

Easton Courier

Suffering from Long-Term Lyme Disease

By Larissa Lytwyn

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Imagine being ravaged by headaches, flu-like symptoms, arthritic-like pain and intense fatigue -seemingly overnight.

Longtime Easton resident, artist Dolly Curtis, 63, said she had been "blessed" with tip-top health before being virtually incapacitated by an insect bite on her foot during the summer of 1991.

"At first my doctor thought I had been bitten by a honey bee," she said. Curtis began a rudimentary treatment using over-the-counter pain medication. She also soaked her foot nightly in Epsom salt baths and applied anti-inflammation ointments regularly.

Despite the treatments, the condition did not improve.

In fact, it worsened.

"I was at a loss at that point," Curtis said. "I had no idea what was wrong with me."

Then one afternoon she overheard a man talking about similar symptoms.

"He found out that the real reason for his problems was Lyme disease," said Curtis. "I thought, Ah-hah!"

Curtis went back to her doctor and told him that she believed the symptoms could be Lyme disease-related.

"At that point, it had been over five weeks since my initial bite," said Curtis.

A blood test came back positive for Lyme.

"And I've had the disease ever since," said Curtis.

Chronic Lyme disease

Over the past few years, basic information about tick-borne diseases, specifically Lyme, has become increasingly available to the public. While the existence of Lyme disease is irrefutable, controversy has risen over the validity of "Chronic" Lyme disease.

Up-to-the-minute research by leading medical researchers, however, most notably the International Lyme & Associated Diseases Society (ILADS), contends that Chronic Lyme is a widespread and often-misdiagnosed condition that is only beginning to be legitimized by the medical community.

Part of the contentiousness surrounding Chronic Lyme is that there are still no reliable tests, nor any definitive cure or vaccine.

The Enzyme-linked immunosorbent assay (ELISA) test will not indicate infection if it's performed too early (two to six weeks) after the tick bite).

Patients with long-term Lyme rarely have a positive ELISA test because they have ceased to produce the antibodies the test looks for, according to the LDA, a national nonprofit dedicated to providing accurate information on the illness.

"Often, doctors will not make a Lyme diagnosis unless there is physical evidence of symptoms, like a rash," said Curtis. "Then they will wait for the lab tests to come back, and it can take a while until the person actually goes on antibiotics. However, a person should be treated immediately if they know they have been bitten by a tick."

However, according to ILADS, fewer than 50 percent of Lyme sufferers recalled a tick bite.

According to the Tolland-based nonprofit organization, the Lyme Disease Foundation, only 60 to 70 percent of patients notice a rash.

"One of the many difficulties in accurately treating this disease is that there are so many variables in symptoms, particularly when the person begins feeling symptoms, as well as what those particular symptoms are," explained Curtis.

Curtis called Lyme "the great imitator" because its symptoms are so similar to that of many other illnesses.

An unmistakable sign is the development of a bull's-eye rash around the site of the bite. The rash can vary in size and coloring. It may appear a few days or even a few weeks after the bite. It can spread to other parts of the body, or there may be additional rashes far from the primary one.

Other symptoms appear simultaneously with the rash (or, in many cases, without it). These symptoms are primarily flu-like, including fever, muscle ache, fatigue, tingling or numbness and joint pain.

The LDA warns that while the flu typically occurs during the winter, a summertime bout could be highly suspect.

"You should insist on no less than four weeks of antibiotic treatment," advised Curtis. "If your doctor refuses, see another." The LDA makes clear that a person suffering from symptoms, such as the rash and flu-like signs, should pursue treatment even if a blood test comes back negative.

"While there are many Lyme symptoms that imitate other diseases, the bulls-eye rash is a really strong indicator," said Curtis. "Don't let a false-negative test fool you."

Curtis is skeptical about the national Centers for Disease Control's (CDC) assertion that the likelihood of getting Lyme is "extremely small" if the tick is attached to the skin for less than 24 hours.

"Just this past June, I noticed I had a tick on my hand after gardening for no more than two hours," said Curtis.

Within hours of the bite, Curtis said, her hand swelled, and it was so painful that she couldn't move it.

"It was like what happened to me 15 years ago with my foot," said Curtis. "Only this time it was my hand."

A steady dosage of amoxicillin, fortunately, treated the symptoms.

ILADS is highly critical of the CDC and other government-directed organizations. "The CDC surveillance criteria were devised to track a narrow band of cases for epidemiological change and were never set up to be used as diagnostic criteria, nor were they meant to define the entire scope of Lyme," ILADS states, citing a National Institutes of Health (NIH) study dated March 25, 1991.

Curtis concurs that Lyme disease is a comprehensive, potentially devastating illness. "It is so widespread, so complicated," she said.

According to the LDA, there are well over 100 different symptoms. The disease is often mistaken for other illnesses including Fibromyalgia or Chronic Fatigue Immune Dysfunction Syndrome, Multiple Sclerosis, Lupus, Parkinson's, Alzheimer's, Rheumatoid Arthritis, motor neuron diseases (including ALS and Lou Gehrig's disease) as well as psychiatric disorders, such as depression and anxiety.

Further, ILADS states that *Borrelia burgdoferi* is not the only bacterium that causes Lyme. There are many pathogenic borrelia strains, spread by hundreds of different kinds of species of deer and dog ticks.

Tick-Borne illnesses

In addition, ticks can spread many diseases besides Lyme, most commonly Ehrlichiosis, Babesiosis, Bartonella and Rocky Mountain spotted fever.

These illnesses carry symptoms similar to Lyme, and is potentially life threatening with people who have compromised immune systems.

Pregnant women also suffer dire risks. The CDC warns that improperly treated Lyme in pregnant women can result in them carrying the illness to the child. Lyme in pregnant women, according to the CDC, can also lead to stillbirth if the illness is not vigilantly monitored and treated through antibiotics.

Prevention

According to the LDA, ticks are most plentiful in areas where woodlands transition into fields, meadows or yards. Ticks are most often found in tall grass.

There are various insect repellants, such as permethrin spray, that may help. Wearing long-sleeved shirts, long pants and a hat are helpful.

While most active in May, June and July, ticks are still very much out and about well into September.

If bitten by a tick, it should be removed promptly by pulling it slowly straight out with tweezers. Grab the tick near its head. Do not apply rubbing alcohol, petroleum jelly or any other substance (aggravating the tick can cause it to regurgitate in your blood, increasing chances for infection). Cover the site with antiseptic ointment after the tick is removed.

Ticks can be sent to area labs for testing.

\$100 million support

On July 25, U.S. Sen. Christopher Dodd (D-CT) announced his support of the Lyme and Tick-Borne Disease Prevention, education and Research Act, a \$100 million piece of bipartisan legislation which would significantly strengthen and coordinate efforts to research, prevent and treat Lyme and other tick-borne illnesses.

The \$100 million would be issued over a five-year period.

Connecticut had the highest incidence of Lyme of any state between 1992 and 2002. Lyme was named after Old Lyme, where the disease was first recognized (records of the condition itself, however, extend back to the 1800s.)

There are numerous area support groups in Connecticut for Lyme sufferers.

The Wilton Lyme Disease support group meets the second Wednesday of every month at 7:30 p.m. at the Comstock Community Center off Schoolhouse Road in Wilton.

The Greater Danbury Lyme Disease Support Group meets the third Saturday of every month in Redding.

The Greater Hartford Lyme Disease Support and Action Group meets the third Wednesday of every month in the Farmington/Unionville Community Center.