ASK KAREN

"There was no place for us to call to give us answers, to find doctors. For all the other rare diseases, there was some mom, some place I could call on a Saturday night and cry my heart out to and have some direction.

"There was nothing *for Lyme Disease,* no place *even for doctors to write to.* Nobody *could get access."*

And so Karen Vanderhoof-Forschner '70 started a foundation.

Buoyed by her own heart-wrenching trials and three-year quest for information, Karen started the Lyme Borreliosis Foundation in January 1988, devoted to prevention, education and treatment of all aspects of Lyme Disease.

Last year - its first year - the foundation, headquartered in the Forschner's family room in Tolland, Connecticut, answered 10,000 pieces of mail and an estimated 50 phone calls a day. Karen - articulate and vivacious - has appeared on "20/20"; "Inside Edition"; "Home Show"; CNN, NBC, ABC, and CBS local news, and been mentioned in *The Boston Globe, The New York Times, Maclean's*, the April *Reader's Digest*, and July *Family Circle* ("Women Who Make a Difference").

"We've put Lyme Disease on the map as a serious, life-threatening illness," says Karen, who was the only non-medical expert of 30 from around the world invited to a three-day strategic planning session at the National Institutes of Health last December. Karen was the final speaker.

Karen was also introduced at the press conference in Washington when the Comprehensive Lyme Disease Act of 1989 (a bill to fund research and treatment) was announced. She is considered such an expert on the tick-borne illness that the national Center for Disease Control [CDC] advises, "Ask Karen Forschner of the Lyme Disease Foundation."

Her expertise has come painfully. In 1985, Karen, a life-insurance consultant, became ill with eye and heart problems and pains in her joints while pregnant. After the birth of her son, Jamie, she was confined to a wheelchair and couldn't feed herself or walk. A specialist in joint inflammation suspected Lyme Disease and treated her with antibiotics.

Jamie, apparently normal at birth, began vomiting and manifesting peculiar symptoms - eye tremors, paralysis, heart disease, brain damage - that eluded diagnosis. Over the next two years, the Forschners were told he had recessive genetic disease, muscular dystrophy, cerebral palsy. Four times they were told Jamie was dying. He was tested by a battery of specialists, who subjected him to brain scans, dyes, probes, electricity, muscle biopsy, four operations, 12 hospitalizations. Nothing helped.

Finally Karen and her husband, Tom, sat down with all the records ("I'm a documenter") - the videotapes, medical records, testing results - eliminating diseases. Lyme was among the notes. In the fall of 1987, a New York neuro-opthamalogist concluded that nothing but an in utero infection could explain Jamie's multiple symptoms, and that Jamie had inherited her Lyme Disease. Karen then went to an international conference in New York City, attended by experts on Lyme Disease. She convinced the hotel to give her free room and videotape facilities; and - armed with photos and videotapes - "asked 600 doctors to help save Jamie's life." As a result, doctors began new treatment of Jamie, now permanently handicapped.

"What we were suffering from was ignorance."

Her son's disease identified, Karen realized that all over the country, scientists and medical people were doing independent research on Lyme Disease, but no one was making the connections. "None of us would talk or interact with each other. There was no place for the public or doctors to go for the implications."

In January 1988, Karen decided to start a foundation as a clearinghouse for information. She and Tom set up the board of directors with experts from the medical, scientific, business and public advocacy fields, many from the conference. (One board member is Dr. Willy Burgdorfer, who discovered the spirochete ["Borrelia burgorferi"] which causes Lyme Disease.) They found an attorney who donated services for the foundation's incorporation, bylaws, and constitution.

Karen Vanderhoof-Forschner '70

The not-for-profit Lyme Borreliosis Foundation has a three-way function: education, research, and patient support. Its volunteer experts give conferences and seminars, videotape and slide programs. They have established joint ventures in a national pregnancy registry and epidemiology (they have charted the increase of the disease from 33 to 43 states), and a tissue bank; for patients there are medical and testing referrals, an information network and support groups in 50 states. Karen is the most active speaker.

The Kimberley graduate, who has a B.S. in biology and the coveted insurance appellations CLU and CPCU, now volunteers full time on the foundation - all day, nights and weekends. Warm, highly organized, and impassioned in her convictions, Karen rattles off statistics without notes. But her blue eyes cloud when she recounts sadly that they live 50 miles away from where the disease was discovered [in Lyme, Conn.], but information *available at the time* did not travel even 50 miles. "If someone had acted immediately, Jamie would not be the way he is," she states. "What we were suffering from was ignorance."

"What scared me before, was I didn't have information," she says. "The *knowledge* we have now keeps us going. Nobody knows more what Jamie needs than me; no one can be a better advocate."

Karen Vanderhoof-Forschner virtually devotes her life to the Lyme Borreliosis Foundation. Asked *why*, she replies quietly, "It's because we have Jamie waiting for answers, and we're running out of time."

For information about Lyme Disease, send a stamped, self-addressed envelope plus $1 to: Lyme Borreliosis Foundation, Inc., P.O. Box 462, Tolland, CT 06084