

INTERNATIONAL LYME AND ASSOCIATED DISEASES SOCIETY, INC.

(a District of Columbia nonprofit corporation)

The purpose of the declarative statement below is to inform the worldwide public of the nature of ILADS and its mission. ILADS is a scientific society dedicated to the accurate diagnosis and treatment of Lyme disease and other chronic inflammatory diseases. Members are accepted into the society based on their merit and practice interests. ILADS has been misrepresented and misunderstood by a variety of sources over time. This statement was written in order to bring clarity and transparency to any who may not fully understand the nature of our organization. Our name is also copyrighted, both in the United States and Europe, such that if the name is misused in a way that harms our organization, legal action may be taken. While we welcome opportunities to share our educational offerings with all relevant parties, it is imperative to accurately and appropriately represent our scientific and integrous organization.

Lyme disease is a bacterial infection caused by members of the *Borrelia burgdorferi sensu lato* complex. Although the disease was initially identified in Europe, it was named after the town where the first group of US cases was described. While historically most cases clustered into certain geographic regions, the infection is increasingly widespread across the globe. Lyme disease is the most common vector-borne disease in the United States, with the Centers for Disease Control (CDC) estimating that more than 476,000 cases of Lyme disease are diagnosed each year.¹ Lyme disease is also the most common vector-borne illness in Europe.²

Lyme disease is a very dangerous infection that is often multisystemic – involving joints, heart, and the nervous system. Although early recognition and antibiotic treatment lead to resolution of illness for the majority of patients, there are many who live with persistent, debilitating symptoms, and persistent infection – which ILADS terms chronic Lyme disease.¹

Lyme disease and other tick-borne illnesses remain poorly understood, and ILADS finds that guidelines that address the illness in surveillance case terms, including those historically promoted by the Centers for Disease Control, do not serve patients well, both due to the restrictive nature of their diagnostic criteria and inadequate recommendations for treatment The <u>ILADS Treatment Guidelines</u> is a thorough review of the best science on effective treatment for particular aspects of

¹Shor S, Green C, Szantyr B, Phillips S, Liegner K, Burrascano JJ Jr, Bransfield R, Maloney EL. Chronic Lyme Disease: An Evidence-Based Definition by the ILADS Working Group. Antibiotics (Basel). 2019 Dec 16;8(4):269. doi: 10.3390/antibiotics8040269. PMID: 31888310; PMCID: PMC6963229.

Lyme disease. Since their publication, numerous studies have validated the persistence of this organism after 'standard' treatment courses.² ³ ⁴

Lyme disease is a clinical diagnosis based on the history and physical findings, and supported by appropriate laboratory tests when they are indicated. These elements must be considered in the context of the individual patient's exposure history, clinical course, constellation of symptoms, patterns of symptom manifestations and with consideration of other diagnoses that may explain or confound the patient's diagnosis. No single element of the diagnostic process outweighs the full and complete evaluation. The strengths and limitations of laboratory testing must be understood by the clinician in order to use testing modalities effectively and avoid some of the pitfalls of diagnosis that can result from over-reliance on laboratory testing to rule in or rule out an illness.

SUMMARY OF ILADS' RECOMMENDATIONS

Generally speaking, treatment decisions hinge on the presence of *Borrelia spp* and co-infections, duration of the illness, the types of symptoms and signs the person has, and how they were previously treated for these specific infections in the past.

- ILADS recommends that prophylaxis be discussed with all who have had a blacklegged tick bite. This is to prevent the onset of infection; technically speaking, antibiotic prophylaxis of a known bite is not treatment because the person is not yet ill.
- When the decision is made to use antibiotic prophylaxis, ILADS recommends 20 days of doxycycline (provided there are no contraindications). Additionally, ILADS recommends against single-dose doxycycline.
- ILADS recommends that most patients with erythema migrans receive an initial 4-6 week course of antibiotic therapy. Subsequent management decisions are based on whether the signs and symptoms remain or relapse.
- ILADS recommends that patients with persistent (chronic) signs and symptoms of Lyme disease receive individualized care that tailors antibiotic treatment to their specific situation. The duration of treatment and the choice of antibiotic or antibiotic combinations are clinical decisions to be made with several factors in mind. Long-term antibiotic therapy is not without risks and should only proceed under close supervision.

² Sapi E, Kasliwala RS, Ismail H, Torres JP, Oldakowski M, Markland S, Gaur G, Melillo A, Eisendle K, Liegner KB, Libien J, Goldman JE. The Long-Term Persistence of Borrelia burgdorferi Antigens and DNA in the Tissues of a Patient with Lyme Disease. Antibiotics (Basel). 2019 Oct 11;8(4):183. doi: 10.3390/antibiotics8040183. PMID: 31614557; PMCID: PMC6963883.

³ Feng J, Auwaerter PG, Zhang Y. Drug combinations against Borrelia burgdorferi persisters in vitro: eradication achieved by using daptomycin, cefoperazone and doxycycline. PLoS One. 2015 Mar 25;10(3):e0117207. doi: 10.1371/journal.pone.0117207. PMID: 25806811; PMCID: PMC4373819.

⁴ Johnson L, Shapiro M, Stricker RB, Vendrow J, Haddock J, Needell D. Antibiotic Treatment Response in Chronic Lyme Disease: Why Do Some Patients Improve While Others Do Not? Healthcare (Basel). 2020 Oct 3;8(4):383. doi: 10.3390/healthcare8040383. PMID: 33022914; PMCID: PMC7712932.