



INTRODUCTION

By all accounts I am a successful and accomplished woman. As founder of a national nonprofit organization, I have met with presidents, movie stars, and best-selling authors. But the reason I am alive today, my body stealthily involved in the silent, miraculous business of life, is because of an invisible gift that has been bestowed on me not once, but twice. As a lupus sufferer since the age of fifteen, I had kidneys so damaged that I've required two transplants—one when I was twenty-one and the other when I was thirty-five.

Tucked inside me at the moment are two tiny kidneys—my second transplant—from an eight-month-old boy whose name and identity I'll never know. In time, doctors assure me, these kidneys will mature and grow in me, as they would have grown in him, and develop into adult-size organs that will flush waste products and toxins from my body.

I don't know my kidney donor's name, where he came from, or how he died, but sometimes I try to imagine him: I see him pale-haired, dressed in a blue outfit, raised in a warm climate.

I can't allow myself to imagine the details of

his death or the anguish of his parents. Yet I can still sense the compassion and love that allowed them to pass along this supreme gift to a stranger suffering from lupus-related kidney failure—tiny organs, dispatched without payment, or return receipt, into a universe of need.

A singular act of grace.

A year from now I will be allowed to write a letter of thanks that will be forwarded to these parents. This is a scene I like to visualize: my envelope being torn open, my note unfolded, my words, pressed into vellum with ballpoint, absorbed into the minds of this couple. I think of them reading in window light, perhaps with a new infant in their arms.

There's a theory in science called Bell's theorem, which claims that two particles once connected are never separated, that they are stuck together by something called space entanglement. This exists in the real world, but we can't see it. But I imagine such a connection with these phantom parents—that we are united in the web of love that is always below the surface, waiting to be perceived.

Humans come equipped with pairs of limbs and organs—eyes, legs, lungs, and ears, but only one of these sets, the kidneys, includes an organ that can be considered a spare. Perhaps due to the nature of our prehistoric diet, we possess more functioning renal tissue than is necessary for survival. Because of this, it's possible to live a full, healthy life with a

single kidney.

What's impossible is living without one.

Kidneys are the only human organs that can be donated from live donors—other organs require that the donor be deceased.

I'm in the rare—and lucky—category of having been the beneficiary of both types of organ donations, from the living and the dead. In 1992, my sister Bonnie gave me her left kidney, offering it up to me with the same sisterly devotion she had always bestowed on me.

It has been suggested that the cells of living tissue may have the capacity to remember and memorize characteristics of the person to whom they once belonged. I've read studies of transplant recipients who acquire strange new abilities, characteristics, and powers similar to their donors'—a man who could suddenly speak Spanish, a woman who gained the ability to paint.

I've had no experience with this kind of cellular memory, no sudden flashes of new talent, although I briefly hoped after my sister's donation that I might acquire some of her ability to sing. What I have been left with is a profound sense of duty to pass on the lessons that I've acquired on my twenty-year journey from illness to health.

THOSE OF US who face chronic illness remember the before and after moments: the day the phone rang, or the doctor walked into your hospital room,

and it was clear that life as you had known it was about to change. You discover that you have cancer or multiple sclerosis or that your child has been stricken with leukemia. You hang up the phone or walk out of the hospital feeling as if your world has been transformed. It's not simply fear that makes you so disoriented—it's because you are in the midst of experiencing a true glimpse of the great preciousness and precariousness of life.

Falling ill is like joining a private fraternity—one you would never enter voluntarily, but whose membership reveals profound truths that most of us are too busy rushing through our days to consider. In the midst of everyday life, you are suddenly jolted by your own fallibility and finiteness, by the fact that you are no more durable than the shoes on your mortal feet.

In a culture that manages to cordon off this reality as if it were the special circumstance of others, you perceive all at once that this is your fleeting, precious human life. And then it's as if a veil has been ripped from your eyes. As the poet Rilke wrote: "Just once for everything, only once."

