

LYME DISEASE

Education · Awareness · Prevention

<http://www.ilads.org/>

Introduction – In 1970, a mysterious and deadly illness began infecting children in a small town of CT. Today, Lyme disease has reached unprecedented pervasive levels now recognized as a virulent global epidemic. Climate change is as a primary factor Lyme is growing exponentially. The CDC acknowledges Lyme disease is *underreported* with only 30,000 cases reported per year, with the true incidence of Lyme disease between 300,000 to one million cases per year – 2 times more common than breast cancer & 6 times more common than HIV infection.

Lyme disease is caused by a spirochete, *Borrelia burgdorferi* transmitted to humans by the bite of a tick. Children 5-9 have the highest rate of Lyme diagnosis and women are diagnosed more often than men. The Lyme bacterium, a cousin to the spirochete bacterium that causes syphilis, has a stealthy survival mechanism *that has yet to be determined* as to how chronic Lyme is related to the ability of *B. burgdorferi* to penetrate tissue sites, live intracellularly, evade the immune system and survive antibiotic therapy. All these morphologies & clever invasion/evasive capabilities explain why Lyme infection can cause such wide-ranging multisystem involvement and why treatment is so highly difficult. This also explains why recurrence of symptoms can still occur after standard antibiotic protocols. Complicating matters further, ticks can also infect you with a number of other serious disease-causing co-infection organisms that may **not** be responsive to antibiotics.

Lyme disease is notoriously difficult to diagnose and reliable blood tests to detect Lyme infection are not yet available, nor is a vaccine. The number of people who are misdiagnosed or underdiagnosed each year is staggering. Lyme can mimic many other serious disorders including: Parkinson's; Multiple Sclerosis (MS); Arthritis; Chronic Fatigue Syndrome; Fibromyalgia; ALS; Colitis/Irritable Bowel Syndrome; Lupus; Thyroid Disease; Prostatitis; Psychiatric Disorders (bipolar & depression); Sleep Disorders; and Alzheimer's disease. **IT IS PRUDENT TO SEEK OUT A LYME-LITERATE MD. WHETHER OR NOT YOU CHOOSE TO GET PROPHYLACTIC TREATMENT AFTER A TICK BITE, IT IS IMPERATIVE TO BE VIGILENT FOR SYMPTOMS THAT MAY SUGGESTS ACTIVE INFECTION.**

The longer the tick is attached, the higher risk of transmission, however, *it is possible to get Lyme disease even if the tick is attached for less than 24 hours.* Furthermore, there are serious flaws in treatment considerations: An erythema migrans rash, which includes both the well-known bulls-eye rash as well as a solid red rash, does **not** universally occur in people with Lyme disease. Studies support rash occurs in only 35-60% of infected people. Using the absence of a rash as proof that there is no infection is extremely poor reasoning. **MAINE EMERGENCY ROOMS ARE NO LONGER SENDING TICK SAMPLES TO THE STATE & PROPHYLACTICALLY TREAT ALL TICK BITES AS LYME-INFECTED.**

International Lyme and Associated Diseases Society (ILADS) is a nonprofit, international, multidisciplinary medical society dedicated to the appropriate diagnosis and treatment of Lyme and associated diseases. ILADS strongly promotes understanding of Lyme through research, education & policy while supporting physicians and

other health care professionals devoted to **advancing the standard of care** for Lyme and its associated diseases. ILADS is a trusted cutting edge resource that has twice published **evidence-based guidelines in 2004 and 2014** to elucidate the foundations of the chronic disease paradigm. Both guidelines have been listed in the [National Guideline Clearinghouse](#) to allow physicians to understand the chronic disease paradigm:

<http://www.ilads.org/lyme/treatment-guideline.php>

PREVENTION

ILADS is committed to the prevention of chronic Lyme disease. The following ILADS tips offer guidance to minimize the risk of contracting chronic Lyme.

