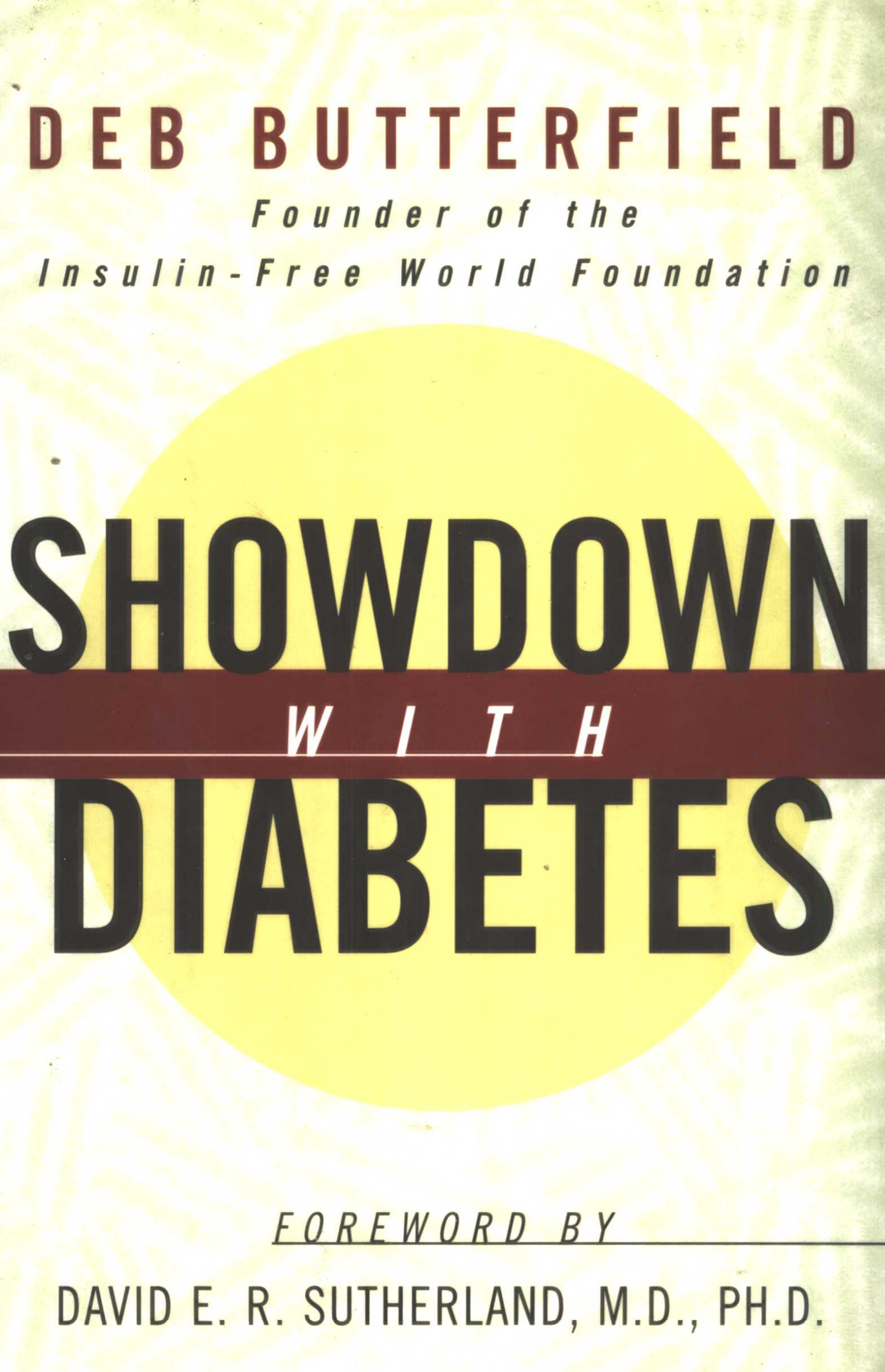

DEB BUTTERFIELD

Founder of the
Insulin-Free World Foundation

SHOWDOWN
WITH
DIABETES

FOREWORD BY

DAVID E. R. SUTHERLAND, M.D., PH.D.