A person doesn't have to fall ill or experience great adversity to have such realizations. But the way humans are wired, it often requires such a shock to knock off the blinders of complacency and self-absorption. It is in the face of suffering that so many of us are thrown into the depths of ourselves,

and come up bearing treasures of strength, insight, and courage we never knew were there.

When I first was diagnosed with systemic lupus, I yearned for something specific—to connect with others who knew what I was experiencing. If I couldn't find them in the flesh, then I wanted to read about them, real people like me who'd struggled and survived. I didn't want romance or fiction, but true stories about transformation and courage. Before I formed my own nationwide support network, I wanted to read words that would help heal and inspire me.

But when I was young, these kinds of books were hard to find.

“If there's a book you really want to read but it hasn't been written yet, then you must write it,” the writer Toni Morrison once said.

So I've set out here to write the kind of book I yearned to read myself, a book made up of separate interlocking stories or vignettes that fit together like links of a necklace.

I'll weave together the inspiration and wisdom I've received from ordinary people and celebrities alike who've taught me not just how to survive chronic illness, but also how to flourish in spite of it: Christopher and Dana Reeve and a nameless hospital cleaning lady who sang “Amazing Grace” to me; Alan Alda, Deepak Chopra, Oliver Sacks, and Naomi Judd. They've made me realize that facing the challenges of illness is really facing the

challenges of life itself.

Along the way, I'll take you through my transformation from a powerless, lonely, and desperately ill teenager, through my formation of a local lupus support group that eventually blossomed into Friends' Health Connection (FHC), the national organization that I founded and ran from my hospital bed and dorm room.

I'll take you along a path zigzagged with the most unusual destinations: one day at the White House Rose garden, shaking hands with President George H.W. Bush, two days later homebound in a wheelchair; one day on Fox television, the next day back in a hospital bed.

I'll share the lessons of valor and hope, courage, and love that have been bestowed on me along the way.

My years of chronic illness have shown me that the private fraternity I thought I was entering wasn't so private at all—it was a club in which most of us would eventually become members, if not ourselves, then through friends and loved ones.

Transplants are miracles of modern medicine, and I've been doubly blessed. I vowed to my sister and the nameless eight-month-old who were my donors that my life would be worth their sacrifice. This book is part of my promise to them.



One

IN THE BEGINNING

I sat at my bedroom window in my wheelchair, watching my high school rowing team pull away from the shore, eight friends smiling and waving as they moved into the choppy water. Not long ago, I'd been one of them.

I loved everything about rowing, the feeling of freedom, the teamwork, the sense of strength and accomplishment. When I rowed, I was at peace and forgot about my problems. Not that I'd had many then. In most ways, I was a typical New Jersey teenager, a shy high school freshman who lived with her mother in a small row house that overlooked Lake's Bay. My mother and I didn't have two dimes to rub together, but with that view from our windows, we considered ourselves rich.

It was after rowing one afternoon that I had the first inkling that something might be wrong with me—a sharp stab of back pain that took my breath away.

“What's the matter?” my mother asked when she saw me wincing.

“I don’t know,” I said, stretching. “I guess I strained a muscle.”

By evening, the pain was excruciating. My mother filled a hot bath with Epsom salts, and later gave me a heating pad. I took a couple of Tylenol and decided I’d stay away from crew practice for a few days. In my young life, this had been the antidote for any ailment. Eventually everything passed, given time and a little rest.

But not this time. Instead of decreasing, the pain grew so intense that I could barely sit up in bed the next morning.

My mother took one look at me and said, “I’m taking you to the doctor.”

But by the time we arrived at the office, the pain had subsided and the doctor advised that we simply continue with the heating pad and baths.

Two days later, I developed chest pains that by evening were so acute I could barely breathe. Now I was beginning to worry.

This time the doctor prescribed antibiotics, thinking I might have an infection. The pains intensified over the next few days, then they too vanished.

This pattern of new symptoms that appeared, intensified, then vanished continued with an itchy red rash, which covered my body. After it mysteriously disappeared, my ankles swelled so severely that I was unable to fit into any of my shoes.

