



Frequently Asked Questions (FAQs)

What is Lyme disease?

Lyme Disease is caused by a spirochete (spiral shaped) bacteria (*Borrelia burgdorferi*) and is transmitted by certain species of black-legged ticks, as well as the lone star tick commonly found in southern states. The nymphal, or immature, form of the tick, which is about the size of a poppy seed, causes most human cases. Because the bite is painless, many people do not realize they have been bitten. Furthermore, ticks harbor many other diseases that can be transmitted to humans aside from Lyme Disease, including other bacterial infections, viruses or parasites. Indeed, there are many diseases (some life-threatening) carried by ticks that can complicate tick-borne disease diagnosis, treatment and recovery, including Babesiosis, Tularemia, Anaplasmosis, Mycoplasma, Ehrlichiosis, Rocky Mountain Spotted Fever, *Borrelia miyamotoi*, Bartonella, Bourbon Virus, Heartland Virus, Powassan disease among others.

Lyme and tick-borne diseases are prevalent across the entire United States. Fewer than half of patients with Lyme disease recall a tick bite. Likewise, fewer than half of patients with Lyme disease recall any rash. Although the bulls-eye red rash is considered a classic sign and warrants a clinical diagnosis, it is not the most common dermatologic manifestation of early Lyme infection. Atypical forms of this rash are actually far more common.

The Lyme disease bacterium has the ability to enter the brain less than 24 hours after a tick bite. Lyme is called the “great imitator,” because it can mimic ailments such as Multiple Sclerosis (MS), Amyotrophic Lateral Sclerosis (ALS), fibromyalgia, lupus, chronic fatigue syndrome, Parkinson’s, Alzheimer’s, and autism.

Infection with Lyme disease bacteria alone can lead to early symptoms such as severe headaches, debilitating fatigue, joint pain, and skin rashes, while long-term symptoms can lead to problems related to the central nervous system, including the brain, as well as the heart, joints and other musculoskeletal problems. Symptoms of Lyme disease vary for each individual patient, and also vary in intensity over the course of the disease.

What are the symptoms of Lyme disease?



Here are a variety of symptom checklists and questionnaires to see if you or your child's symptoms may be connected to Lyme Disease:

[Dr. Horowitz Questionnaire](#)

[Symptoms of Lyme Disease in Children](#)

[Lyme Research Alliance Checklist](#)

[National Capital Lyme Checklist](#)

[Psychiatric Lyme Disease Brochure](#)

[Lyme Disease: A Neuropsychiatric Illness](#)

How do I prevent Lyme disease?

Considering there truly is [no safe harbor of time a tick can be attached](#) to avoid infection with bacterial, viral or parasitic infections, prevention is critical:

1. Avoid tick-infested areas. Be sure to walk in the middle of trails. Treat skin, clothing and gear with appropriate repellants (permethrin on clothes/gear, DEET on skin). Tuck pants into socks.
2. Perform at least daily tick checks anytime you are outdoors, even if only in your yard. Ticks can be as small as a poppy seed. Shower within 1 hour of being outdoors to help prevent ticks from attaching.
3. [Carefully remove any attached ticks](#). Use fine-point tweezers to grasp the tick as close to the skin as possible. Gently pull the tick straight out, without twisting. Save the tick for [testing](#).



4. [Consider prophylactic antibiotic treatment](#), weighing the risks/benefits if you have a known tick bite, even before symptoms appear. A disseminated infection can be much more difficult, if not impossible, to eradicate. A Lyme infection can reach the central nervous system within as little as 24 hours.

Where can I find a Lyme Literate Medical Doctor (LLMD)?

To Find a Lyme Literate Medical Doctor (LLMD) you can use the following resources:

[International Lyme And Associated Disease Society \(ILADS\)](#)

[Lyme Disease.org](#)

[Lyme Disease Association](#)

How can I get tested for Lyme disease?

A key challenge in the diagnosis and treatment of Lyme Disease stems from the lack of sufficiently sensitive and reliable markers of the disease. Based upon currently available tests, it is difficult to determine who has the disease, the effectiveness of a course of treatment, and the end point of treatment. Due to difficulty in culturing the actual bacteria, Lyme Disease tests rely upon an antibody response. Due to testing unreliability, most Lyme Literate Medical Doctors (LLMDs) advise patients to skip the initial Lyme Disease ELISA screen, and instead start with the confirmatory test, the Western Blot.

Many prefer to have a Western Blot through the lab [IGeneX](#) for four reasons:

1. IGeneX tests for multiple strains of *Borrelia Burgdorferi* (Bb), the bacteria that causes Lyme Disease (commercial labs such as Labcorp and Quest only test for a single strain of Bb; this is particularly important for those who live outside of the NE);



2. IGeneX also considers additional highly relevant bands 31 and 34 (assuming you did not have the Lyme vaccine that was briefly on the market);

3. IGeneX reveals intensity for specific bands (not present, equivocal, low, medium and high); and

4. IGeneX has outperformed other labs in proficiency testing, scoring over 98% for the past 9 years. Insurance often covers IGeneX testing, particularly if you pre-certify and/or file a form provided by IGeneX when seeking reimbursement. Medicare also covers IGeneX testing.

