Introduction: Current State of Lung Transplantation," *Current Opinion in Organ Transplantation* 14, no. 5 (October 2009): 463–465; S. A. Lodhi et al., "Solid Organ Allograft Survival Improvement in the United States: The Long-Term Does Not Mirror the Dramatic Short-Term Success," *American Journal of Transplantation* 11, no. 3 (March 2011): 453; Anil J. Tindade and Scott M. Palmer, "Current Concepts and Controversies in Lung Transplantation," *Respiratory Care Clinics of North America* 10, no. 4 (December 2004): 427–447; David P. Mason, "Lung Transplantation 2007: We are Making Progress," *Current Opinions in Organ Transplantation* 12, no. 5 (October 2007): 451–452.
36. There appeared to be associations between chronic rejection and the number and intensity of incidents of acute rejection, certain infections, early ischemic damage to the donor lung during harvest, gastroesophageal reflux, and poor antigen matching with the donor, so those are all considered risk factors. G. M. Verleden et al., "Is it Bronchiolitis Obliterans Syndrome or is it Chronic Rejection: A Reappraisal?" *European Respiratory Journal* 25, no. 2 (2005): 221–224; Timothy J. Kroshus and Vibhu R. Kshettry, "The History of Lung Transplantation," in Hakim and Papalois, *History of Organ and Cell Transplantation* (London: Imperial College Press, 2003), 217; "Bronchiolitis Obliterans," University of Pittsburgh Medical Center, http://path.upmc.edu/divisions/pulmpath/bron02.htm, accessed March 29, 2010.
37. "Combatting Organ Rejection," Lung Transplant News, Columbia University Medical Center, http://www.columbialungtransplant.org/news_ger.html, accessed March 29, 2010; "Bronchiolitis Obliterans," University of Pittsburgh Medical Center; R. Morton Bolman, III, "Advantage-FK 506: Reduced Chronic Rejection for Lung Transplant Recipients," *Annals of Thoracic Surgery* 60 (1995): 495–496; Ramsey Hachem, "Photopheresis for the Management of Lung Transplant Rejection," *AirWays* 14, no. 6 (January 2008): 1–2.
38. Arcasoy, "Editorial Introduction"; "Proteins May Predict Lung Transplant Rejection," The American Physiological Society, http://www.the-aps.org/press/conference/ftlauderdale/7.htm, accessed March 30, 2010; Mason, "Lung Transplantation 2007."
39. Douglas E. Wood, "Lung Volume Reduction Surgery: Tempest in a Teapot," *Journal of Thoracic and Cardiovascular Surgery* 125, no. 3 (2003): 457–459; Jorge I. Mora and Denis Hadjiliadis, "Lung Volume Reduction Surgery and Lung Transplantation

in Chronic Obstructive Pulmonary Disease," *International Journal of COPD* 3, no. 4 (2008): 629–635; A. Fishman et al., "A Randomized Trial Comparing Lung-Volume-Reduction Surgery with Medical Therapy for Severe Emphysema," *New England Journal of Medicine* 348, no. 21 (May 22, 2003): 2059–2073; K. S. Naunheim et al., "Long-term Follow-up for Patients Receiving Lung-Volume-Reduction Surgery versus Medical Therapy for Severe Emphysema by the National Emphysema Treatment Trial Research Group," *Annals of Thoracic Surgery* 82, no. 2 (August 2006): 431–443; Anne Barnard, "Emphysema Surgery Questioned," *Boston Globe*, August 28, 2001, C4; Scott D. Ramsey and Sean D. Sullivan, "Evidence, Economics, And Emphysema: Medicare's Long Journey With Lung Volume Reduction Surgery," *Health Affairs* 24, no. 1 (January/February 2005): 55–66.

