



Women Who Make a Difference

By Marianne Jacobbi



Battling Lyme Disease

"We decided if our son was going to live, it was up to us."

Karen and Tom Forschner had tried for 12 years to have a child, so when Karen learned in November 1984 that she was pregnant, they were ecstatic. Karen, 37, an intensely energetic woman, thought she'd continue as a consultant in the insurance industry until the baby was born, and then cut back to part-time work.

In January, however, she came down with what she thought was a bad case of flu. "I had a fever, with dizziness and stiff joints," she recalls. Her symptoms persisted, and six weeks later she noticed a red circular rash on her thigh. Her doctor said she just had a "bug"; he dismissed the

Photo by Bill Bernstein/Outline

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The baffling illness that struck Karen Forschner when she was pregnant has proved devastating to her son, Jamie, with her here at age 3.

swelling of her knees and ankles as a possible complication of her pregnancy.

But by May, Karen's joints were still badly swollen, and her vision was blurred. On July 7—six weeks before her due date—Jamie was born.

The 7½-pound baby boy appeared totally healthy, but Karen was confined to a wheelchair. "My joints were so swollen I couldn't walk," she says. "And I was having heart palpitations."

By the second day of Jamie's life, he too became ill. "He began to develop swollen glands," Karen recalls, "and

the doctors believed that he had a brain infection." For a short time the baby was treated with antibiotics and seemed to be improving.

A month later Karen saw a specialist in joint inflammations, who diagnosed the illness that had been plaguing her for nine months. She had Lyme disease, caused by bacteria known as *Borrelia burgdorferi*, which is spread by a bite from an infected deer tick. The insect can also be carried by a variety of other animals, including house pets.

The disease usually begins with flu-like symptoms, and is often accompanied by a very distinctive rash. Untreated in the early stages, it can lead to complications that include crippling arthritis, irregular heartbeat and palpitations, meningitis and extensive nerve damage.

"I'd never even heard of Lyme disease," Karen says. Looking back, she realized she must have been bitten by a tick the previous January—six weeks into her pregnancy—when she and Tom were clearing brush in the yard of their Connecticut home. Karen's new doctor put her on a weeklong regime of oral antibiotics.

But now she had a new concern: Had this illness, which had gone undiagnosed throughout her pregnancy, affected her son? Jamie had begun vomiting so severely that he was no longer able to keep food down, and he'd developed chronic respiratory problems.

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"Several specialists said there was absolutely no connection," she recalls. "I was told Lyme disease doesn't affect pregnancy." She became even more determined than ever to find out what was making her baby so sick.

LIVING A NIGHTMARE

The next two years were a nightmare. "Jamie was melting away before our eyes," Karen says. "He was vomiting every day and couldn't take in liquids or food. He seemed to be in the hospital all the time—even on Christmas and his birthday."

Karen and Tom consulted dozens of doctors. One specialist suspected Jamie had a rare genetic disorder; another believed he was brain-damaged; a third thought he might have cerebral palsy.

By the winter of 1986, when the child was 1½ years old, a doctor told the Forschners he had "only weeks to live." Remembering, Karen looks across the room at Tom, who is stroking Jamie's curly blond hair. "We decided that if Jamie was going to live, it was up to us," she says.

Karen had earned her college degree in biology, and now she began poring over medical literature. Having kept a careful record of Jamie's symptoms, she began systematically ruling out one disease after another. By his second birthday, she thought she knew what was wrong.

"I was convinced he had Lyme disease too," Karen states. "I was still trying to shake the heart and joint problems connected with my bout with it. Everything fit! I was excited. I thought we'd simply get Jamie treated, and he would be fine."

A doctor gave Jamie a blood test for Lyme disease and confirmed what Karen suspected. He was put on intravenous antibiotics, and for the first time in two years his vomiting stopped. The progress was short-lived, however; in a matter of weeks, the child was sick again.

In September Karen went to an international conference in New York

City attended by the foremost authorities on Lyme disease. "I went right up to doctors and told them, 'My son is dying. I need your help.'"

She came away from the conference deeply troubled. "I learned that Lyme disease during pregnancy does indeed affect the fetus," Karen says, "that the symptoms can come and go, and that some people may never be cured. In a handful of cases, people have died from it."

