



Health

**Lyme Inc.**

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### **Ticks aren't the only parasites living off patients in borreliosis-prone areas.**

Three years ago Heather Jenkins, a 30-year-old mom in Huntersville, N.C., was constantly fatigued and prone to colds. Her internist referred her to Dr. Joseph Jemsek, a self-described "Lyme Literate" doctor. During the initial consultation he asked if she had been bitten by a tick or gotten a rash. No, she replied, but she had gone camping once in Tennessee. He suggested she may have picked up Lyme disease there and sent her blood to a California lab that specializes in tests for tick diseases. A week later the test results came back: She had been infected by *Borrelia burgdorferi*, the spirochete that causes Lyme disease.

Jemsek installed a tube in Jenkins' arm and every two weeks for a year and a half sold Jenkins a \$3,000 course of Rocephin, a powerful antibiotic, to infuse on her own at home. When she developed infections around the catheter in her arm the nurse would switch it. When her arms wore out she got a port implanted in her chest. As she waited for Jemsek to treat her latest infection, she collapsed on the floor, vomiting. Drug-resistant bacteria had overtaken her entire body. Jenkins landed in a hospital intensive care unit for four weeks, barely surviving. A doctor at Carolina Medical Center, where she recovered, told her that their labs could find no evidence in her blood that she'd ever had Lyme. "I was outraged," she says, and is now suing Jemsek. The near-death odyssey cost her insurance company \$400,000. The action is pending, and Jemsek has made no comment.

Lyme disease, with 20,000 cases reported annually, ranks low on the list of the most prevalent infectious diseases. But it ranks first in rancor generated in the medical community. The disease is caused by bacteria related to syphilis that enter the body through a tick bite. The typical Lyme infection responds to simple antibiotics, although symptoms like arthritis and fatigue may linger in a subset of patients. Researchers at academic medical centers who study the disease say that so-called chronic Lyme, or post-Lyme, is very rare, hard to detect and not treatable with any further doses of antibiotics. The mainstream doctors warn about an epidemic of bunk diagnoses and dangerous treatments. Insurers often refuse to cover the cost of treating chronic Lyme.

Arrayed against the establishment is a fraternity of Lyme specialists, many of whom have built large practices treating ostensible Lyme patients with expensive courses of antibiotics.

Last year the North Carolina state medical board brought Jemsek in for a disciplinary hearing. Ten patients testified to nightmarish experiences. A widower said his wife had died from a morphine overdose related to Jemsek's Lyme treatments. Jemsek disputed all the charges vigorously. He also had 200 supporters show up, many of whom believe he cured them of a terrible disease. The Lyme Disease Association, a group that supports Jemsek, says that 30

chronic Lyme doctors have been similarly targeted by medical boards. Jemsek ultimately received a "suspension with stay" that allows him to keep practicing.

The light penalty may reflect the power of Lyme support groups, which blast politicians with mail and phone calls to ensure their access to expensive care. Standing with them now is Connecticut Attorney General Richard Blumenthal, who has received awards from Lyme groups and late last year announced that he was investigating the Infectious Diseases Society of America, an 8,000-member organization of doctors trained to understand diseases like AIDS, malaria and tuberculosis. Their crime? Issuing Lyme treatment guidelines to doctors that warned against using long-term infused or oral antibiotics.

Blumenthal, who hasn't yet issued any lawsuits in the case, says that the IDSA's guidelines may be in violation of antitrust laws. "Lyme disease is an extraordinarily insidious and widespread problem in Connecticut. We want to make sure that patients and physicians have unfettered choices," he declares. Insurance companies, he goes on, may be colluding with the IDSA to deny care. It's an odd charge, since a 1996 policy statement from the Federal Trade Commission and the Department of Justice says that treatment guidelines issued by medical societies do not limit competition. "You want medicine to advance by debate, not hampered by lawsuits," says Robert Buchanan, a medical-antitrust attorney in Boston.

