

## PRAISE FOR *RAISING LAZARUS*

"*RAISING LAZARUS* IS THE RAREST KIND OF BOOK—a candid memoir of desperate illness and uncertain healing that manages, without a trace of self-pity or the common swagger of the battlefield veteran, to be both riveting as a story and profoundly encouraging to other threatened human beings: which is to say, almost everyone alive. I don't know of a man or woman who couldn't learn from it."—Reynolds Price

"...ROBERT PENSACK, MD HAS OPENED THE LID OF HIS SOUL and let us all have a good, long look inside. And when we look away, we find that we cannot look at anything else in quite the same way anymore. The sheer, incredible depth of his honesty gives the reader the closest thing to actually understanding what it feels like to battle against an inexorable disease for thirty years and come out on top."—*Colorado Medicine*

"THIS MOVING STORY OF A PHYSICIAN'S PERSONAL EXPERIENCE WITH ILLNESS is written with a rare combination of honesty and empathy for patients and their doctors. The authors have captured the loneliness and fear of bearing a hereditary illness, as well as the remarkable courage of one patient's struggle to survive."—*The Lancet*

"IN HIS IMMENSELY MOVING ACCOUNT, [Pensack] combines inspiration with cutting-edge science to produce a work that ranks with the very best of medical memoirs."—*Library Journal*

"ABLE TO HEAL OTHERS BUT NOT HIMSELF, physician Robert Pensack published a moving account of his lifelong struggle with congenital heart disease in *Raising Lazarus*."—*People*



*Sometimes, illness is a conduit through which we redefine our lives. Such is the case of forty-four-year-old Robert Pensack. Raising Lazarus is a portrait of life that signals one man's defiance of death, and his physical and emotional resurrection. Through Pensack's existence, we come to consider and value the true wonder of the ordinary in our own lives...*

At age fifteen, Pensack was diagnosed with HCM, an enigmatic heart condition that haunted his family's bloodline for three generations. In order to save himself, he became a doctor—and his own best patient. After undergoing multiple surgeries in his twenties—one which left a hole in his heart—Pensack finally had to have a heart transplant.

While waiting for a donor, Pensack met Dwight Arnan Williams, a writer who—through hundreds of hours of interviews before and after the surgery—collaborated with Pensack to trace this heroic journey to overcome a failing body through the will of the mind. A journey of one brave man confronting the frailty and preciousness of life.

## RAISING LAZARUS



ROBERT JON PENSACK, M.D.  
AND DWIGHT ARNAN WILLIAMS

# RAISING LAZARUS

**A Memoir**

AN AUTHORS GUILD BACKINPRINT.COM EDITION

*Raising Lazarus*  
*A Memoir*

All Rights Reserved © 1994, 2005 by Robert Pensack

No part of this book may be reproduced or transmitted in any form  
or by any means, graphic, electronic, or mechanical, including photocopying,  
recording, taping, or by any information storage or retrieval system,  
without the written permission of the publisher.

AN AUTHORS GUILD BACKINPRINT.COM EDITION

Published by iUniverse, Inc.

For information address:

iUniverse, Inc.

2021 Pine Lake Road, Suite 100

Lincoln, NE 68512

[www.iuniverse.com](http://www.iuniverse.com)

Originally published by Riverhead Publishing

**The characters in this book are real, but the  
names and identifying characteristics of some  
have been changed in order to protect their privacy.**

**The authors gratefully acknowledge permission to reprint the poem  
“To Remember Me” by Robert N. Test; reprinted courtesy of The Living Bank.  
First published in *The Cincinatti Post***

**Book design by Fritz Metsch**

ISBN-13: 978-0-595-34952-4

ISBN-10: 0-595-34952-8

Printed in the United States of America

## ACKNOWLEDGMENTS

The writing of this book has been both a catharsis and a re-immersion into many painful memories. I am indebted to more people than I can list here. Many of them appear within these pages.

During my prolonged illness there were many who generously offered loving assistance in the care of my children: Mrs. Julie Gelfond and the staff of BMH Synagogue Preschool; the BMH Synagogue congregation and Rabbi Stanley M. Wagner; Ms. Sam Mask; Ms. Lisa Kurowski; the Berman, Peterson, Dekoven, and Pesch families. Of special note, my eternal thanks to Vicki, Michael, and Chris Carrington.

I must also express my gratitude to the people of Steamboat Springs, Colorado, and to the staff of Routt Memorial Hospital, whose selflessness and kindness were without boundaries. I would also like to single out Larry and Margy Bookman as well as Annie Jeckel for their special help during the time of my family's greatest need.

