



## Residents grapple with Lyme disease

By Kali Schumitz

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In 2002, Danna Pristach took her 12-year-old son to the doctor after a tick bit him while he was playing flashlight tag in the neighborhood. He tested positive for Lyme disease and was given a two-week course of antibiotics, and the family assumed that would be the end of it.

Now 19, Peter Pristach spends most of his days sitting in an oversized beanbag chair in the family's Centreville living room. He has had to delay finishing high school at a point when most of his former classmates from Westfield High School are getting ready to begin college.

After two-and-a-half years battling chronic Lyme disease, Peter says he feels like a different person and wants to change his name to Andrew.

"I'm in unbelievable pain. I've lost all but maybe six friends. I can't go to school. I really can't do anything that I was doing before," said Peter, who loved outdoor sports like paintball and dirt biking before he got sick.

Getting Peter healthy has consumed enormous amounts of the Pristach family's time and energy. Danna spends hours battling with insurance companies to cover some of the massive treatment costs. She and her husband, Bob, have missed many days and hours of work to care for Peter and take him to doctors' appointments. After graduating from Georgetown University, Peter's older sister, Kelsey, took eight months off from pursuing a career in finance to help in the daily care of her brother.

"A tiny tick that we could barely see has caused a devastating illness that has completely taken over our lives," Danna Pristach said.

### A growing concern

Fairfax County had about 100 confirmed cases of Lyme disease in 2006. By 2008 that number reached 189 confirmed cases, according to Jorge Arias, supervisor of the county's Disease-

Carrying Insect Program, adding that there are probably additional people the county does not know about who contracted Lyme.

“Overall, it seems to be going up,” he said. There is an increase in the number of deer and ticks in the county.

Although many doctors still do not recognize chronic Lyme disease as a legitimate illness, the Pristach family is among at least a half-dozen Fairfax County residents who contacted the Times to share their struggle to get diagnosis and treatment for the disease. One Fairfax-based lunch group for mothers of teens and young adults with Lyme has about 60 members.

In Loudoun County, an estimated 100 cases per 100,000 people have been reported. In Fairfax, that number is between 10 and 25 people.

Lyme, named for the Connecticut town where it was first identified, is caused by a bacteria called *Borrelia burgdorferi*. It originates in the white-footed mouse and is transmitted to humans by black-legged ticks, commonly called deer ticks.

“[Deer] are the Metro system. They will distribute the ticks all over the county,” Arias said.

Fairfax County officials and U.S. Rep. Frank Wolf (R-Dist. 10) have been working to raise awareness of the disease over the past few years, drawing hundreds of area residents to town hall meetings about Lyme.

### Challenging diagnosis

In November 2006, four years after the tick bite, Peter Pristach became severely ill. He had headaches and muscle pain. His feet started feeling cold all the time, and then later he could not walk. Once a good student and avid reader, he began having trouble processing information. He temporarily lost his hearing.

“It was scary,” his mother said. They took him to see numerous specialists, and some of the best doctors in their respective fields could not figure out what, if anything, was wrong with Peter. The doctors suggested other conditions, like depression or syphilis, were causing his symptoms.

It took six months before any doctor even mentioned Lyme disease and even longer to find a doctor who would treat it. Peter has seen more than 20 doctors since he first became ill and is now treated by two doctors, one in South Carolina.

Kelly Eisenhart, 23, of Herndon was playing three high school sports as well as travel soccer and

national-level field hockey. At the beginning of her junior year of high school she “basically collapsed.”

“I was sleeping about 20 hours a day. I was told, ‘you’re just being lazy, you’re not sick,’” Eisenhart said. “When I finally got diagnosed with Lyme disease, we were so relieved to finally have an answer.”

Seven years later, Eisenhart is still receiving treatment from a doctor out of the state while going to George Mason University part time.

The disease is difficult to diagnose in part because of lack of knowledge and recognition of chronic Lyme, and because of the physical characteristics of the bacteria that disguise it from the immune system and prevent it from generating antibodies that show up on tests, said Dr. Samuel Shor, who treats Lyme patients at his medical practice in Reston.

Shor said the symptoms can vary based on the species of bacteria. Some tend to cause joint problems and arthritis, some cause neurological problems, some go to the heart, some go to the brain, some cause a rash, some do not.

Add in co-infections — other bacteria that can also be transmitted with the tick bite — and the fact that Lyme patients tend to be more susceptible to common infections like the flu and staph, and treatment becomes more of a challenge.

“Lyme disease is one big complication,” Eisenhart said.

### Becoming activists

Because of their challenges in getting diagnosis and treatment, Lyme disease patients and their families have a tendency to become activists for their cause.

“I have a hard time with any doctor anywhere trying to make less of this than it is,” said Danna, who now brings binders of medical records and pamphlets on Lyme when Peter sees a new doctor. “We’ve kind of become Lyme advocates, without meaning to.”

Eisenhart started a support group for young adults to overcome the isolation she felt from being sick. The Pristachs also get support from other local families.

“The Lyme community is very close, in part, because they have all been told they are crazy,” said Bob Pristach, who also contracted Lyme disease but had more successful early treatment.

This week, there are hearings in Washington, D.C., to consider changing the diagnosis and treatment guidelines for Lyme, and many families are hoping that this process ultimately leads to more recognition in the medical community and better insurance coverage of treatment, which can cost tens of thousands of dollars.

A research funding bill that Wolf sponsored also just cleared the House of Representatives. He first began working on Lyme disease after meeting with Eisenhart and two other activists.

Wolf's bill would increase the Centers for Disease Control and Prevention's budget for Lyme research to \$8.9 million. The bill also encourages more input from patients and differing points of view.

This information is welcome news to Shor, who is in the process of applying for a National Institutes of Health grant to research possible connections between Lyme and chronic fatigue syndrome, another condition that he treats.

While he believes that the doctors setting the standards are ignoring what information is out there, "the problem is that we need more research," Shor said.

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