Despite intimidation from elected officials like Blumenthal, the establishment has scored some hits against Lyme specialists. In 1993 Vithaldis Shah, a New Jersey doctor, had his license yanked for five years for sickening Lyme patients with long-term antibiotic treatments and receiving a payment from the infusion company. In 1996 a doctor in Michigan was suspended after conspiring with a home infusion company and misdiagnosing Lyme patients. In 2000 a study described the death of an anonymous woman from complications arising from treating unsubstantiated Lyme with antibiotics.

In Connecticut Dr. Charles Jones, a pediatrician, is under investigation by the state medical board for prescribing, over the phone, antibiotics for chronic Lyme to two children in Nevada, a desert state with few ticks. Jones, who pulled up to a June hearing in a stretch limo to the cheers of fans, has testified that he did not finalize a Lyme diagnosis until he saw the children in person. Since the hearings began, more upset patients have joined the action against Jones. Blumenthal, however, has criticized the medical board for its investigation.

Mainstream doctors say their guidelines are based on scientific evidence. An early study identified 25 patients with gallstones or bile blockage resulting from antibiotic treatment of unsubstantiated chronic Lyme. A more recent study of infused antibiotics published in the *New England Journal of Medicine* was cut short after Lyme sufferers with persistent symptoms did not respond to a course of antibiotics any better than they did to a placebo. One patient getting antibiotics had a pulmonary embolism; another had gastrointestinal bleeding.

Another paper in the *Annals of Internal Medicine* calls chronic Lyme a "functional somatic syndrome," similar to other nebulous ailments like Gulf War Syndrome, chronic fatigue and fibromyalgia. Another study in the same journal found that 60% of Lyme disease patients lacked any evidence of previous or active Lyme infections. Some of these patients suffered from depression, arthritis or other diseases. "There are lot of people who have fatigue or musculoskeletal pain. We want to help them but not with long-term antibiotics," says Dr. Gary

Wormser, an infectious disease expert at New York Medical College who helped write the guidelines that prompted Blumenthal's attack. After the latest IDSA guidelines came out in November, Wormser and his Valhalla, N.Y. lab were the target of a protest attended by hundreds of chronic Lyme patients and supporters; one sign said "Wormser Lies ... Patients Die."

Many of the chronic Lyme patients are upset that their insurance companies won't cover unlimited treatments. WellPoint will pay for only four weeks of IV antibiotics, citing published peer-reviewed studies. But science is no match for the Internet, where Lyme patients swarm chat boards to bemoan the persecution of their doctors and egg on politicians. Some celebrities have joined in the fray, such as novelist Amy Tan and Daryl Hall of rock duo Hall and Oates, both of whom say they suffer from chronic Lyme.

Tan's doctor is Raphael Stricker, president of the International Lyme & Associated Diseases Society, which represents chronic Lyme doctors and patients. Stricker's San Francisco clinic also advertises its ability to treat obesity, infertility, erectile dysfunction and AIDS. In 1990 Stricker was forced out of UC, San Francisco after the school claimed he falsified data in what had been a seminal AIDS study. Before he discovered Lyme he spent two years as associate medical director at a penis enlargement clinic.

Stricker and many of his chronic Lyme allies send their blood tests to a California lab called Igenex, which was once investigated by Medicare and the state of California for pumping out too many positive tests. Nick S. Harris, chief executive of Igenex, says he passed both investigations easily, but in 2001 the federal Office of the Inspector General put Igenex on a list of noncompliant labs. It paid fines totaling \$48,000. Harris says his firm has had no recent brushes with regulators. Harris says that his tests are more sensitive than ones given by lab giants Quest Diagnostics and LabCorp, yielding positive results 25% of the time. The big national labs typically return positive results 8% of the time. He acknowledges that his results are more open to interpretation, which could facilitate more positive diagnoses. "Patients, because of the Internet, have become my best salesmen," Harris says.

Jemsek, who in 2005 collected \$6 million from Blue Cross Blue Shield of North Carolina, is still practicing, having declared his earlier practice bankrupt. He opened a new cash-only practice, spending \$8 million on a building with a waterfall and grand piano. On the Internet patients exchange tips about how to keep seeing him. In his statement to the medical board after the stayed suspension of his license, Jemsek, who declines to be interviewed, said: "I've got 400 letters of support here, many single-spaced and several pages long."