Showdown with Diabetes

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Foreword

by David E. R. Sutherland, M.D., Ph.D.

Showdown with Diabetes relates two odysseys. The first is the personal odyssey of Deb Butterfield as she traverses a road with diabetes from a condition to a disease, degenerating into disability, and finally a successful uphill battle to insulin independence with a pancreas transplant. The second, a story within a compelling story, is the epochal one of advances in the understanding and treatment of diabetes in this century, the misconceptions of how diabetes affects individuals, and the limitations of our current therapeutic options.

I met Deb for the first time at the University of Minnesota Hospital pretransplant clinic in 1993, where she came as a candidate for a pancreas-kidney transplant to treat insulin-dependent diabetes mellitus. In spite of her advanced diabetic complications, she sat with a big optimistic smile as we discussed the mechanics of a double organ retransplant. Deb is typical and atypical of the diabetic patients I have treated with pancreas transplants over the years. She is typical in that, like most people who ultimately succeed in achieving their objective of insulin independence, she fought through layers of naysayers. Yet Deb is atypical in her extraordinary ability to express her feelings, to strip away the myths surrounding diabetes, transplants, and related matters, and to rally others to action to improve the lot of diabetics, both *today* and tomorrow.

I have been involved with transplants for people with diabetes for more than twenty years. A small cadre of transplant surgeons took on the challenge in the 1970s, and now, in the 1990s, approximately eleven thousand pancreas transplants have been done worldwide. It is the only treatment that consistently—in nearly 90 percent of the cases—induces continuously normal blood-sugar levels without the need for insulin, meal planning, or blood-glucose monitoring.

Only one percent of the cells in the pancreas, the islet cells, are involved with insulin production. Thus, even as pancreas transplantation was evolving into a highly successful treatment of diabetes, an army of investigators has been researching how to achieve insulin independence with a technology requiring only a simple, lasting injection of islets. This, too, can work, but currently only 10 percent of islet recipients have become insulin independent. Both pancreas and islet transplants require the use of drugs to prevent them from being rejected by the immune system. Much of today's research to cure diabetes is directed at the longer-term prospect of eliminating the need for these drugs. *Showdown with Diabetes* addresses today's treatment choices and sheds light on the decisions that diabetic people must make as to whether to forego actual advances in treatment while waiting for the promise of others that may be "just around the corner."

Through her personal story and her analysis of the benefits and shortcomings of insulin in Part 2 of her book, Deb provides insights into the paradox of how advances in technology to manage diabetes have shifted the responsibility for the disease from the ailment to the person who has it. Of course, tight control may delay or decrease the probability of developing secondary complications of diabetes. However, to attempt this level of control, the diabetic individual must rigidly adhere to a schedule of medical management that is incompatible with the roller coaster we call life. I agree with Deb: The burden of living with diabetes is often grossly underestimated by even the doctors and nurses directly involved. It is more than finger pricks, injections, and meal planning. It is living in the shadow of the debilitating, long-term complications of the disease—and of knowing that even one's best efforts may be insufficient to prevent them.

The objectives of modern research should be to free diabetic people from this burden. Prevention of diabetes in the first place is the ideal. Failing that, transplantation of insulin-producing cells, either within an intact pancreas or as an injection of cells, must do. Better yet would be to circumvent the need for ongoing drug therapies by regenerating the ability of a person's native islets to produce insulin. But, as *Show-*

down with Diabetes explains, right now only pancreas transplants are a reality, and although they cannot cure diabetes, they are a better treatment for many diabetics than intensive insulin management. Pancreas transplantation is wholly underutilized. It works. And until something better comes along, labile diabetics and those prone to complications—if not any diabetic patient—certainly should consider it. Deb's experience of living with diabetes and of achieving insulin independence with a pancreas transplant highlights the crux of today's treatment choices—do the side effects of immunosuppression exceed the problems of diabetes? It sheds light on the judgments, probabilities, and informed consent inherent in these choices.