Although the doctor tracked my reports, took

bloodwork, and examined me closely, he couldn't figure out what was wrong. My symptoms were elusive; it was hard to pin them down.

Finally he referred me to a specialist. By the day of my appointment, all my symptoms had subsided except for my swollen ankles. My mother and I arrived at his office, expecting this new doctor would prescribe another medication for what was probably an allergic reaction.

Although I'd never seen this doctor's face before, his cool, sober demeanor as we walked in gave me a sense of foreboding.

After a routine examination, he studied my bloodwork, then touched my ankles, which were so full of fluid they could be molded like lumps of clay.

Then he looked up and a strange word floated from his mouth. *Lupus*. I saw it, like in a cartoon caption, odd and ominous, hanging in the air.

The word meant nothing to me, but my mother's reaction did; she covered her face with her hands. In her work as a nurse, she'd spent years caring for patients with chronic illness. As I watched her sniff and take out a Kleenex, it hit me that this must be serious, something that Tylenol and bed rest weren't going to solve.

My health had always been part of my identity, something I was as certain of as my strong legs and pumping heart. Now I was being told baffling facts about kidney function, inflammation, and antibodies.

But when the doctor said I was to be admitted to a children's hospital in Philadelphia the following day for testing, I realized a chapter of my life was abruptly ending and a new one was about to start.

When I returned home, I looked up lupus in our medical dictionary: a chronic autoimmune disease, potentially debilitating and sometimes fatal, that was first discovered in the Middle Ages. The illness follows an unpredictable course, with episodes of activity, called flares, alternating with periods of remission. During a flare, the immune system attacks the body's cells and tissue, resulting in inflammation and tissue damage.

The words "sometimes fatal" stood out to me, as if they were written in blood. Just as harrowing were the lists of possible manifestations: dermatological, musculoskeletal, hematological, renal, hepatic, pulmonary. What else was there?

How had this ancient disease that only affected one in many hundreds in the United States ended up in Atlantic City, residing in a teenager like me?

For that, there was no answer.

"THERE'S ALWAYS ONE MOMENT in childhood when the door opens and lets the future in," Graham Greene wrote. I don't know if most people remember that moment, but I do.

At the children's hospital, I shared a room with a three-year-old girl with a winsome face and shiny black hair cut in a bob. She was so vibrant and lively,

I assumed she was someone's daughter or sister, until I glimpsed a tiny hospital ID bracelet on her wrist.

Her name was Michelle, and we bonded from the moment we met. She brought a herd of plastic ponies to my bedside and we brushed their manes and made-up stories.

"Why's she here?" I asked when her parents arrived, looking drawn and worried.

"She has a hole in her heart," her mother told me. "She's having open-heart surgery tomorrow."

A steady stream of doctors arrived to talk to Michelle's parents. I heard the terse murmur of their voices behind the curtain that separated our room. Through it all, Michelle dashed between the beds, oblivious to the drama around her. She was so vital and energetic, it was hard to believe that anything serious was wrong with her.

I'd never known a sick child before, and now I was in a hospital full of them. It seemed unnatural seeing toddlers on IVs, babies on ventilators, adolescents with leg braces, struggling to walk. A parade of pediatric malfunction passed my door, children smashed in motor accidents, suffering from muscular dystrophy and leukemia. This alternate world had existed all along, behind my formerly sunny, innocent life.

The next day I was to find out the results of my kidney biopsy, and Michelle was headed to surgery. Before she left, she walked over and hugged me so tightly that I could smell the baby shampoo in her

hair. Then she solemnly handed me a drawing she'd made of a house, a girl, and a tree.

"This is you, isn't it?"

She nodded.

"Well, it's beautiful, thanks. I'll see you later."

I waited all day for them to bring Michelle back, trying to distract myself by reading and crocheting, but it was no use. Breakfast came and went, then lunch, and still there was no sign of her.

Early in the evening, I was talking on the pay phone in the hallway when an alarm sounded, and doctors began running down the hall from all directions. A woman's voice intoned a code over the loudspeakers, a foreign babble.

