

State joins Lyme debate

Bill would allow doctors to prescribe long-term antibiotics

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HARTFORD -- State Rep. Kimberly Fawcett has proposed a bill that puts Connecticut in the middle of a nationwide dispute over whether Lyme disease can be chronic.

The Fairfield Democrat joined the fray after her husband was diagnosed with the tick-borne disease last summer. He was prescribed the standard three-week course of antibiotics but relapsed soon after he completed the treatment.

"Within a week, he was violently sick again," Fawcett said.

When the couple sought additional treatment from her husband's primary-care physician, they were told to find another doctor or a specialist, she said.

Doctors "feel like it's something they want to avoid getting involved with if they can," Fawcett said.

The reason is that some in the medical profession question whether Lyme disease can persist, and whether it merits long-term antibiotic treatment, which carries potential dangers.

Fawcett proposed a law that makes it clear physicians have the right to prescribe long-term antibiotics for Lyme disease, which she thinks many would do if they did not fear being reported to the state Department of Public Health.

Her bill, co-sponsored by state Rep. William Tong, D-Stamford, was the subject of a public hearing Friday by the legislature's Committee on Public Health.

Lyme disease, discovered in the mid-1970s in Lyme, a town in eastern Connecticut, is transmitted to humans by the bite of infected blacklegged ticks, according to the federal Centers for Disease Control. Symptoms include fever, headache, fatigue and a rash. If untreated, infection can spread to joints, the heart and the nervous system. Most cases can be treated with a few weeks of antibiotics, according to the CDC.

In 2006, the Infectious Diseases Society of America issued Lyme disease guidelines for doctors.

In a letter to Connecticut legislators this month, Anne Gershon, president of the Virginia group, opposed Fawcett's bill, saying there is no such thing as chronic Lyme disease.

"There are no convincing published scientific data that support the existence of chronic Lyme disease," Gershon wrote.

The concept has been promoted by "a small group of physicians," but the dangers of long-term antibiotic therapy are well-documented and should not be encouraged, she wrote.

The society is respected among medical professionals, but critics point to an anti-trust investigation of the group by Connecticut Attorney General Richard Blumenthal.

Last year, the investigation uncovered "serious flaws" in how the group crafted the Lyme guidelines, including an effort to "block" scientists and physicians "with divergent views on chronic Lyme" from the oversight panel.

Blumenthal's probe, and personal experiences, have supporters of Fawcett's bill convinced that chronic Lyme disease is real.

State Rep. Peggy Reeves, D-Wilton, a co-sponsor of the bill, said her husband and 24-year-old daughter have suffered from Lyme disease since the 1990s.

"My husband right now is on four (prescriptions) at the same time," Reeves said.

They had to go to New York to find a doctor willing to treat the illness long-term, Reeves said.

Connecticut doctors who prescribe long term Lyme treatments are "persecuted" by the state Department of Public Health, she said.

William Gerrish, a department spokesman, said the agency does not have a policy against long-term antibiotic treatment of Lyme disease. But the department submitted a letter to lawmakers opposing Fawcett's bill because it would strip the agency of its ability to review complaints and violations "particularly in cases where the care being provided to a patient deviates from current evidence-based practice."

Blumenthal said he supports Fawcett's bill in concept, but his office is reviewing it to consider "whether it may be too broad and what its effect will be on other treatment situations unrelated to Lyme disease."

At Friday's public hearing, no doctors testified that they were having trouble treating Lyme patients or being bothered by the state.

"None of them will come on the record," Fawcett said. "It's so controversial and really dangerous to get involved with."

Representatives from the Connecticut State Medical Society testified in favor of Fawcett's bill. They said they were not taking a position on the existence of chronic Lyme disease, but on the right of doctors to treat patients as they deem fit.

Medical society Vice President Matthew Katz said he did not know of any members who have been persecuted by the state health department over how they treat Lyme disease. But the recent case of Dr. Charles Ray Jones, a New Haven pediatrician renowned for treating the illness, has heightened concerns in the medical profession, Katz said.

In December 2007, the state Medical Examining Board, responding to an investigation by the Department of Public Health, fined Jones \$10,000 and put him on probation for two years for diagnosing children with Lyme disease and treating them with antibiotics before examining them. Jones is appealing the decision.

Katz said news coverage focused on the doctor's reputation as a last resort for those complaining of chronic Lyme disease.

"What appeared in the paper and on the news -- Lyme disease mistreatment -- it raised a lot of concerns," Katz said.

State Sen. Jonathan Harris, D-West Hartford, co-chairman of the public health committee, said the topic is more complicated than he thought.

"I'm really starting to get my arms around it. We have to dig down a little more deeply on this to make sure we are doing the right thing," Harris said. "I'm convinced the bill is a well-intentioned effort to get people the care they need."

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