Deb's mission is not simply to tell her story; it is to create awareness of what diabetes really means to the individuals afflicted and what solutions are available now, and to indicate where research is leading us. From *Showdown with Diabetes* to her work as the executive director of the Insulin-Free World Foundation, the nonprofit organization she founded, Deb wants what we all want—an insulin-free world. She wants the portions of her story that are common anecdotes—the uncertainties, complications, and restrictions of diabetes—to be uncommon anecdotes. She wants those elements of her story that are uncommon—achieving insulin independence—to be common.

Preface

> Chronic illness is at the same time a personal misfortune and a sign of progress.
>
> —*Cheri Register,* Living with Chronic Illness

Diabetes mellitus is a chronic disease that is characterized by the body's inability to regulate blood-sugar levels. A person becomes diabetic when the body can no longer properly metabolize food into energy. The two most prevalent forms of diabetes are Type 1 and Type 2. People with Type 1 diabetes, and 10 percent of the Type 2 diabetic population, require insulin injections to survive. Both types lead to secondary diseases of the nerves, eyes, kidneys, and heart. The cells that regulate sugar levels in the body fit in a thimble with room to spare, but when I was a child these cells were destroyed by my immune system, and my life was irrevocably changed by Type 1 diabetes.

I was relegated to a lifetime of trying to substitute for that tiny mass of cells by controlling the amount of sugar in my blood with insulin injections, dietary restrictions, and blood-glucose tests. It was in large part guesswork based on how food, exercise, excitement, illness, stress—indeed, all of life's variables—would affect my metabolism. And the stakes were high. Uncontrolled blood-sugar levels lead to a host of disabling complications: blindness, amputation, kidney failure, heart attacks, strokes, and premature death. Every twenty-four hours in the United States alone, diabetes causes 75 people to go blind, 80 to suffer kidney failure, and 150 to need amputations. Diabetes kills one American every three minutes; every year 2.8 million of the world's citizens die from diabetic complications. I was not alone in my childhood diagnosis. Diabetes is the leading chronic ailment among American children. Today, 135 million people worldwide have diabetes, and the numbers are rising at an alarming rate. The majority, 85 percent of those who are diagnosed with diabetes, have no prior family history of the disease. In the last forty years the incidence of diabetes has tripled, and in the next twenty years it is expected to double again. Diabetes is truly a global epidemic.

Showdown with Diabetes recounts my odyssey from the time I was ten years old. Thus, the story that follows has a course and texture familiar to anyone confronted with the relentless permanence of a chronic disease. Like a runner in a marathon, I left the starting gate believing that I could overcome the challenges of diabetes, not knowing that those challenges would become bigger, much bigger, as time wore on. As a child and then as a teen I hid my diabetes, ricocheting between denial and submission, furtively managing the multiple injections, blood-glucose tests, and doctors' appointments behind a smokescreen of bravado. But diabetes didn't slow me down. I traveled the world, snow-skied, water-skied, hiked in the Rockies, swam in the Caribbean, graduated from university and worked on Wall Street—never thinking that eye, nerve, kidney, and heart disease happened to "healthy diabetics" like me. Fifteen years into the race I felt invincible and, with no signs of secondary complications, I believed I had beaten the odds. But just as marathon runners hit a "wall" of exhaustion as their bodies' fuels are depleted, I ran headlong into a wall of secondary complications. As a young professional, I juggled my career with my secret ritual of needles and secondary diabetic complications, all the while fighting off the disruptive episodes of diabetic shock caused by low blood sugar that punctuate the lives of most diabetic people.