40. Edwin K. Silverman and Robert A. Sandhaus, "Alpha-$_1$ Antitrypsin Deficiency," *New England Journal of Medicine* 360, no. 26 (June 25, 2009): 2749–2757; Georges S. Juvelekian and James K. Stoller, "Augmentation Therapy for Alpha1-Antitrypsin Deficiency," *Drugs* 64, no. 16 (2004): 1743–1756; "Augmentation Therapy," Alpha-$_1$ Association, http://www.alpha1.org/whatisalpha1/augtherapy.php, accessed March 30, 2010.
41. Keith Wailoo and Stephen Pemberton criticized the way gene therapy was marketed as a "cure" for CF even though researchers knew it wouldn't cure patients with CF or fix damage already done to their lungs and that the studies were small-scale and done by researchers aware of the financial import of their findings. They described the relationship between medical personnel, CF families, venture capital, and the biotech market as "problematic." After a number of unsuccessful trials, some of the pioneering companies and researchers abandoned gene therapy efforts for CF. Wailoo and Pemberton, *The Troubled Dream of Genetic Medicine; Ethnicity and Innovation in Tay-Sachs, Cystic Fibrosis, and Sickle Cell Disease* (Baltimore: The Johns Hopkins Press, 2006), 66, 81, 99–102, 110.
42. Jane Davies, "Clinical Reviews: Cystic Fibrosis," *British Medical Association* 335, no. 7632 (December 15, 2007): 1255–1257; Cystic Fibrosis Foundation, "Drug Development Pipeline," http://www.cff.org/research/DrugDevelopmentPipeline and "Research Milestones," http://www.cff.org/ResearchMilestones, accessed April 2, 2010.
43. Quoted in "Research in Pulmonary Hypertension," Pulmonary Hypertension site, http://www.phassociation.org/Page.aspx?pid=526, accessed March 30, 2010; "Breakthrough for Fatal Lung Disease," Ivanhoe Broadcast News interview with cardiologist Michael Kutryk, February 4, 2008, http://www.ivanhoe.com/channels/p_channelstory.cfm?storyid=17988, accessed March 30, 2010; Ronald J. Oudiz, "Pulmonary Hypertension, Primary," eMedicine, http://emedicine.medscape.com/article/301450-print, August 29, 2007.
44. Pulmonary Fibrosis Foundation, "Research," http://www.pulmonaryfibrosis.org/research, accessed June 13, 2011.
45. "Breathing Life into Damaged Lungs; World-First Technique Will Expand Lung Donor Organ Pool," Toronto General and Western Hospital Foundation, December 19, 2008, www.tgwhfa.ca/newsmedia/news/2008/2008-12-19_exvivolung.asp, accessed January 21, 2009; "Growing Organs for Transplant Closer to Reality; Tissue-engineered Bladders Successfully Implanted," *Transplant News*, April 17, 2006, http://findarticles.com/p/articles/mi_m0YUG/is_7_16/ai_n17212525/, accessed

April 5, 2010; Sheryl Ubelacker, "Teen had Artificial Lung, Now Playing Soccer Again," *The Canadian Press*, February 17, 2009; "U-M laboratory Receives Grant to Prepare Artificial Lung for Clinical Trial," University of Michigan Health System Newsroom, August 3, 2007; Robin Turner, "Revolutionary Artificial Lung Set to Save Thousands of Lives," *Wales News*, December 24, 2008, http://www.walesonline.co.uk/news/wales-news/2008/12/24/revolutionary-artificial-lung-set-to-save-thousands-of-lives-91466-22542628/; "Scientists Create 'Portable Lung,'" BBC News, March 9, 2009, http://news.bbc.co.uk/go/pr/fr/-/2/hi/uk_news/wales/7931243.stm, accessed April 5, 2010; Martin F. Downs, "Artificial Lung Closer to Clinical Trial," WebMD Lung Disease and Respiratory Health Center, http://www.webmd.com/lung/features/artificial-lung-closer-to-clinical-trial, accessed April 4, 2010.

Index