

# Despite growing awareness, Lyme often remains undiagnosed

by LOIS H. ALCOSSER

The symptoms of Lyme disease mimic so many other illnesses that it can remain undiagnosed and untreated for years. It is accepted now that the telltale bull's-eye rash may not appear at all and complaints of headaches, fatigue and joint pain are so commonplace that they usually aren't enough to suggest a test for Lyme. In fact, 50% of all tests for Lyme are urged by patients themselves.

Yet it's now known that Lyme disease can cause heart damage, arthritis, meningitis and eventually affect the nervous system and brain. Patients with undiagnosed Lyme disease who have memory loss, cognitive disorders and depression are often directed to a psychiatrist, without any physical examination at all. Loss of mental functioning from Lyme disease calls for intensive antibiotics, not simply antidepressants.

Dr. Amiram Katz, a neurologist who is director of the Lyme Disease Center in Southport, sees patients with late Lyme disease, when the Lyme spirochetes, the spirally undulating bacteria that travel through the blood stream, have invaded the spine, the nervous system and the brain.

"Some of my patients have seen 35 physicians," he said.

Recent studies indicate that 39% of families in Ridgefield and 54% in Wilton have had Lyme disease episodes. Dr. Katz predicts that at the rate Lyme is increasing, in 10 years, the entire population of these towns could be affected.

Capt. Roger Oulette, a commercial airline pilot living in Redding, is one of Dr. Katz' patients. Undiagnosed for seven years, he tested negative with one test, positive with another.

This is one of the major problems. There are two tests currently being used, the ELISA (enzyme linked immunosorbent assay) and the Western Blot. The International Lyme and Associated Diseases Society in Bethesda considers neither of these tests 100% reliable.

Dr. Katz confirms that different labs come up with different results and the same lab can report different results at different times. Since most of his patients suffer late and chronic Lyme, he considers a spinal tap the definitive test.

Everyone agrees by now that ticks infected with the *Borrelia burgdorferi* bacteria that transmit Lyme are most often carried by deer, but mice, squirrels, woodchuck and other small, furry, warmblooded animals are also host carriers. Birds can carry ticks across continents.

Dr. Ralph Hunt of the Wilton Hospital for Animals regularly treats dogs with Lyme disease and, very rarely, cats.

"Any household that has a pet with Lyme disease usually also has at least one member of the family with the disease," he said.

The actual process of the tick's transmission of the bacteria takes 12 to 24 hours, which is why it is so important to do body scans for ticks and remove them as soon as possible. After the tick burrows into the skin and starts to feed, the spirochetes inside the tick's gut begin to reproduce and are ejected into the bloodstream of the victim. There are spiny barbs around the tick's mouth that dig into the skin and attach firmly.

When there is any suspicion of Lyme, treatment with antibiotics should be administered immediately and continued for at least 30 days. But that may not be enough. According to the International Lyme and Associated Diseases Society (ILADS): "There has never in the history of this illness been one study that proves even in the simplest way that thirty days of antibiotic treatment cures Lyme disease."

Dr. Katz believes that patients must be symptom-free for at least two months before they can be considered cured. ILADS says: "Many patients require treatment for one to four years. Relapses occur and maintenance antibiotics may be required."

Capt. Oulette is now on intravenous medication, which he administers himself, twice daily. Experts say he is an example of what can happen when Lyme goes undiagnosed for a long period of time.

His symptoms of migraine headaches, joint pain, and fatigue were attributed to allergies and he saw an allergist for years, without relief.

"I had every allergy test under the sun. I also tried acupuncture, massage, a chiropractor and naturopathic medicine. They helped a little, but only temporarily," he said.

Yvonne Kosakow of Wilton was also misdiagnosed. She was sick for 13 years. She began to lose her memory and was told it was "stress related." Finally, a spinal tap was performed, revealing Lyme disease. She is allergic to intravenous antibiotics and takes her medication orally. She said Lyme has changed her life and she devotes herself to Lyme education and support. She has helped initiate Lyme disease support groups in Wilton, for adults and teenagers. "People come from as far as Long Island and Albany," she said.

Patrick McAuliffe, a school psychologist in Ridgefield, conducts an adolescent support group for Lyme sufferers. "Most of the kids in the group are still being treated. They're experiencing tremendous fatigue, cognitive disorders and poor executive functioning. That means these youngsters have trouble organizing/remembering, making decisions and feeling capable, which makes school very difficult. Some are so afflicted, they're homebound. The group is a good way for them to be with others who have similar problems. They feel safe and supported. When it comes to Lyme treatment, physicians range from very conservative to very aggressive. The average person doesn't know where his/her physician is at. Much more education and good research is needed."

Dr. Douglas Bunnell of Wilton leads the adult support group. "I know of no other disease that can affect every part of the body, with symptoms that seem to disappear and then recur."

Dr. Bunnell reiterates the predicament arising from disagreements among physicians about treatment. "Our support group is filled with people who continue having Lyme disorders, who aren't completely better, who were undiagnosed or misdiagnosed for long periods of time. Many of them were told their symptoms are all stress related, or due to menopause. Many of them with sudden onset psychiatric symptoms are given medication for depression and anxiety."

"Our support group is teaching people about Lyme, but it's also telling them: look, if you're going to undergo years of treatment and get better very slowly, you can still

function as best you can; not give up and let the disease take a chunk out of your life."

Dr. Steven Phillips is considered the Lyme disease guru of Ridgefield. He has been treating patients, doing research and publishing papers on various aspects of Lyme for the past seven years.

His testimony at a state hearing in Hartford helped pass legislation now in place that mandates insurance coverage for Lyme disease treatment. "But," he said, "there simply isn't any cookbook way to treat Lyme."

"Though 30 days of antibiotic treatment is considered standard, doctors find they are treating Lyme for more than three months. There are hundreds of strains of Lyme bacteria."

"Two different patients will have two different sets of symptoms. There are also cases of Lyme that are asymptomatic. Not everyone who's bitten gets the disease."

"In this area, deer are major carriers. In a sample count, deer were found infested with as many as 104 engorged ticks."

Dr. Phillips corroborates the unreliability of most tests. "There are new tests coming up constantly, including tests for Lyme plus co-infection, that is, diseases like ehrlichiosis or tick-borne encephalitis, which can be transmitted along with Lyme. At present, the co-infection tests are better than the tests for Lyme alone."

Can a patient become 100% Lyme-free?

"They can get better. My dad had Lyme and it affected his heart in a way that became life threatening. After intensive antibiotic treatment, he's better and his heart is better," said Dr. Phillips.

Lyme has bred all sorts of controversies. Some groups want to radically reduce the deer population while others advocate animal rights.

Meanwhile, there is specific advice about protection: Removing leaf litter, using insect repellents, deer fencing, doing daily body checks and tucking pants into socks or boots. Examination after gardening, hiking, any prolonged outdoor activity is mandatory, but some people insist that even with all the precautions, they have still acquired Lyme.