

Lyme disease activists take their battle to the Legislature

By [Jeremy Olson](#)
iolson@pioneerpress.com

Updated: 02/08/2010 10:50:15 PM CST

Doctors who defy current treatment guidelines and prescribe long-term antibiotics for Lyme disease would gain legal protection under a bill in the Minnesota Legislature.

The proposal is the latest in a long-running dispute among doctors and patient advocates over the exact symptoms and duration of the tick-borne disease.

Advocates for Lyme disease sufferers say the current recommendation — treatment with 10 to 28 days of antibiotics — is insufficient for people with advanced or chronic levels of the disease. Conversely, some doctors say they don't believe Lyme can reach a chronic stage and worry that long-term antibiotic use just leads to resistance and drug side effects.

Lawmakers in Monday's meeting of the Senate Committee on Health, Housing and Family Security got an earful from both sides. Michelle Backes, of Lindstrom, Minn., said long-term antibiotic therapy relieved the numbness, pain and tremors caused by her Lyme infection but only after a prolonged search for a doctor who would prescribe it. Three other Minnesotans shared similar stories.

"People are sick," said a tearful Backes. "They need help."

At issue are guidelines drafted by the Infectious Disease Society of America, a professional society of 8,000 physicians. The society finds no medical evidence to support the use of long-term antibiotics or any evidence that Lyme can be chronic.

"No one believes these patients do not have suffering and symptoms," said Dr. Johan

Bakken, of Duluth, who was part of the committee that created the society's guidelines. "What we are contesting is whether Lyme disease is the correct diagnosis for these individuals."

Bakken said the guidelines are not legally binding and questioned the need for the bill. The measure would prohibit the Minnesota Board of Medical Practice from disciplining doctors who prescribe long-term antibiotics.

Other doctors testified that the guidelines have had a chilling effect on diagnostic practice. And while the Minnesota board hasn't disciplined any doctor related to this issue, boards in Connecticut and other states have.

"The fear of a board investigation is enough for a physician to say, 'I'm sorry, don't want to treat you,' " said Dr. Nick Lafond, a family practice physician in Delano.

Senators struggled with the issue. Several expressed sympathy for the patients who testified — including 15-year-old Chris Thompson of St. Paul, who has missed school due to Lyme-related pain and headaches — and a desire to give doctors the freedom to make the best clinical judgments without reprisals.

At the same time, they worried about legislation that would meddle in medicine and tell doctors how they can and can't practice. Even the lead author of the bill, state Sen. John Marty, DFL-Roseville, said the Legislature hadn't taken a step like this before.

The debate is important in the Midwest and Northeast, which host the greatest number of blacklegged ticks that carry Lyme-causing bacteria. Minnesota has seen its number of confirmed Lyme infections increase fourfold from 283 cases in 1999 to 1,050 cases in 2008.

Lawmakers in Rhode Island and Connecticut already have enacted similar legislation giving legal protection to doctors who prescribe long-term therapy for chronic Lyme disease. In lieu of legislation, New York issued policy guidance permitting doctors to issue these prescriptions, said Pat Smith, president of the Lyme Disease Association, in a telephone interview.

Bills in Massachusetts and Virginia are under consideration.

Lyme infections can lead to muscle and joint pain, fevers, chills, fatigue and difficulties with concentration or memory loss. The infectious disease society acknowledges that these symptoms can persist even after short-term antibiotic therapy.

Bakken said one reason for the prolonged symptoms may be the strong reaction by the immune system that continues to create problems even after the bacteria is gone. He also said that Lyme is misdiagnosed and that some patients have other disorders such as depression and chronic fatigue.

Joining in opposition to the bill was the Minnesota Medical Association, which represents the state's doctors. Whether doctors should prescribe long-term

antibiotics or not, the association's Dave Renner said it's a "bad precedent" to legislatively dictate medical practice for specific conditions.

The committee advanced the bill to the Senate floor, but set an expiration date of July 1, 2015. After that, the Legislature could revisit the issue and consult new research and information about Lyme and its treatment.

Jeremy Olson can be reached at 651-228-5583.