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Lyme Disease Hits Home

by Stacy Troiano, Town Times

INITIALLY DISCOVERED 30 YEARS AGO in Lyme, Connecticut, Lyme disease has not only continued to affect lives, but it has become a widespread epidemic in the northeast almost without residents knowing. Stories about West Nile virus and encephalitis are taking over front pages everywhere, while Lyme disease flies under the radar. Doctors and citizens alike need to become more aware of this rampant, debilitating illness.

Lyme disease is reported worldwide and throughout the United States, but the states of New York, Massachusetts and Connecticut account for the majority of the cases. It is a bacterial infection caused by a spirochete form of bacteria known as *Borrelia burgdorferi*, and it is transmitted to animals and man through the bite of infected ticks. The tick usually responsible for transmitting the disease in northeastern United States is the black leg tick, also known as the deer tick, however, there is growing evidence that there may be other vectors of transmission besides this isolated type. A tick bite is painless, so most victims do not know they've been bitten, which allows the tick to remain attached long enough to spread its infection.

In about 50 percent of Lyme disease cases, a characteristic bull's eye rash appears around the site of the tick bite after a few days, but it's very important to understand that even if a rash does not appear, it does not mean there is no Lyme infection; the rash is just one symptom. Other common symptoms of the beginning stages of Lyme disease include flu-like symptoms, headache, sore throat, stiff neck, fever, muscle aches, fatigue and general malaise. If left untreated, later stages of Lyme disease can cause complications such as arthritis, meningitis, facial palsy, heart abnormalities and other neurological symptoms. Heart, eye, respiratory and gastrointestinal problems can also develop.

"There is not a person who I've met in Durham that doesn't either have Lyme disease or know someone closely who has it," said

Sandra Ulbrich of Durham, who has been infected with Lyme disease for 16 years. I had a chance to talk to Sandra about her journey through the disease, and I was totally taken by her story. In 1989, Sandra began feeling ill, and her records read like a classic Lyme patient with throbbing headaches, fatigue, swollen glands and problems with her right shoulder and right hip. At that point doctors medicated her, but they didn't know what it was.

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Two years later, Sandra was not only uncured, but she was feeling progressively worse with severe fever added to her growing list of symptoms. She was put on different medications, but doctors still could not tell what it was. She began to have pain all over her body which kept getting worse until it became diffuse achiness everywhere. Some doctors ventured that she suffered from depression or chronic fatigue, but Sandra was not buying it. In 1992, she tested positive for Lyme disease, but the "specialist" at Yale told her she was not positive enough and insisted she didn't have it.

As time went on for Sandra, the infection continued to bring out more and more symptoms including intestinal problems and intense dizziness. She began feeling what she described as lightning bolt shockwaves going into her brain, and she saw a neurologist who also was stumped.

The late stages of Lyme disease wreak havoc on the brain. Sandra went in for a brain biopsy about one and a half years ago, which

found a demyelinating lesion in her right parietal lobe. Doctors still were avoiding a Lyme disease diagnosis. Some doctors thought it was cancer, others said maybe she had a stroke, and still others thought it could be multiple sclerosis because of bacterial similarities. Sandra had done her reading on the subject, and with help from her sister who is a doctor herself, she was nearly certain that the other diagnoses were incorrect, and the cause was actually Lyme disease that had now manifested itself in the brain.

The hyperfusion and encapsulated lesion in her right parietal lobe would require brain surgery for Sandra, and at the time she entered the hospital she could not raise a finger or a toe on her left side; it was completely dead. "This was devastating to me. I'm a trained classical pianist. Music is a very big part of my life, and now I couldn't use my left hand," she said. Sandra's new doctor wanted to see all of her records, including any tests given for Lyme disease, from years ago when the symptoms began. The doctor who had performed the test and had deemed Sandra "not positive enough" claimed that he no longer had records from that long ago. Sandra was not satisfied. She persisted and called the doctor's secretary who informed Sandra that she did indeed find her records, including the positive Lyme test. After about 12 years, Sandra was finally diagnosed correctly.

"I wanted to talk about Lyme disease not for myself because the damage is done, but I want people, especially in this area, to be aware of what an epidemic it's become and what it can do to a person," Sandra said. Connecticut has one of the highest infection rates for Lyme disease in the country, and misdiagnosis and proper treatment are clearly a problem. "Any kind of fever, any kind of aches and pains, any stiff neck or headaches, do not let doctors tell you its depression or chronic fatigue or anything else. Investigate Lyme. Get on some antibiotics." Sandra also stressed that the most important thing to remember if you are possibly infected with Lyme is that the tests are not

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always reliable. Clinical symptoms are the only way to truly tell whether or not the disease is there.

“I was very lucky to have such amazing support from my family. I just want to use my experience to make people aware. That’s the most important thing. Just be aware that it does happen, and in this area almost everything carries it. There’s no such thing as being too cautious,” Sandra said.

There’s no way to be completely impervious to a tick bite, and not all deer ticks carry Lyme, but there are precautions to take that will greatly lessen your chances of being infected. Always inspect yourself for ticks whenever you have been outside. Wearing lightly colored clothing will make it easy to see any ticks that may have attached themselves. Wash and dry clothes to kill any remaining ticks. Clear brush from any yard area and keep grassy areas mown. And most of all, wear insect repellent, preferably with Deet. If a tick is found on the body, immediately remove it. To safely remove a tick, grasp the mouth of the tick with tweezers as close as possible to the attachment site, being careful not to squeeze or puncture the body of the tick, which may contain infectious fluids. More information on Lyme disease can be found through the International Lyme and Associated Diseases Society (ILADS).

After being able to talk extensively with Sandra Ulbrich, I found myself very engrossed in her story. Here is a woman who had suffered from nearly every single symptom of Lyme disease, and is now doing everything she can to inform other people. I started reading many articles, researching anything I could find about Lyme disease, and telling a number of people about what an amazing person I had met in Sandra; I couldn’t stop thinking about her story. When I was leaving her house after we had talked, she told me that if she could affect even one person and make them become more conscious of the widespread problem of Lyme disease around here, then she would be happy. I hope I am the first of many.

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