

## [The 'silent epidemic': Living with Lyme disease](#)



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Adam Bartley of Brookwood Lane used to spend much of his free time running around the courts of the Weston Racquet Club, where he taught tennis.

In great physical shape, he was also one of the top 25 active volunteers in the Weston Fire Department.

At 26, he now lives like an elderly man, spending most of his time inside his house. Sensitive to heat, he stays out of the way of the sun, and is so fatigued he sleeps most of the day.

“I used to be a tennis pro and a firefighter, and now I am Lyme disease,” he said.

For eight years, he has been bravely fighting Lyme disease, which some call the ‘silent epidemic’ because its complex variety of symptoms can make it difficult to diagnose.

The disease has so encompassed Mr. Bartley that it has changed his life forever and now defines him. “I have no life. I can’t hold a job. Some days I sleep most of the day,” he said.

Like many others who suffer from Lyme, Mr. Bartley went undiagnosed for a long period of time.

“He had it for two years before a doctor diagnosed him with it,” said Mr. Bartley’s mother, Linda. At first, the family thought Mr. Bartley’s symptoms — which included memory loss, headaches and mood swings — were caused from head injuries sustained in a snowboarding accident.

Then he had a spinal tap, and a diagnosis was made for Lyme disease.

### **Ticks**

Lyme disease is caused by a bacterial infection transmitted to humans by the bite of infected black-legged (deer) ticks. It may be acquired in any Connecticut town, particularly in wooded areas. The rural nature of Weston is a perfect home for the tick.

According to the Centers for Disease Control and Prevention (CDC), Lyme disease was first recognized in the United States in 1975, after an unusual outbreak of arthritis near Lyme, Conn.

Since mandatory reporting was instituted in 1991 by the CDC, nearly 300,000 cases of Lyme disease were reported. But CDC officials said the cases may be widely underreported, and a more realistic total could be more than one million.

Connecticut leads the country in reported cases of Lyme disease, with 3,000 in 2007. Fairfield County had more Lyme cases than any other county in the state, with 470.

The symptoms of Lyme vary from person to person and often mimic other illnesses. According to the CDC, early manifestations of Lyme infection may include fever, headache, fatigue, depression, and a characteristic ring-shaped skin rash.

Left untreated, late manifestations involving the joints, heart, and nervous system can occur.

Blood tests used to test for Lyme are not always reliable, and the disease can be misdiagnosed as fibromyalgia, chronic fatigue syndrome, multiple sclerosis, or arthritis.

Mr. Bartley never knew he was bitten by a tick. He also never developed the telltale ring rash.

## **Treatment**

The course of treatment for Lyme disease has caused divisions within the medical community.

Doctors who follow the recommendations of the Infectious Diseases Society of America (IDSA) prescribe a short-term, 14- to 28-day antibiotic regimen to treat Lyme.

Other doctors, notably Dr. Charles Roy Jones, a New Haven pediatrician, treat Lyme disease with long-term antibiotics, often more than the 28-day cap imposed by the IDSA.

Connecticut Attorney General Richard Blumenthal filed an antitrust lawsuit against the IDSA, claiming it used a flawed process in coming up with guidelines for treating Lyme disease. Mr. Blumenthal's lawsuit alleged conflict of interest with IDSA board members and insurance companies.

The IDSA recommended against long-term antibiotic treatment for Lyme disease, and the guidelines have been used by insurance companies to deny medical coverage.

In a settlement on May 1 with Mr. Blumenthal, the IDSA agreed to reassess its 2006 guidelines with the assistance of an outside arbiter.

## **Deer**

As if misdiagnosis, debilitating symptoms, and treatment controversies weren't enough to contend with, Lyme victims in Connecticut are also caught up in a debate about whether there should be a thinning of the deer herd in order to reduce the number of carriers of the ticks that spread Lyme disease.

According to statements in the Tick Management Handbook, prepared by Dr. Kirby Stafford, available at [www.caes.state.ct.us/](http://www.caes.state.ct.us/), deer are key to the reproductive success of deer ticks, and are the single most important animal in the tick's life cycle.

Experts in the handbook recommend reducing the density of deer to below 10 to 12 per square mile in order to prevent ticks from perpetuating their species successfully. They claim towns that have thinned their deer populations to those levels have also eradicated Lyme disease from their communities.

In 2006, a report by the Weston Select Committee on Deer Management estimated there were approximately 25 deer per square mile in Weston, more than twice the handbook's recommended number of deer, based on an aerial survey of the town.

Harvey Bellin, who was a member of the Deer Committee, has disputed that number based on personal observations. He believes there are far fewer deer than that.

First Selectman Woody Bliss said in his opinion, the only "cure" for Lyme is to get rid of the ticks. He would like to see the deer population reduced in Weston to achieve that goal.

His late wife, Prue, an avid gardener, had Lyme disease four different times. “She was not conscious of being bitten by a tick on a couple of those occasions,” he said.

When his wife was diagnosed with cancer, Mr. Bliss said she was told by her doctor that she might not react well to chemotherapy treatment because her immune system was compromised by Lyme disease. “And she didn’t react well to it,” Mr. Bliss said.

With all the controversies about Lyme swarming around, all Mr. Bartley wants to do is try to live a normal life and educate people about Lyme disease so they can recognize the symptoms and prevent others from being misdiagnosed. “I just want people to know how serious Lyme can get,” he said.

### ***Lyme film to be shown at University of New Haven***

The Department of Biology and Environmental Science at the University of New Haven (UNH) is sponsoring a showing of the film *Under Our Skin: The Untold Story of Lyme Disease* on Thursday, Aug. 7, at the UNH campus.

The film, which was produced by Andy Abraham Wilson of the California-based Open Eye pictures, focuses on the controversies surrounding the diagnosis and treatment of Lyme disease.

The event will be hosted by Dr. Eva Sapi, an associate professor at UNH. Special guest will be Dr. Charles Ray Jones, a New Haven pediatrician featured in the film. Dr. Jones has been the subject of a controversial investigation into his treatment of Lyme disease patients.

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The event will take place at Dodds Theater on the UNH main campus. Doors open at 5:30 p.m., and the film starts at 6:30.

Admission is free and open to the public. For more information, visit [www.unh-lyme.org](http://www.unh-lyme.org).