As I hung up I saw two new figures running down the hallway. Their features grew terribly familiar as they approached. It was Michelle's parents, their faces smeared with tears, heading in the same direction as the doctors.

My mother came out and hurried me back into the room. When she shut the door, I stood there, looking at Michelle's bed, at the picture on the table that she had drawn for me. I took out a little prayer book I'd brought along and began a prayer, infusing it with all the love and intention I could muster. A long, terrible female scream pierced the silence.

A young floor nurse walked in a short while later. Her sad face was statement enough, but then she told us. Michelle hadn't made it. She'd suffered a heart attack and died.

So there it was, and I had to face it: Life wasn't fair. Prayers weren't always answered. The young and innocent could be lost. The door had swung open, and I had been pushed through to the other side.

THE KIDNEY BIOPSY confirmed that I indeed had systemic lupus, the most common and serious form of the disease, and that I was currently in an active stage, or flare. The doctor prescribed very high doses of steroids in an attempt to put the disease in remission. He rattled off possible side effects of these drugs—susceptibility to infection, insomnia, weight gain, depression, sensitivity to the sun.

I still couldn't believe this was happening—that my body, my old friend and companion, was betraying me this way. And what had I done wrong? I'd always been active, eaten well, and rarely even caught a cold or flu. But as in a horror movie where the werewolf watches his body alter in the mirror, mine was turning on me. The doctor's description of lupus—how the immune system actually makes a mistake and begins to attack its own tissues, corresponded with how I was feeling, as if a mutiny were taking place inside me. My own body was attacking and destroying itself.

Apart from the lupus, the steroids caused their own metamorphosis. I sat back, a bewildered observer, as my body transformed itself before my eyes. I rapidly gained weight from a new, steroid-induced appetite, and my face turned moon-shaped

and swollen. My legs were striped with stretch marks from water retention and swelling; my long hair fell out in clumps.

When I passed myself in the mirror, I was stopped short by this pale, swollen creature, who would have a hard time getting into a boat, let alone rowing one.

On rare visits from old friends, I could tell that my swollen body and pill bottles made them nervous. I sat listlessly while they complained about broken nails or pimples or how much they'd spent on a pair of jeans.

I wanted to take them by the shoulders and say, "Listen!" I wanted to tell them about Michelle. But they didn't want to know about this parallel reality. And who could blame them? A few months before, I had also believed we were all golden, that our youth granted us immunity. I wasn't surprised when most of them stopped visiting.

For me, the hardest part of being sick was the isolation. With chronic illness, you enter another country, and it can feel as if you're the only inhabitant. Those you've known before are back on the other side of the mountain, in the carefree valley of the healthy, their oblivious days unmarked by blood tests or CAT scans. No matter how much they try, it's difficult for them to comprehend what you have seen from your new perspective.

I remembered overhearing older people say, "When you've got your health, you've got

everything,” and thinking they were crazy. There were so many other things to want—good looks, clothes, and money. I still wanted all those things, but they had now slid far down the list of what mattered. Illness sharpens your vision and narrows your desires. You can see, all at once, just how precious life is.

ONE AFTERNOON when I hadn't been out of the house for weeks, my mother asked me to ride with her to the grocery store.

I didn't want to be out in public with my thin hair and thick ankles; I was mortified as much by how I looked as by the fact that I was ill.

“C'mon, it'll do you good,” she insisted.

I relented, but laid down in the backseat so no one would see me. As I watched the telephone poles and electric wires pass by, I felt futureless. Self-pity, like a great dark bubble, burst in me. I buried my face in my hands and cried out, “Why me? Why did this have to happen to me?”

My mother studied me in the rearview mirror. “Maybe you got sick for a reason,” she said after a moment. “Have you ever thought of that? Maybe you were meant to help others.”

“What are you talking about? What reason? I'm the one who needs help!”

“Well, just think about it,” she said.

THREE AND A HALF MONTHS LATER, when I returned to school, there were several theories about why I'd

been absent so long. Since I'd left school slender and healthy and returned pale and heavy, the main rumor seemed to be that I was pregnant. As upset as I was by this gossip, I was just as concerned my classmates would discover the truth about how sick I was—or that I had a disease they might not understand.