For spiritual guidance and their genuine concern for my well-being, I want to express my appreciation to Rabbi Mordecai Twerski and Zalman Torneck.

To all of my family members I owe the highest level of gratitude for being there for us: to my father, Harvey, who taught me about tenacity and perseverance, and his wife, Joan Pensack; my sister Laurie Pensack and her husband, Johnnie Dirden; to my

## ACKNOWLEDGMENTS

brother Richard Pensack for his help and critical editing of the manuscript; to my aunt and uncle, Judy and Irwin Pensack, for a lifetime of support whenever I needed them.

My acknowledgments would not be complete without mentioning my indebtedness to my agents, Mark Joly and Arthur Klebanoff, whose critical advice on literary matters was indispensable.

I would also like to thank my editors at Putnam, Laura Yorke and Eileen Cope, and at Riverhead, Julie Grau and Nicky Weinstock.

My special thanks to Dr. Thomas Starzl for his inspiring and beautifully written foreword as well as his personal interest in my welfare.

Finally, my deepest gratitude goes to my wife, Abbe, whose bravery and undying love for me are documented in these pages.

R.J.P.

I have learned the easy way that the greatest gifts a writer can receive at the beginning of his or her career are a mild sense of confidence and wherewithal; I have been so lucky as to have received both from many people. But it is the love and generosity of my mother, Faith Williams-Heikes, and her husband, J. R. Heikes, that have been most meaningful. Also, my brother Rod and his wife, Kim, along with my sisters Jennifer and Theresa, have made a lot of bad loans through the years based solely on hope, and they need to be thanked.

Without the support and literary judgment of a few friends, this book would have been much less than what it is. I would like to thank the entire staff of the *Steamboat Pilot* newspaper, and in particular John J. Brennan, Joanna Dodder, Toni Bufkin, Suzanne Antinoro, Deb Proper, Keith Kramer, Sean Callahan, and Brad Bolchunos. Other close friends need to be thanked as



#### ACKNOWLEDGMENTS

well: Steve and Linda Kozler, Amy Williams, Rob House, Trace Reddell, Diane Miesen, Mark and Audry Small, Dick Gottsegen, Richard Pensack, Lisa Skinner, Bruce Daley, Michael Durian, and Thomas Easterling III. I would also like to thank Dr. Thomas Starzl, one of my medical and literary heroes, for writing such a poignant foreword.

I owe one of the greatest debts I've ever incurred to Bob and Abbe Pensack, whose story will never fail to inspire. They will dwell in my heart for the rest of my days.

Finally, I would like to thank our intrepid agent, Mark Joly, and our hardcover editors, Laura Yorke and Eileen Cope. Their literary acumen is equaled only by their kindness and charm. And thank you too, little Harper Bookman.

D.A.W.



*Raising Lazarus* is dedicated to the thousands of men  
and women who have thought of others in their  
hour of deepest grief and given “the gift of life”  
through organ donation.

This book is further dedicated to my children,  
Max Jacob and Miriam Rose,  
and my loving wife, Abbe,  
without whom Lazarus would never have risen.

R.J.P.

This book is also dedicated to the memory of  
Arnan Williams (1932–1991).

D.A.W.



## FOREWORD

*Raising Lazarus* is a book that will be read by a variety of people through different lenses. For those who have not been ill, it will be the grand adventure story of a man who at a young age realized, like Christian in *The Pilgrim's Progress*, that he was condemned to a mortal journey laden with an intolerable burden. The burden would be with him on the athletic playing fields which he loved, follow him to the classrooms, and insinuate itself into the most intimate moments of his private life. He had been sentenced to death by a hereditary taint, without being told the exact moment of the execution. Trapped in a personal dungeon, he searched for a crack in the prison wall that would permit him to escape. For this, he needed accomplices. These come and go through the pages of the book in the form of doctors, nurses, family members, and friends.

The incredible near-death experiences along the way would have crushed or driven mad someone with less resiliency. Instead, Bobby Pensack became Dr. Pensack, drifted to psychiatry, and constructed his harrowing experiences into a framework with which to treat victims of war-related and other kinds of life-threatening stress. He, and they too, suffered from terror, not cowardice. The fear was not of dying, which would have been the easy way out, but of vulnerability. Here is where the healthy reader will leave the one who has been through a Pensack experience. Those who have tasted his vulnerability will remember

## FOREWORD

how they also walked through crowded malls or sat in lecture halls, keeping a physical and emotional distance from others, knowing how easily their fragile shell could be discovered and broken. It is this secret world that Dr. Pensack reveals, in which he fought, first to survive, second to retain his sanity, and above all to be useful.

