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Lyme Legislation Gains Support as Experts Predict Rise in the Disease

By Nellie Bristol, CQ HealthBeat Associate Editor

A predicted surge in Lyme disease cases this year is drawing new attention to legislation to expand federal efforts to combat the disease, which could help quell controversy over the merits of long-term treatment.

A bill ([S 1381](#)) sponsored by Sen. [Richard Blumenthal](#), D-Conn., and a more limited version ([HR 2557](#)) in the House by [Christopher H. Smith](#), R-N.J., would establish an advisory committee on tick-borne disease to coordinate federal efforts. The Senate bill also pushes federal development of better diagnostic tools, including a test to distinguish between active and past infection, and would encourage increased surveillance and prevention. It also calls for better physician education on the issue. “In all those areas I believe the government is failing to do enough,” Blumenthal said.

New York Democratic Sen. [Charles E. Schumer](#) recently encouraged lawmakers to support the bill, quoting experts who say the mild winter could result in a longer tick season this year. “The winter may not have dumped buckets of snow and coated the roads with ice, but it did leave behind the ticks that can cause Lyme disease and other illnesses come summer and spring,” Schumer said. Several experts say the lack of extreme cold led to an earlier active tick season and other factors are resulting in a larger-than-usual tick population. As a result, they say, this could be a record year for Lyme cases.

Provisional data from the Centers for Disease Control and Prevention already show evidence of an increase, especially in the mid-Atlantic region. As of May 19, CDC had tallied 5,421 cases nationwide, compared with 4,667 at the same time last year. The mid-Atlantic has had 3,575 cases this year, double the 1,774 reported by the same time in 2011. New Jersey and Pennsylvania were hit particularly hard.

Disagreements Over Treatment

The increases could be problematic in a disease that often is difficult to diagnose and for which there are differences in opinion in the medical community over long-term effects. A controversy has brewed for years over whether short-term antibiotics fully treat the disease or if some patients harbor continued infection that warrants longer treatment. Some physicians, led by the International Lyme and Associated Diseases Society, argue that current treatment guidelines, particularly those developed by the Infectious Diseases Society of America (IDSA), are too proscriptive and do not give enough weight to the possibility that some patients are not cured with initial rounds of treatment.

Physicians acknowledge that some patients suffer symptoms, including fatigue and joint pain, for months or even years after treatment. Some call for further aggressive antibiotic administration,

while others say that can be harmful to the patient. Some suggest the symptoms may not be connected to Lyme disease at all.

The controversy spilled over into consideration of a previous version of legislation to establish the federal advisory committee, introduced in 2009. The IDSA opposed the measure, saying the makeup of the committee was tilted toward a minority of physicians who believed there is a chronic form of Lyme disease, a notion the infectious disease group rejects. While the new bill is largely similar to the previous version, the group has not issued a position on the legislation this time.

Bill supporters hope additional federal attention to the disease will solve the mystery. “In large parts of the country, especially in the northeastern-Virginia-to-Maine corridor where Lyme is endemic, citizens are very frustrated by this disease,” said Richard Ostfeld, a disease ecologist at the Cary Institute of Ecosystem Studies. “The government isn’t, in their minds, adequately protecting their health.”

Ostfeld is among those predicting a rise in disease this year. His research shows that a particularly large crop of acorns two years ago began the cycle. The acorns supported more white-footed mice over 2011 that are now sustaining an increased population of Lyme-carrying ticks.

Researchers are working to understand the bacteria that causes Lyme disease and to find ways to better diagnose it. The National Institutes of Health spent \$28 million on Lyme disease research in 2011, according to Joseph Breen, Bacteriology Program Officer for the National Institute of Allergy and Infectious Diseases. A large portion of the research focuses on better diagnostics, particularly those that can distinguish between active infection and long-term disease to help discover ways to address lingering symptoms. Being able to make that distinction could go a long way toward addressing controversy around the illness in the medical community, Breen said. “Then I think we could clarify that and approach that in a different way,” he said.

Banner year or not for Lyme, Blumenthal hopes the legislation will create a more solid continuous federal approach to a disease that affects thousands every year. “Lyme has been so pernicious and insidious a disease in past years that we don’t really need a heightened level of suffering to make the case, but I will use every bit of evidence available to argue that we should enhance our efforts to fight Lyme,” he said.

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