But it was impossible to camouflage. I was too weak to climb the high school stairs anymore and instead had to take the service elevator. The kids saw me there, in my oversize Nikes, standing with the janitors between the mops and brooms. They saw me on the sidelines at gym class, watching passively while the others ran and kicked balls.

The school was the same, the world was the same, but I was different. I'd become so identified with those who were sick and suffering that I was shocked by how cavalierly my classmates treated their bodies. I'd just been with people who would have done anything to simply feel well again. Now, here were my friends, drinking and smoking, living as if their bodies were eternal, as if they could abuse and misuse them forever.

ONE EVENING WHEN A GROUP of old friends invited me out with them, I climbed into a car filled with smoke and chatter.

“He really called you? What did he say?” one girl was asking, while I shifted in the backseat, trying to find a comfortable way to arrange my painful legs.

En route to one of their houses, we stopped at the supermarket. As soon as we got out of the car and began walking toward the entrance, I realized I couldn't keep up with them. My muscles were weak, and my feet felt like two large stones. The others rushed ahead, their high heels clicking into the distance. They didn't even notice when I fell down in the middle of the busyparking lot.

I was too frail to push myself up so I sat there, knowing it was only a matter of time before a car appeared. Yet I couldn't bring myself to call out for help. It was a sobering truth—I would rather risk my life than admit my vulnerability.

Eventually I crawled over to a parked car, grabbed onto the bumper, and hoisted myself to a standing position. I gradually regained my balance and made my way inside the supermarket where I spotted my friends. I continued to trail behind them and realized they'd never even known I was missing.

In fact, the girl they thought they knew was gone for good.

Of all the many things that pained me about my illness, this was the most acute—saying good-bye to this former self, to my adept and strong body. I knew that in order to survive I'd need to find something equally compelling to which to say hello.

Was there anyone who could identify with how I was feeling, who'd been diagnosed with this disease that made me feel like a stranger in my own

body? My doctor patiently answered my questions, and my mother consoled me all she could. But I yearned for something specific—another person who had literally been in my shoes—the large male Nikes, which now were the only shoes I could wear.

And if there were such people, how would I ever find them? This was before personal computers were common, let alone the Internet.

My mother's words kept echoing in my mind: maybe there was a reason.

I'd always been active in fundraising. Whenever the Jerry Lewis Telethon came to Atlantic City, I headed out to the boardwalk on weekends to solicit donations. In elementary school, I'd raised more money than any other kid in the school for the MS Read-a-thon. But those had been other people's diseases; now I had my own.

Even at fifteen, I realized I desperately needed companionship and connection. I made a decision: if there were no support groups in our area, I'd have to start one myself.

I had been regularly seeing a lupus specialist, Dr. DeHoratius, who was based in Philadelphia, and I asked if he'd agree to give a lecture. Once he was onboard, I lined up the community room in our local library. Then I notified the health reporter at the local newspaper, and she agreed to write a feature article publicizing the event.

On the day of the lecture, my mother and I

arrived at the library early and stood in the empty community room. All of a sudden, I wondered what I was doing. What if nobody else showed up?

Instead of anxiously watching the clock, I walked over to the nonfiction section and browsed through a book of quotations.

Words by the poet W. H. Auden caught my eye: “We are all here on earth to help others; what on earth the others are here for I don’t know.”

Of all the passages I could have found that afternoon, this was the one I was meant to find. I repeated the quote in my mind as I walked back to the community room and peered in the window. To my amazement, while I had been gone, the room had filled with dozens of people, row after row of heads, mostly female. I could see their earrings and scarves, the glint of light on their eyeglasses.

So I wasn’t alone, after all.

A thought, then a wish, then a plan, and now here was this concrete reality, a room of living, breathing people.

A feeling welled up in me—one I hadn’t experienced since I’d become sick—a swell of satisfaction, optimism, and purpose.

At that moment, the organization that would be the root of my salvation and the answer to my mother’s question was born.