<http://www.ilads.org/lyme/lyme-tips.php>

1. Know that Lyme disease is a nationwide problem contrary to popular belief. Lyme disease is not just an "East Coast" problem. In fact, in the last ten years, ticks known to carry **Lyme disease have been identified in all 50 states and worldwide**. Although the black legged tick is considered the traditional source of Lyme disease, new tick species such as the lone star tick and a pacific coast tick, have been found to carry *B. burgdorferi*, the corkscrew-shaped bacterium that causes Lyme disease. **Avoiding a tick bite** remains the first step in preventing chronic Lyme disease. One needn't have been "hiking in the woods" in order to be bitten by a tick. There can be ticks wherever there is grass or vegetation, and **tick bites can happen any time of year**. Spraying one's clothes with DEET-containing insecticide, wearing long sleeves & long pants, & tucking pants into white socks, continue to be the best ways to avoid ticks attaching to the skin. **Don't forget the post-walk body check.**
2. **Check your tick facts:** Ticks can vary in size from a poppy-seed size nymphal tick to a sesame-seed size adult tick. The ticks can carry other infectious agents besides the spirochete that causes Lyme disease, including Ehrlichia, Anaplasmosis, Babesia, and Bartonella. Lyme disease can sometimes be hard to cure if these other infections are not treated at the same time.
3. **Show your doctor every rash.** The bull's eye rash is the most famous, but there are many other types of rashes associated with Lyme disease. In fact, Lyme disease rashes can be mistaken for spider bites or skin infections. Take photos and make sure a medical professional sees the rash before it fades.
4. **Don't assume that you can't have Lyme disease if you don't have a rash.** Lyme disease is difficult to diagnose without a rash, Bell's palsy, arthritis, or meningitis, but you can still have Lyme and not have any of those signs or symptoms. Many people react differently to the infection and experience fatigue, headaches, irritability, anxiety, crying, sleep disturbance, poor memory and concentration, chest pain, palpitations, lightheadedness, joint pain, numbness and tingling.
5. **Do not rely on test results.** Currently there is no reliable test to determine if someone has contracted Lyme disease or is cured of it. False positives and false negatives often occur, though false negatives are far more common. In fact, some studies indicate **up to 50%** of the patients tested for Lyme disease receive false negative results. As a result, the CDC relies on physicians to make a clinical diagnosis based on a patient's symptoms, health history, and exposure risks. Doctors who are experienced in recognizing Lyme disease will treat when symptoms typical of the illness are present, even without a positive test, in an effort to prevent the development of chronic Lyme disease.
6. **Be aware of similar conditions** **Chronic Lyme disease** is called the "great imitator" because it is often misdiagnosed as another condition such as Multiple Sclerosis, Fibromyalgia, chronic fatigue, or anxiety. Misdiagnosis is a common experience for patients with chronic Lyme disease. Treatments that work for these other illnesses are not appropriate for treating Lyme disease. **Currently, the only effective treatment for Lyme disease is antibiotics. Ask your doctor to carefully evaluate you for Lyme disease even if your tests are negative.**
7. **"Wait and See" approach to treatment may be risky.** Up to fifty percent of ticks in Lyme-endemic areas are infected with Lyme or other tick-borne diseases (*other studies support higher percentages*). With odds like that, if you have proof or a high suspicion that you've been bitten by a tick, taking a "wait and see" approach to deciding whether to treat the disease has risks. **The onset of Lyme disease symptoms can be easily overlooked or mistaken for other illnesses. Once symptoms are more evident the disease may have already entered the**

central nervous system, and could be hard to cure. This is one case in which an ounce of prevention really is worth a pound of cure.

8. Don't be afraid to get a second opinion. Recognize that opinions on how to diagnose and treat Lyme disease vary widely among physicians. It is worth getting a second or even a third opinion, especially if you are symptomatic and your doctor advises not to treat, or symptoms recur or persist after treatment. Keep in mind that your physician may focus too narrowly on diagnosing and treating a single symptom. For example, a physician may diagnose a pain in your knee as "arthritis", and not see this as just one part of a larger set of symptoms that adds up to a diagnosis of Lyme disease, which requires different treatment.

9. Know your treatment options. Work with your doctor to identify the appropriate treatment option if your symptoms persist. There is more than one type of antibiotic available. Longer treatment is also an option. You should also work with your doctor to make sure you don't have another condition.

10. Expect success. Have hope.

Basic Information about Lyme Disease

by the International Lyme and Associated Diseases Society

<http://www.ilads.org/lyme/about-lyme.php>

- 1. Lyme disease is transmitted by the bite of a tick, and the disease is prevalent across the United States and throughout the world.** Ticks know no borders and respect no boundaries. A patient's county of residence does not accurately reflect his or her Lyme disease risk because people travel, pets travel, and ticks travel. This creates a dynamic situation with many opportunities for exposure to Lyme disease for each individual.
- 2. Lyme disease is a clinical diagnosis.** The disease is caused by a spiral-shaped bacteria (spirochete) called *Borrelia burgdorferi*. The Lyme spirochete can cause infection of multiple organs and produce a wide range of symptoms. *Case reports in the medical literature document the protean manifestations of Lyme disease, and familiarity with its varied presentations is key to recognizing disseminated disease.*
- 3. Fewer than 50% of patients with Lyme disease recall a tick bite.** In some studies this number is as low as 15% in culture-proven infection with the Lyme spirochete.
- 4. Fewer than 50% of patients with Lyme disease recall any rash.** Although the erythema migrans (EM) or "bull's-eye" rash is considered classic, it is not the most common dermatologic manifestation of early-localized Lyme infection. Atypical forms of this rash are seen far more commonly. *It is important to know that the EM rash is pathognomonic of Lyme disease and requires no further verification prior to starting an appropriate course of antibiotic therapy.*
5. The Centers For Disease Control And Prevention (CDC) surveillance criteria for Lyme disease were devised to track ***only* a narrow band** of cases for epidemiologic purposes. **As stated on the CDC website, the surveillance criteria were never intended to be used as diagnostic criteria**, nor were they meant to define the entire scope of Lyme disease.
- 6. The Elisa screening test is unreliable. The test misses 35% of culture proven Lyme disease (only 65% sensitivity)** and is *unacceptable* as the first step of a two-step screening protocol. *By definition, a screening test should have at least 95% sensitivity.*
- 7. Of patients with acute culture-proven Lyme disease, 20–30% remain seronegative on serial western blot sampling.** Antibody titers also appear to decline over time; thus while the western blot may remain positive for months, it may not always be sensitive enough to detect chronic infection with the Lyme spirochete. For "epidemiological purposes" the CDC eliminated from the western blot analysis the reading of bands 31 and 34. These bands are so specific to *Borrelia burgdorferi* that they were chosen for vaccine development. Since a vaccine for Lyme disease is currently unavailable, however, a positive 31 or 34 band