This book also is an epic of progress in the field of transplantation which dawned in 1962 at almost the same time that Bob Pensack's medical diagnosis was made, and reached full bloom in time to save him thirty years later. Remarkably, he played a role in this evolution by helping to produce one of the antirejection drugs with which he was treated at the time of his greatest need twenty years later. Although none of us knew it when he was working on this project in 1972, the time bomb inside his chest was already ticking. At the end of the countdown, the two transplant surgeons who labored all night to reawaken his sluggish new heart were men who had been taught surgery while I was their chief at the University of Colorado.

The coincidence did not end there. In January 1994, Bob Pensack called me with the news that his transplanted heart had been undergoing recurrent rejections, each episode eating away part of its precious function and requiring dose escalation of his antirejection drugs to levels that were degrading the quality of his new life. He had heard of a new drug, still known by a number (FK-506), developed by us in Pittsburgh but not yet released by the FDA, which was superior to anything previously available. A visit was arranged, and I was startled to see this vital young man for the first time in many years. The drug switch was carried out without incident, followed by a happy phone call a few weeks later reporting that the biopsy was free of rejection. The theme of "physician heal thyself" was intact.

This remarkable book came from the memories of Dr. Robert Pensack, translated through the words of his talented literary

## FOREWORD

collaborator, Mr. Dwight Williams. Those who go through its pages will find the experiences and lessons lingering in their own minds whether or not they have a particular interest in medicine.

THOMAS E. STARZL, M.D., PH.D.

*Dr. Starzl is the founder and director of the Pittsburgh Transplantation Institute at the University of Pittsburgh School of Medicine. In 1967 he performed the first successful human liver transplant at the University of Colorado School of Medicine in Denver. He is one of the pioneers in the field of human organ transplantation, and author of The Puzzle People (1992), his memoirs as a transplant surgeon.*





*I sing of warfare, and a man at war.*

—VIRGIL,

*THE AENEID*

*I am Lazarus, come from the dead,  
Come back to tell you all, I shall tell you all.*

—T. S. ELIOT,

“THE LOVE SONG OF J. ALFRED PRUFROCK”



PRELUDE TO A  
RESURRECTION



# I

---

Hold me in your mind's eye: a forty-two-year-old man lying on his kitchen floor in the aftermath of disease that has haunted a bloodline for three generations. Max, my three-year-old son stands over me, his small arms stiff at his sides, the smooth crown of his forehead crimped in wonder. He casually asks what Daddy's doing on the floor, but I cannot answer him. Apart from the convulsions of my heart and a fist I throw against my chest, I am calm. I feel about me a static serenity, as though time were arrested, my life frozen in the act of collapse. When it comes to facing mortal threat I can say without pride or arrogance that I do it with infinite equanimity; familiarity has bred a measure of acceptance and comfort. So in the dim light of waning consciousness I want to take in the face of my son.

Max.

In my field of view he appears large and omnipotent. His feet seem incommensurably wide, his head diminished as though hovering miles above the narrowed shoulders. Time is dilated, somehow congruent with the distorted perspective. I have no fear other than that the parting glimpse of his father will be sadly ironic, a pathetic picture burned into his inchoate memory of Gulliver in the land of Lilliput.

Every now and then the calm is interrupted by the strike of a fist, an involuntary yet learned reflex acquired through a lifetime of provisional survival. It is, seemingly, an act of a third person

## RAISING LAZARUS

attempting to coerce the ventricles to synchronize their work. Nausea rushes up like a wave from abdomen to face, sweat pearls along the temples. Eventually Max's face fades, and when it does the spectral memory of my mother assumes its place. It abruptly occurs to me that I have outlived her by eleven years. The same bug in the genetic code that showed itself to her as a young woman has finally crippled me in my manhood. *Blood of my blood, flesh of my blood, memory of my flesh.* It is our family's baneful legacy.

Continuity of thought fades, only to return in brief serried episodes. Visions both real and imagined vanish and are magically replaced by voices and the rumble of nearing feet over the floor. Then, as if out of the ether of unmade history, my wife's face appears above me, startled, with our infant daughter, Miriam, on her hip. She hysterically summons an ambulance on the portable phone, pounding out the numbers with her thumb, the receiver cradled in the valley of her palm. She then sits beside me, asks simple questions, slowly assumes composure, and eventually an erratic rhythm returns to my chest. As she holds a cool dishrag to my forehead I see her eyes are glazed with fear, her voice broken. I try to gather small bits of poise which she instantly picks up on. So long as I lie still and quietly allow this sick heart to stir warm blood through my body, the mind thrives, the senses come alive. Concentration is needed, calm.

