



Lyme Disease Straight Talk

Q & A

When did this disease start, and where?

The bacteria (*Borrelia*) that cause Lyme disease are ancient. In 2011, *Borrelia* DNA was identified in the bone of a 5000 year old mummy discovered in the Alps dubbed Otzi, or the "Ice Man," along with bone lesions indicating that he had the disease. Although historic medical texts lists diseases with similar symptoms over the past several hundred years, the first cases of what came to be called Lyme disease in the United States were reported in Old Lyme, CT in 1975, with the tick identified as the vector and *Borrelia* as the cause identified by Burgdorfer in 1981.

Why is this disease called "The Great Imitator"?

The symptoms of Lyme disease often mimic the symptoms of many other diseases. Lyme disease is often misdiagnosed as the flu, migraines, multiple sclerosis, chronic fatigue, ALS, lupus, mental illness, and dozens of other ailments.

What is all of this talk about "co-infections"? I thought there was just one disease called "Lyme disease".

Lyme disease is currently described as being "caused" by infection with *Borrelia burgdorferi* only, but more often there are other bacteria involved as well. Several species of *Borrelia* cause disease, with *B. myamotoi* being the most recently identified. In addition, people with Lyme disease are also often infected with other tick-borne pathogens, including the protozoa *Babesia*, the bacteria *Bartonella*, *Ehrlichia*, *Anaplasma*, and/or *Mycoplasma*. Although the diseases caused by these organisms all have different names (for example, *Ehrlichia* causes ehrlichiosis), they may all contribute to the complex and protean symptoms of Lyme disease. All are serious diseases that require professional medical attention.

Tell me about the two medical Lyme tests ("ELISA" and "Western Blot").

The recommended testing strategy for Lyme disease involves two tests (a "two-tier" approach). The ELISA is the first tier, and tests for antibodies in the blood indicating infection or exposure to *Borrelia*. The second test, the Western Blot, is a more complex test that looks for very specific antibodies. It's important to note that the ELISA test has a sensitivity of less than 50% (meaning, it's wrong more than half the time), and when the "two-tier" approach is implemented, the sensitivity increases only to about 70%.

Because the sensitivity of the first tier test is so low, people who have a negative test may be told that they don't have Lyme disease, even if they have all the symptoms. If a Western Blot is done, you might still be told that your test was negative because the standards of interpretation vary. Many people who actually do have Lyme disease will be told that they don't.

Do these tests cover co-infections?

The Western Blot and the ELISA test are only for Lyme disease caused by *Borrelia burgdorferi*. Your doctor would have to specifically request other tests for the other pathogens.

Can you give me examples of tick-disease symptoms?

There are dozens of possible symptoms. For Lyme disease they include:

- *Headache*
- *Burning or stabbing sensations; shooting pains*
- *Joint pain, swelling; stiffness of joints or back*
- *Muscle pain or cramps*
- *Neck stiffness, pain; neck creaks or cracks*
- *Chest pain; rib soreness*
- *Sore throat; swollen glands*
- *Upset stomach or abdominal pain*
- *Shortness of breath; cough*
- *Change in bowel function*
- *Bladder dysfunction; irritable bladder*
- *Testicular pain; pelvic pain*
- *Unexplained breast pain*
- *Unexplained milk production*
- *Numbness; tingling; tremor*
- *Facial paralysis (Bell's Palsy)*
- *Twitching of the face or other muscles*
- *Skin hypersensitivity*
- *Fatigue, tiredness, poor stamina*
- *Unavoidable need to sit or lie down*
- *Unexplained fevers, sweats, chills or flushing*
- *Unexplained menstrual irregularity*
- *Unexplained weight loss or gain*
- *Unexplained hair loss*
- *Eyes: double, blurry, or vision loss, floaters light sensitivity*
- *Ears: hearing loss; buzzing, ringing, pain, sound sensitivity*
- *Pulse skips; cardiac impairment*
- *Heart block; heart murmur*
- *Heart palpitations; heart valve prolapse*
- *Sleep: disturbed; too much; too little; frequent or early waking*
- *Sexual dysfunction or loss of libido*
- *Mood swings; depression; irritability*
- *Forgetfulness; poor short-term memory*
- *Difficulty thinking; confusion; poor attention*
- *Problem absorbing new information*
- *Difficulty with speech, writing*
- *Difficulty with concentration and reading*
- *Difficulty finding words; name blocking*
- *Disorientation; getting lost, going to wrong places*
- *Lightheadedness; poor balance*
- *Vertigo, wooziness*
- *Increased motion sickness*
- *Exaggerated symptoms or worse hangover from alcohol*

Since the symptoms vary so much, how do I know if I, or a loved one, even has a tick-borne disease?

If you are bitten by a tick, or if you start to experience some of the symptoms listed above, Lyme disease should be on your mind. If you are bitten by a tick and you know it, request that your doctor prescribe a full course of antibiotic (not just a single day treatment). If you have "mysterious" symptoms but don't remember a tick bite, ask your doctor to test for Lyme disease (the Western Blot) and also the tick-borne co-infections. Unfortunately, your doctor may be reluctant and you may have to strongly advocate for an antibiotic.

You mention the term “Lyme Literate” doctor, can you please explain what this means?

There are a number of doctors in the country who have had so much experience with Lyme patients that they have become experts in the field. Most of these doctors follow the clinical practice guidelines developed by the International Lyme and Associated Diseases Society (ILADS).

How do I go about finding a doctor who works with the ILADS guidelines?

There are Lyme disease advocacy groups across the country who will help you find a doctor. If you don't know of a support group in your area, LymeDisease.org is a national organization who can provide you with a place to start. Their website is www.lymedisease.org

Will my health insurance cover Lyme medical costs?

Health insurers typically cover blood tests, and if there's a diagnosis of Lyme disease they will cover antibiotics (IV for 1 month, oral antibiotics longer term). However, since there is no consensus on why Lyme disease symptoms don't go away after short-term treatment, your insurance may decline claims for medical care that does not conform to the rigid IDSA clinical practice guidelines. You should be prepared to appeal the decisions of your insurance company as they pertain to Lyme disease coverage and consider seeking legal counsel if your claims are unfairly denied.

What are some preventive measures that I can do to protect me and my family?

Prevention is critical. Wear light colored clothing when you are in a tick environment. Tuck your pant legs into your socks and spray your clothing with an insecticide that kills ticks. Wear a hat. Use an insect repellent that contains DEET (30% is recommended). Check yourself and your family for ticks after you've been outside. Remove your clothing and put them in the dryer for 5 minutes on hot to kill ticks on clothes. Treat your yard or perimeter with an insecticide containing permethrin. Talk to your veterinary about tick prevention treatments for your pets.

Is there a movie about Lyme disease?

Under Our Skin is an award-winning documentary produced by Andy Abrahms Wilson that explores the complex medical and political issues that define the Lyme disease epidemic and political debacle. It can be found at most libraries or through Netflix streaming, Hulu, and other streaming providers.

How can I help?

You can help by being informed and helping others to get informed. You can help by asking your elected officials to fully understand the issues, and then advocate for doctor protection; insurance reform; guideline reform; better medical education; and more (and better) research! Visit www.lymedisease.org for comprehensive information, and www.ilads.org for detailed medical information.