is highly indicative of Borrelia Burgdorferi exposure. Yet these bands are **not** reported in commercial Lyme tests.

8. **When used as part of a diagnostic evaluation for Lyme disease, the western blot should be performed by a laboratory that reads & reports all of the bands related to Borrelia Burgdorferi.** Laboratories that use FDA approved kits are restricted from reporting all of the bands, as they must abide by the rules of the manufacturer. *These rules are unfortunately set up in accordance with the CDC's surveillance criteria and increase the risk of false-negative results.* The commercial kits may be useful for surveillance purposes, but they offer too little information to be useful in patient management.
9. **There are 5 subspecies of Borrelia Burgdorferi, over 100 strains in the USA, and 300 strains worldwide.** This diversity is thought to contribute to the antigenic variability of the spirochete and its ability to evade the immune system and antibiotic therapy, leading to chronic infection.
10. **Testing for Babesia, Anaplasma, Ehrlichia and Bartonella (other tick-transmitted organisms) should be performed.** The presence of co-infection with these organisms points to probable infection with the Lyme spirochete as well. If these coinfections are left untreated, their continued presence increases morbidity and prevents successful treatment of Lyme disease.
11. A preponderance of evidence indicates that active **ongoing spirochetal infection with or without other tick-borne coinfections is the cause of the persistent symptoms in chronic Lyme disease.**
12. **There has never been a study demonstrating that 30 days of antibiotic treatment cures chronic Lyme disease.** However there is a plethora of documentation in the US and European medical literature demonstrating by histology and culture techniques that *short courses of antibiotic treatment fail to eradicate the Lyme spirochete.* Short treatment courses have resulted in upwards of a **40% relapse rate**, especially if treatment is delayed.
13. **Most cases of chronic Lyme disease require an extended course of antibiotic therapy to achieve symptomatic relief.** The return of symptoms and evidence of the continued presence of Borrelia Burgdorferi indicates the need for further treatment. The very real consequences of untreated chronic persistent Lyme infection far outweigh the potential consequences of long-term antibiotic therapy.
14. **Many patients with chronic Lyme disease require prolonged treatment until the patient is symptom-free.** Relapses occur and retreatment may be required. There are no tests currently available to prove that the organism is eradicated or that the patient with chronic Lyme disease is cured.
15. **Like Syphilis in the 19th century, Lyme disease has been called the great imitator** and should be considered in the differential diagnosis of rheumatologic and neurologic conditions, as well as Chronic Fatigue Syndrome, Fibromyalgia, Somatization Disorder and any difficult-to-diagnose multi-system illness.
16. **UP TO FIFTY PERCENT OF TICKS IN LYME-ENDEMIC AREAS ARE INFECTED.**
The onset of Lyme disease symptoms can be easily mistaken for other illnesses. Once symptoms are more evident the disease may have already entered the central nervous system & could be hard to cure. **Some studies report greater than 50%.**
17. **40% OF LYME PATIENTS END UP WITH LONG TERM HEALTH PROBLEMS.**

ADDITIONAL RESOURCES

▪ **How to safely remove a tick:**

Irrespective of the time of year or size of the tick it is prudent to save all ticks in order to get it tested for Lyme and other possible pathogens. In the Fall, deer ticks are much larger compared to their tiny size in the Summer. The concern is that people erroneously disregard a large tick as a potential concern because of its size.

<http://www.ilads.org/lyme/what-to-do-if-bit-by-tick.php>

MAINLY TICKS - Tick Identification, Removal and Submission Kit: <http://www.mainelyticks.com/>

TICK KEY: <http://www.amazon.com/RED-TickKey-Tick-Removal-Tool/dp/B00136R1V6>

TICK TWISTER: http://www.amazon.com/Tick-Twister-Remover-Small-Large/dp/B00X7072HY/ref=zg_bs_2975390011_1

▪ **Lyme Disease Videos by ILADS** (*includes UNDER OUR SKIN which exposes a hidden story of medical & scientific malfeasance & neglect*). <http://www.ilads.org/lyme/lyme-videos.php>

▪ *Information provided in this article can be further researched at:*

<http://www.ilads.org/>

-- Kathleen Mary, Arrowsic Health Officer