For thirty minutes I lie still on my back as if floating on the ocean, warding off intrusions of claustrophobia, breathing with care. Eventually the sound of paramedics' boots rushing up the stairs fills the kitchen. Abbe leads them to where I lie, utterly still but for my blinking eyes. My heart continues to race, but with a coordinated rhythm. A gurney is quickly brought in and set parallel to my body as a circle of faces forms above me. I tell them I'm a doctor, that this is not a typical heart attack, that I know exactly what's going on. Nobody at the hospital knows

## PRELUDE TO A RESURRECTION

much about this disease. As if in an attempt to defuse the tension, one of the paramedics asks what my specialty is. As he presses two fingers against my neck, sensing the tentative pulse, I tell him I'm a psychiatrist. "Really?" he says, incredulous, as though thinking, a shrink dying on his kitchen floor before his wife, son and daughter. . . .

They carefully lift me by the shoulders and ankles onto the gurney and haul me down the staircase to the ambulance. Outside it is fall, the valley floor brilliant with color. The autumn sun stands over the distant mountains, the perfect blood orange poised to glide into the jagged purple horizon. I inhale as the stretcher tosses to the rhythm of the paramedics' heavy steps, taking it all in. There is a sad realization that charges this attack with a certain finality. I am on my way to a hospital; I may never be outside again.

I see Abbe's eyes gazing down on me as the sirens come to life. We have a wordless moment together while the hue and cry haunts the distance like a dim memory that has suddenly been awakened in us both. I keep my eyes on her, impressing this picture of my wife in memory, instilling it with meaning. At the hospital friends who are doctors and nurses crowd about the stretcher. I joke with them, make light of it all, though my shaky voice gives me away, then the emergency room doctor asks a suit of questions pertinent to this disease that he knows I live with. The exchange of information is quick, and finally dovetails into questions concerning my sanity. And what can I say about that? "I'm simply trying to keep it all together," I tell him.

A few tests are done in the ER suite, then I'm moved up to a private room at the far end of the hallway. It's a small rural twenty-bed hospital and quiet anyway, but the added seclusion is a display of consideration. Gradually it is decided upon that the arrhythmia was brought on by sleep deprivation, and that I should remain in the hospital for a while because here they have

## RAISING LAZARUS

electricity, your best friend during such an attack. Sleep and electricity.

The room quiets once everyone leaves. My wife turns out the light, then lies down in the cool darkness on the bed next to mine. She drifts into sleep while I lie awake watching the steady rise and fall of her sleeping silhouette and listening to the soft whistle of her passing breath. I curl into thought, my mind lost in that state somewhere between sleep and wakefulness. If I close my eyes and allow my mind to trip backward, I can feel the closeness, the nearing of all those malevolent stories, sense my proximity to danger, as though moving into a valley rumored to have been visited by cholera or the plague. The steady ictus of my heart fills my ears. I wonder if this is it, if this has been my trip to the bitter end.

For eight months now I've been waiting on a heart transplant list, reduced every night to gleaning the television channels for the unhappy news of a fatal car wreck, a burglary, a suicide—anything that may yield a clean head wound, leaving the heart unblemished and the brain effectively dead. This seemingly aberrant behavior isn't unique to me. On the contrary it is common among those on heart transplant lists. I know because they have openly shared this with me without pause or shame.

In my case the memory of my mother's blood has manifested itself in my heart, gradually reducing me to an invalid, and finally a cannibal of sorts. The progress of days has led to exile. In order to live I must do so beyond the realm of nature and common human experience, so I have developed a kind of blood-sense. Through it all I have experienced the isolation of those who have seen too much, whose victories were all Pyrrhic victories. What I have come to know with terrifying intimacy isn't something that can be shared around dinner tables. The traumatized Vietnam veteran, the Holocaust survivor with flat, distant eyes—these are my people, those with whom I feel kinship. Mor-



#### PRELUDE TO A RESURRECTION

talities, like love, are something that can come to be known only by way of experience. Through a lifetime I have been in the process of dying, consistently surprised when reminded that life is appallingly brief, and briefer still for me. The prospect of an early death has amounted to little more than embarrassment and loneliness, even though the routine of living can be, and usually is, just one goddamn thing after another. A new heart was somehow supposed to be my bloody-red carpet of victory.