PREFACE

MY STRUGGLE WITH LYME DISEASE

My husband, Tom, and I lost our son when he was two weeks shy of his sixth birthday. Jamie died from a disease the nation's medical and scientific communities thought he could not get. They were wrong.

In 1985, I was bitten by a tick while I was pregnant and soon became ill with a multitude of problems, including a rash, serious joint swelling, profound fatigue, migraines, and intense pain. A physician diagnosed me with crippling arthritis, told me it was incurable, and predicted I would eventually live my life in a wheelchair. He, too, was wrong.

My family's struggle with Lyme disease is a tragedy, but it is also a story of courage and hope. Out of our personal nightmare emerged the Lyme Disease Foundation and nationwide awareness of the risks of tick-borne illnesses.

Jamie was our first child, the blond-haired, blue-eyed light of our life. The day Jamie was born he had his first of many spinal taps, because the doctors saw signs of a brain infection. By the time he was 6 weeks old, he had begun to vomit repeatedly and had alarming eye tremors, indications of an ongoing brain infection. At 6 months, he showed signs of malnourishment because he was unable to absorb his food. Hearing tests showed that he was totally deaf, although we later discovered that was not true. Physicians saw signs of permanent damage in his eyes. Surgery to realign his stomach to stop the life-threatening vomiting was unsuccessful, leaving him with a stomach too small to eat normal meals.

Soon after Jamie's birth, when our struggles through one medical crisis after another were just beginning, a mysterious condition called Lyme disease was emerging. Weeks later it was mentioned as a possible cause of the illness that had plagued me during my pregnancy. I was told that if that were so, a couple of antibiotic pills were all that was necessary to cure me. I was also assured that my infection could not have spread to the child I was carrying. But there were already scientific publications showing mother-to-fetus Lyme infection. Jamie would not be tested until signs of a congenital spirochetal infection were seen in the back of his eyes by a neuroophthalmologist. When laboratory tests were positive for Jamie, our five pets, and me, we

suddenly had some hope. Perhaps a simple antibiotic treatment would curb the vicious onslaught of symptoms.

Over the year, I learned there was nothing simple about treatment, but after repeated doses of antibiotics, I slowly regained my health. For Jamie, it was not to be. At first, he responded to the short-term antibiotic shots but within weeks he relapsed. Local doctors repeatedly resisted our pleas to re-treat Jamie with longer-term antibiotics, warning that the medication itself was dangerous. Tom and I were persistent, and short-term treatment was followed by re-treatment, temporarily improving my son's condition. For a time, he was able to attend kindergarten and he began learning to talk. His muscle tone and vision improved, and he was able to eat again. We were finally finding the little boy inside the ravaged body. We stopped treatment.

Sadly, these gains did not last. In his final weeks of life, Jamie's brain became inflamed. Our son was put on life-support systems, but the swelling could not be controlled. On June 21, 1991, he passed away.

One struggle had ended, but another one continued. In the years that we were fighting for Jamie's life, Tom and I had also given birth to an organization, founded so that others would not have to face hardships like ours. We had been astonished at how little was known about the condition that eventually took Jamie from us. Most scientists did not believe it was possible to transmit Lyme infection in utero, but my own medical search demonstrated otherwise. The breadth of symptoms associated with the illness was poorly understood in this country, and no one knew what to do with patients who did not respond to a single course of antibiotics.

Our personal plight had gained the attention of the television program *20/20*, and countless articles had been written about us in the national and international media. We were the catalyst for making Lyme disease a household term. As our story became known, our telephone began to ring. Hundreds of people around the country were recognizing their own symptoms in the descriptions of Jamie and me, and they wanted to know where to go for help. The response from the scientific community was surprising—researchers studying the disease in isolation from one another were desperate for opportunities to meet with colleagues to talk about the strange tick-borne diseases they were beginning to see. It had become obvious that an umbrella organization was badly needed to find the truth about Lyme disease.

To meet the needs of patients and researchers, we launched the Lyme Borreliosis Foundation in 1988, the first organization in the world dedicated exclusively to Lyme disease. We had searched for an existing organization to work with. We had no desire to duplicate efforts. When it became clear no such nonprofit group existed, we created the foundation as a place for team-

work and a catalyst for change. Three years later, the name was changed to the Lyme Disease Foundation because it was much easier to pronounce. I walked the halls of Congress, telling my family's story, educating representatives about the disease, and explaining why millions of dollars were needed to learn more about it. Senator Joseph Lieberman and Congressman George Hochbrueckner became invaluable partners. Later, Senators Kennedy, Dodd, and Santorum became major leaders, too. Thousands of patients and their physicians contacted their representatives to plead for funding. Together, our efforts were instrumental in securing the first targeted federal funding for Lyme disease education and research. The foundation began to sponsor an annual international scientific conference; made connections with European researchers, where this disease has been studied for more than a century; and for the first time established a network of community educators, support groups, and researchers. This would make one clear, unified voice for us to work together to find real answers.

Through our efforts, and those of other partnerships formed among concerned families and scientific professionals, attitudes toward Lyme disease have begun to change. Today, the medical community is finally addressing some neglected issues. They have awakened to the fact that the bacteria that cause Lyme disease can, under rare circumstances, be transmitted from mother to fetus via the placenta. Patients who do not respond to a single course of antibiotics are now offered other treatment options, although we still cannot predict what will work. Patients are being tested for a wide variety of tick-borne disorders. And attention is finally being paid to prevention strategies that can keep us all safe.

We are a long way from eliminating Lyme disease and other tick-borne infections altogether, but there is no doubting our enormous progress. Armed with the information I have provided in this book, you may now be able to keep your family safe. And I expect the news will keep getting better as science advances and more people become knowledgeable about strategies for personal protection.

Please keep in mind that the disease descriptions in this book include a wide variety of symptoms experienced by various patients. Most patients experience only a few of these symptoms.

To think, it all began with the birth of a beautiful little boy named Jamie. Jamie's gift to the sister he never met is one of prevention and good health. A gift that is priceless.

—Karen Vanderhoof-Forschner