

Eric Huck, co-founder of PA Lyme Resource Network and president of Harrisburg Area Lyme Disease Support Group, has been in a fight for nine years. That's how long he's been battling Lyme disease, but the effects of the disease itself are only part of the fight. "We are fighting the government. We are fighting the CDC. We are fighting the insurance companies," Huck said.

The root of the fight with insurance companies lies at the intersection of medicine and government. The Infectious Disease Society of America is a key group. It is an organization of physicians, scientists and other health care professionals who specialize in infectious diseases with the purpose of improving health as it relates to infectious diseases. "It is the IDSA that sets the guidelines on what a disease is, what a disease is not, how you treat it," Huck said.

In 2006, a panel of 14 doctors set up the guidelines for the treatment of Lyme disease. "The guidelines basically say Lyme disease is difficult to get, easy to cure," Huck said.

The IDSA guidelines were adopted by the Centers for Disease Control, which gave doctors direction on how to treat the disease for the first time. "Doctors were in the dark on what to do. They had nowhere to go for a uniform body of rules," Huck said.

## **Guidelines**

The guidelines, however, came under scrutiny. In 2008, Sen. Richard Blumenthal, then the attorney general of Connecticut, announced that an antitrust investigation found flaws in the process IDSA used in writing the guidelines. A news release announcing the decision said the guidelines are "commonly applied by insurance companies in restricting coverage for long-term antibiotic treatment or other medical care and also strongly influence physician treatment decisions."

Blumenthal also found that several IDSA panelists were found to have conflicts of interest, according to the press release. The IDSA maintained throughout the investigation that the guidelines were developed after proper review of medical and scientific studies as well as evidence by experts in the prevention, diagnosis and prevention of Lyme disease. The investigation ended with an agreement between the two parties to create a review panel to examine the guidelines and to update or revise them as needed.

Members of the Lyme disease community thought this reexamination would lead to changes in the guidelines, Huck said. Instead, they were shocked to see the panel hold its course and not offer revisions. When the IDSA refused to change its guidelines, the CDC followed suit and did not change its guidelines.

Now, insurance companies have the rationale they need to be able to authorize only 2-4 weeks of treatment. Many of those companies will not cover additional treatment, Huck said. That works for most patients. Huck said some people will say they had Lyme disease and were fine after treatment, adding that about 70 percent are like that. But for the other 30 percent, insurance won't cover antibiotics prescribed for longer terms so people are paying out of pocket in an attempt to get better.

According to the IDSA website, the guidelines are under revision in a process that began in 2015, and results are expected to be published in the summer of 2018. Draft guidelines will be available prior to publication, and will be open for a 45-day comment period.

A second organization, the International Lyme and Associated Disease Society, also created guidelines. The society is an international medical society that promotes understanding of Lyme and associated diseases through research, education and policy. Guidelines from the two organizations have significant differences. For example, the IDSA recommends a single dose of an antibiotic if a tick bite meets certain criteria while ILADS recommends a minimum 20-day cycle of a different antibiotic for any tick bite in which there is evidence of tick feeding. The two sets of guidelines also differ on the type of antibiotics to prescribe, and the length of time for which they should be used.

One set of guidelines recommends against treating a patient a second time if the patient continues to show symptoms of Lyme disease after initial treatment, while the other recommends undertaking retreatment after discussion with a patient and proper assessment.

“It’s very controversial. It’s very conflicted and people’s children’s lives are in the balance,” Huck said.

## **Legislative solutions**

Differences in opinion on treatment protocols caught the attention of the state Legislature as Lyme disease has continued its march across the state, with cases now being reported in all 67 counties.

Passed in 2014, the Lyme and Related Tick-Borne Disease Surveillance Education, Prevention and Treatment Act (Act 83) established a task force to address issues surrounding Lyme disease. The task force issued its report in September 2015, and made 14 recommendations in the areas of prevention, education, awareness and surveillance. The report identified that “health care practitioners today have limited testing options for Lyme disease that are covered by insurance.”

More recently, Rep. Matthew Baker introduced House Bill 174 on Dec. 13, 2016. The bill provides for patient access to diagnostics and treatments for Lyme disease and related tick-borne illnesses, and would require insurers to cover treatment plans for Lyme as prescribed by health care practitioners regardless of the length of treatment.

Local Reps. Steve Bloom, Will Tallman and Greg Rothman voted in favor of the bill. House Bill 174 was passed over to the Senate’s Banking and Insurance Committee on May 31. In that same committee is a similar bill that was introduced in the Senate. Senate Bill 100 was referred to the Banking and Insurance Committee in January. No votes have been reported on either bill since their respective referrals to the committee.

For now, Lyme disease patients and their advocates work and wait. Pennsylvania Lyme Resource Network has been using letters and email in a communication campaign to let the committee know the financial challenges people with Lyme disease face. Huck said he knows people who have lost their homes and spent all of their money dealing with the disease.

“It shouldn’t be like that in America,” Huck said.

[http://cumberlink.com/news/local/closer\\_look/living-with-lyme-patients-struggle-with-insurance-coverage/article\\_474e0e78-5199-5ec0-8bde-bfd836e8f348.html](http://cumberlink.com/news/local/closer_look/living-with-lyme-patients-struggle-with-insurance-coverage/article_474e0e78-5199-5ec0-8bde-bfd836e8f348.html)