She vowed then and there to wage an all-out war on the baffling illness that had crippled Jamie—and strikes thousands of Americans every year.

"With every other disease, no matter how obscure, there was some place to call for information," Karen says. "But with Lyme there

the evening.) The Forschners have spent their life savings combating the disease and trying to help their son, who is now nearly 4 and so severely handicapped that he still cannot sit or walk or feed himself.

In 1988 alone Karen's home office received 10,000 inquiries about Lyme disease. Every day dozens of people call for help. When Michelle Jones of Toms River, New Jersey, contracted Lyme last summer, she was seven months into her second pregnancy. She called the LBF.

"My gynecologist had had no experience with this disease," Michelle says. "I'd read about the foundation in the paper. Karen gave me the name of a doctor in Connecticut who had treated a lot of pregnant women. My daughter was born very healthy. I will always be grateful to Karen."

The Centers for Disease Control (CDC) says the LBF is its main education arm in the fight against Lyme disease. "A lot of patients call us with questions," says Bill Letson, M.D., a CDC medical officer in Fort Collins, Colorado. "We refer them to the foundation because they have excellent information to share."

Lecturing frequently, Karen and other LBF board members strongly advocate more aggressive treatment, standardized testing (current blood tests for Lyme can be inconclusive) and increased awareness about the disease and its effect on pregnancy. Most victims recover completely if they undergo intensive medication with antibiotics within the first several weeks or even months after being bitten by an infected tick.

She is also lobbying for two bills that are now before Congress: the Comprehensive Lyme Disease Act of 1989, which would provide grants for research, education and treatment; and a second bill to designate July 23 through 30 as "Lyme Disease Awareness Week."

Passage of these two bills, Karen says, depends upon members of Congress being made aware that Lyme disease is a national problem. Cases have now been reported in 43 states across the country. Karen has helped to start an information network that includes 50 LBF "chapters" nationwide.

The Forschners are *(Continued)*



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was nothing organized; nobody really seemed to know anything."

SPREADING THE WORD

On March 18, 1988, she called the first meeting of the board of directors of the Lyme Borreliosis Foundation, Inc. (LBF), the nonprofit organization of which she is founder and president. Tom is secretary. Board members include many of the doctors and researchers whom Karen had met at the conference. LBF is dedicated to "education and research," Karen says. "Our goal is to go out of business—after Lyme disease has been stamped out."

Running the foundation is Karen's full-time job. (Tom, a banker, pitches in when he gets home from work in

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determined that this disease—which struck their son even before he was born—won't ravage the lives of any more families. They hold out hope

HOW TO PROTECT YOUR FAMILY

Lyme disease is caused by the painless bite of a deer tick infected with the bacteria. (The deer tick is not carried by deer alone; it may be found on other animals as well, including household pets who go outdoors.) In the spring, ticks are still young and almost impossible to see—they are about the size of a comma on this page. By fall, they are larger and easier to find.

Ticks should be considered a year-round threat and can be anywhere: woods, seashore, the front yard. Avoid any known tick-infested areas. To date, the majority of Lyme disease cases are concentrated in six northeastern states and Minnesota and Wisconsin.

Recommended Clothing According to the Lyme Borreliosis Foundation (LBF), preventive measures include wearing light-colored clothing with long sleeves (so you can readily spot any adhering ticks) and tucking pants into your socks when you are in any grassy, woodland or garden areas. Once indoors, check yourself, family members and pets carefully.

Repellents and Pesticides Using tick and insect repellents that contain DEET may help.

Also, certain lawn pesticides are useful against ticks, although their effectiveness alone and in combination is still being tested by health officials. Labels should specifically state that the product kills ticks. Under "active ingredients," look for the following: carbaryl, diazinon and chlorpyrifos. Some research indicates that these chemicals are effective in the fall, against adult ticks. (Follow instructions for use carefully, since they can be toxic to birds.) Damminix, a product manufactured by EcoHealth, has been

that one day Jamie will walk and talk and be able to lead a normal life, but the truth is that no one really knows what the future holds for him. Yet if the fierceness of their battle against Lyme disease is any indication, Jamie has a fighting chance. ■

Marianne Jacobbi is a freelance writer living in Massachusetts.

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