Within a four-year period diabetes killed the nerves below my knees, caused bleeding in the back of my eyes, the amputation of part of a toe, a skin graft, and had reduced me to needing assistance to walk. Every time something went wrong I said to myself, "If this is the worst that ever happens, I'll be fine"—but it wasn't the worst. Diabetic kidney disease set in, and every system in my body started to close down. I combed through reports of imminent cures and scientific testimonials offering "promise" and "hope." It always seemed that we were on the verge of a stunning breakthrough, but I could find no usable solutions. My career began to suffer and, living alone, unable to drive, and barely mobile due to neuropathy, the nerve disease that affects 60 percent of the diabetic population, I became a recluse. My life with diabetes became a macabre race against time as I progressed toward disability.

But here the trajectory of my story tracks in a direction largely unknown to the diabetic community; I was freed from my life of needles, restrictions, and progressive deterioration by a pancreas and kidney transplant. No more insulin injections, dietary limitations, or blood-glucose tests, yet my blood-sugar levels are normal—nondiabetic. Best of all, I am living the kind of life that I thought had passed me by. Married now, and with an expectation of a healthy future before me, I look forward to a long life with my husband. We travel widely for pleasure as well as for work, and even the simplest joys are now mine for the taking: ice cream cones on hot summer days without needing to inject insulin, long bike rides without worrying about insulin shock, and good enough vision to drive at night. I came back from the darkest of my days with diabetes to the freedoms, health, and sense of future that I had all but lost to diabetes' insidious attack.

At the end of 1996, my husband and I founded the Insulin-Free World Foundation, a nonprofit charitable organization that provides information on how advances in clinical diabetes can benefit people with diabetes now and in years to come. We have a focused objective—to act as an information exchange by compiling and redistributing information to bring science closer to people whose lives depend on it.

Today, more than seventy-five years after the first *treatments* for diabetes, we have entered the era of *cures*. Every year more than twelve hundred people are choosing to have pancreas transplants, with more than 80 percent of them being freed from their lives with diabetes. For one out of three people who live with diabetes, traditional management techniques cannot and will not prevent its deadly progress. Still, many of those in its viselike hold—joined by a medical establishment and a multi-billion-dollar maintenance industry—continue to direct their energies toward perfecting ways to live with diabetes rather than toward simpler, safer, and less expensive ways to cure it.

My objective in sharing my story is to expose diabetes so that the world will know that it is a deadly disease and that eradicating it must be a national, and international, priority. For people who are living with diabetes, I hope that my story—from diagnosis, to secondary complications, to an insulin-free life—will serve as a fire drill. Although most diabetic people will never need a pancreas transplant, it is important to know that, just in case, it is an option—and that research to improve on this solution is progressing quickly.

Part 2 of *Showdown with Diabetes* looks at the evolution of diabetes from the beginning of the twentieth century, and places the first treatments and cures within the framework of the medical advances that made them possible. For those who have witnessed or benefited from the progress made in the 1980s and 1990s, there is no question that a universal cure for diabetes is both a worthy pursuit and a very real possibility. I hope that *Showdown with Diabetes* helps to promote a community of energies—political, economic, scientific, and humanitarian—where lasting cures can quickly become a reality for all those who live with diabetes.

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Part I

My Story

Prologue

> Most chemists believe that the course of a chemical reaction is always predictable. But some catalytic reactions in both inorganic and organic chemistry can behave in bizarre and unruly ways.
>
> —*Stephen Scott,* Clocks and Chaos in Chemistry

A telephone ringing nearby jarred me from a comatose sleep. The clock said three o'clock. It was teatime in London. I lay still, looking around the strange room; it was a hotel room. I was wearing my business suit. There were pages of notes beside me on the bed. Oh, no! Had I missed the meeting—and my presentation? I should have been there three hours before! I noticed two empty orange juice cans. And a candy wrapper. Had I had an insulin reaction? Yes. I remembered something. I *did* have a reaction—in the middle of my presentation! Had I embarrassed myself? What had I said? I answered the telephone wondering if it was someone from the meeting calling to tell me what had happened. It was. It was the managing director calling