



Lyme Disease and State Policy Primer for State Legislators

The Infectious Diseases Society of America (IDSA) is the largest infectious diseases medical society in the United States, representing more than 10,000 physicians and scientists. The Society's members focus on the epidemiology, diagnosis, investigation, prevention and treatment of infectious diseases in the U.S. and abroad. Our members care for patients of all ages with serious infections, including Lyme disease.

What is Lyme disease? Lyme disease is a tick-transmitted bacterial infection caused by *Borrelia burgdorferi* that in many patients can cause a skin lesion (erythema migrans, classically causing the familiar “bull’s-eye” rash), often accompanied by muscle and joint aches. **If left untreated, infection can spread to the joints, the heart, and the nervous system.**

How is Lyme disease diagnosed? Lyme disease is diagnosed by medical history, physical exam, and sometimes a blood test. The blood test works best for patients who have had symptoms for more than four to six weeks because that’s how long it typically takes for the human immune system to make antibodies against the Lyme bacterium. In patients who are newly infected, diagnosis is usually made clinically. Scientific advances may well lead to improved testing strategies for the diagnosis of Lyme disease. IDSA continues to advocate for progress in this area.

Except in very rare cases, Lyme disease causes well-characterized presentations. There is a public perception that Lyme disease can present in a myriad of ways routinely, which is incorrect and may lead to over-testing and over-diagnosis. This practice can lead to individuals who do not have Lyme disease receiving dangerous treatments, including long-term antibiotic therapy as well as delay in reaching an accurate diagnosis.

Can Lyme disease cause a chronic infection after antibiotic treatment? There is not sufficient evidence to support this. It’s important to distinguish between having an active, chronic infection versus having lingering symptoms from a previous infection. Scientific evidence indicates that a 10-28 day course of antibiotics, depending on the stage of Lyme disease, will kill the Lyme disease bacterium in humans. Some patients may continue to experience symptoms such as fatigue, pain, or joint and muscle aches even after the infection has been cleared. While prolonged courses of antibiotics have been proven ineffective in speeding relief of these lingering problems, doctors can talk to patients about other ways to relieve these symptoms, which normally get better over time.

Some people use the term “chronic Lyme disease” for these symptoms. However, this lacks a precise definition. Some people do not quickly recover fully after Lyme disease and have persisting symptoms; however, as there is no evidence of active infection nor evidence to support the effectiveness of additional antibiotic therapy, post-treatment Lyme disease syndrome (PTLDS) is a better term for these symptoms.

Is long-term antibiotic therapy appropriate for Lyme disease? No. The potential benefit of long-term use of antibiotics for the treatment of Lyme disease has been examined and found ineffective in multiple well-done clinical trials, and is potentially harmful both to treated patients and to the public’s health (due to the creation of antibiotic-resistant bacteria). Long-term antibiotic therapy can cause many serious health consequences for patients, including protracted and intractable diarrhea, severe colitis, antibiotic resistance, allergic reactions, bloodstream infections and clots from intravenous catheters, and even death, without any scientifically-founded prospect of benefit.

IDSA's 2006 practice guidelines for the clinical assessment, treatment, and prevention of Lyme disease are widely recognized and referenced by physicians across the country. A special Review Panel in 2010 unanimously supported all of the recommendations in the IDSA guidelines, including the conclusion that long-term antibiotic treatment is unwarranted for Lyme disease and potentially dangerous.

To provide an update to these previous guidelines, IDSA, the American Academy of Neurology (AAN), and the American College of Rheumatology (ACR) are jointly developing new guidelines for the diagnosis and treatment of Lyme disease with input from eight other major medical and scientific organizations whose members care for patients with Lyme disease. Experts representing the fields of cardiology, pathology, microbiology and entomology (though ticks are not insects but arachnids) are also included among the panel's membership. Finally a healthcare consumer, three patients and a parent of a patient with confirmed Lyme disease are represented. IDSA, AAN and ACR are also providing multiple opportunities for public comment throughout the development process for the new guidelines.

Approximately 20 clinical and scientific organizations in North America and Europe, and numerous scientific and public health bodies agree with IDSA's perspective. Multiple randomized trials fail to support the use of long-term antibiotics as an appropriate treatment for Lyme disease including most recently a large trial comparing two different antibiotic regimens (*New England Journal of Medicine* 2016; 374:1209-1220 March 31, 2016). Three reviews -- one published in the *New England Journal of Medicine* (*N Engl J Med* 357:14; October 4, 2007), one in the *American Journal of Medicine* (2008) 121, 562-564, and a more recent report in *Expert Reviews in Anti-Infective Therapy* (*Expert Rev. Anti Infect. Ther.* 9(7), 787-797 (2011) -- give evidence-based assessments of Lyme disease diagnoses and the recommended treatments that substantiate IDSA's position. Numerous studies have found that long-term therapy neither ameliorates nor prevents symptoms attributable to Lyme disease.

Lyme diseases state policy issues: There have been and continue to be legislative efforts in several states, many of which are well-intentioned but therapeutically dangerous, that would sanction prolonged courses of antibiotics for patients with Lyme disease, as promoted by a very small group of doctors, despite the lack of evidence for efficacy and with serious concern for adverse events. Such legislation can take many forms, including:

- Requiring health insurers to cover Lyme disease treatments that are not supported by scientific evidence, including long-term antibiotic use and experimental drugs;
- Restricting state boards of medicine (which are charged with protecting the public from harmful medical practices) from disciplining physicians who prescribe dangerous therapy for Lyme disease and other suspected tick-borne infections;
- Mandating specific communications between doctors and patients regarding Lyme disease testing and/or treatment;
- Making it easier for patients who do not have Lyme disease to access inappropriate and dangerous treatments by calling into question negative diagnoses;
- Requiring state health agencies to provide misinformation about Lyme disease diagnosis and treatment.

For more information on Lyme disease, please visit <http://www.idsociety.org/Lyme/>, <http://www.cdc.gov/lyme/>, or <http://www.niaid.nih.gov/topics/lymedisease/Pages/LymeDisease.aspx>.

IDSA has developed a free, online CME program to help physicians recognize, diagnose, and treat Lyme disease. For more information, see <http://lymecourse.idsociety.org/>.