Western Blot test results will include both IgG and IgM assays. It is critically important that one not look at the NEGATIVE or POSITIVE summary result of the Western Blot test. Instead, it is important to carefully consider Lyme-specific bands (those bands that represent evidence of serological exposure to *Borrelia burgdorferi*). Many Lyme specialists believe that a single Lyme-specific band, along with clinical presentation, is sufficient to diagnose Lyme Disease (with an acknowledged 3% false positive rate).

Likewise, in [China](#), a single positive IgG band coupled with a single IgM band is considered to be a positive Western Blot. The following bands are generally considered to be “significant” or Lyme-specific: 18 (most sources), 22-25, 28, 30, 31, 34, 35, 37, 39, 58 (some sources), 66 (some sources), 83 and 93.

In comparison, the CDC has taken an alarmingly restrictive position on Lyme testing, transforming criteria that was developed for surveillance purposes, into diagnostic mandates. The two-tier testing paradigm for Lyme Disease recommended by the CDC misses approximately 1/2 of actual cases pursuant to numerous [peer reviewed studies](#). According to CDC criteria, you must first test positive using a highly unreliable antibody screen (EIA or IFA). Next, the CDC requires a highly criticized combination of 2 IgM bands (that they only recognize in the first 4-6 weeks of infection) or 5 IgG bands.

In a [March 2015 study](#), Johns Hopkins’ researchers found that 39% of patients with physician diagnosed erythema migrans rashes (which alone is diagnostic for Lyme Disease) remained seronegative on a Western Blot. Even more tellingly, the majority of seropositive individuals on both acute and convalescent serology had a negative IgG western blot, demonstrating that IgG seroconversion on western blot was very infrequent. In Virginia, [recently passed legislation](#) requires health care providers



to notify those tested for Lyme Disease that current laboratory testing can often produce false negative results. Unfortunately, many people are led to believe that they are “negative” for Lyme Disease based upon faulty tests.

How can I treat Lyme disease?

We recommend treating under the direction of an ILADS Trained Physician. There are a variety of modalities available.

Treatment Guidelines/Protocols

[ILADS](#)

[Dr. Burrascano Treatment Guidelines](#)

[Treatlyme.net](#)

[Cowden \(herbal\)](#)

[Buhner \(herbal\)](#)

[Byron White](#)

[Klinghardt](#)

[Detailed critique of IDSA Guidelines:](#)

[Kills Lyme Germs: A Brief Antibiotic Guide](#)



I have Lyme disease, and I don't have a support system. How can I find support?

You can obtain patient recommendations for Lyme Disease specialists, get advice from patients, and connect through local or online Lyme Disease support groups. There are many Facebook forums for Lyme Disease and related co-infections.

I am struggling financially. Where can I get help paying for Lyme disease treatment?

As a matter of public policy and consistency, we cannot share personal gofundme type fundraisers, similar to other non-profit groups. We have collected a list of financial assistance organizations – many of which are dedicated to specifically helping those individuals who may be suffering from Lyme Disease.

<http://lymediseasechallenge.org/financial-assistance/>

[Lyme-Tap – Lyme Disease Testing](#) Lyme-TAP is a patient assistance program helping patients with financial hardship pay for diagnostic Lyme testing who would otherwise be unable to afford testing.

[Needy Meds](#)

[Net Wish](#)

[Rx Assist](#)

[Bridges to Access](#)

[Demystifying Needy Meds Card](#) When can it help with insurance?

[Financial Assistance Information from The National Institutes of Health](#)

[Lyme Aid 4 Kids](#) For Patients Under Age 21

[Lyme Light Foundation](#) For Patients ages 3-25

[What is Lyme Resources](#)



[Partnership for Prescription Assistance](#)

[Prescription Hope](#)

[AAA Members Prescription Savings](#)

[Transportation Assistance and Free Air Fare](#)

[Payment to Caregivers](#)

[Free Drug Card](#) Prescription Financial Assistance

[Modest Needs](#)

[Lyme Disease Fundraisers](#)

[Saving Money on Lab Testing](#)

[Government Benefits by State](#)

[Feeding America](#) Nationwide Food Bank Locator

[National Association of Area Agencies on Aging](#) Services Available to Older and Disabled Americans

[Suggestions for Getting By on a Limited Budget](#)

[Filing for Disability When You Have Lyme Disease](#)

[Lesko.com](#) Wide Variety of Free and Reduced-cost Health Services

[Infusions for Lymies](#)

[LiveLyme Foundation](#)