

LYME MISSED: MISDIAGNOSED & MISTREATED

We are experiencing an absolute epidemic of Lyme disease in the United States. Making things even worse is that many physicians don't understand or deny that Lyme is so serious. It's a tragedy!

Lyme disease was so-named because it was "discovered" in Lyme, CT. It is most common in New England, up and down the east coast, and the Midwest. But I've known individuals with Lyme who live in Texas, south America, Europe, and Asia. As I said, it's an epidemic.

When we speak of Lyme disease, we mean not only *Borrelia*, the name of the Lyme organism itself, but many co-infections that infected individuals also have. These co-infections include Babesia, Bartonella, Brucella, Chlamydia, Ehrlichia, Mycoplasma, Rocky Mountain Spotted Fever, Tularemia, and a variety of viruses. You get Lyme by being bitten from a tiny deer tick, a tick so small that you can barely see it. Some individuals who are bitten by the deer tick may find the tick on their body or see a "bull's-eye" rash, but most people don't find the tick and don't have a rash.

Infections with *Borrelia* and its co-infections brethren typically have a gradual onset, often with a flu-like illness. People can have unexplained fevers or hot and cold spells. Memory, planning, reading, brain processing, and judgment may be impaired. In severe cases it can literally become impossible to string together words to make a sentence. Fatigue and exhaustion are common. Sleep problems—often severe—are almost invariably present. Headaches are common. Infected people are often moody and irritable. Individuals may have gastrointestinal disturbances. Sensitivity to sounds is increased, so that people can feel assaulted by the world around them. Light sensitivity is common. Bell's palsy can occur—a mild or not so mild—one-sided facial drooping. In fact, in my opinion, Bell's palsy is always due to Lyme disease until proven otherwise. Infected individuals can have erratic blood pressure changes or life-threatening changes in heart electrical rhythms. My experience, and that of others who are very familiar with Lyme, is that chronic fatigue syndrome and fibromyalgia are often caused by Lyme and co-infections.

What a list! The reality is that infection with Lyme and its co-infections can cause or contribute to virtually any medical, neurological, or psychiatric problems. As a psychiatrist, I've seen Lyme mimic ADD, anxiety disorders, depression and bipolar disorder, OCD, and schizophrenia. Sometimes, but not all of the time, when we treat the underlying infections, we see all of these "psychiatric" problems melt away. Lyme is also likely involved with ALC (Lou Gehrig's disease), multiple sclerosis, autism, and various forms of dementia, including Alzheimer's disease.

How do you make a Lyme diagnosis? Well, blood tests are fallible, so currently a diagnosis of Lyme is a *clinical* one. This is so important that it bears repeating: Lyme is a clinical diagnosis, made by a clinician with extensive experience with these infections. Individuals suspected of having Lyme should consult a "Lyme Literate Medical Doctor" ("LLMD"), typically a clinician

who is a member of the leading organization for Lyme called ILADS (International Lyme and Associated Diseases Society, www.ilads.org).

As I've just explained, a diagnosis of Lyme and co-infections is made by an LLMD who takes a detailed clinical history, does a thorough physical exam, and orders appropriate laboratory testing.

Laboratory testing for Lyme leaves much to be desired. Let me explain why. Commonly-done testing by Quest or LabCorp, using the standard "Western Blot" testing, often gives a result that is a false-negative. That means that, if you get a negative result, you don't know if you can trust it. Therefore, we commonly use specialty labs to try to diagnose Lyme such as IGeneX labs (www.igenex.com). IGeneX focuses solely on Lyme and co-infections, so they've become very good at detecting these illnesses. Even IGeneX testing is not perfect, but it typically is much better than most other labs.

What many don't understand, and why Lyme testing with most labs is often worse than useless—because it can be misleading—is that CDC (the United States Centers for Disease Control) criteria for Lyme are based on surveillance criteria, not criteria for actual clinical diagnosis. This is a complicated, complex, politically-charged issue. I won't go into all the nuances of this. Suffice it to say that even many doctors don't understand that the so-called CDC criteria, upon which most testing (but not IGeneX and other specialty labs) is based, are not useful for making an actual clinical diagnosis in a patient, because of their high false negative rate. This has confused many doctors, who are not aware of the nuances of this diagnostic issue, resulting in many infected patients being told that they do not have Lyme when they actually do. It's a real disaster, one of the most confusing and contentious issues I've seen in my many years as a physician, resulting in missed diagnoses and misdiagnosis. Often, struggling individuals end up being told that they have a psychiatric disorder because their physicians cannot figure out what is wrong. What a mess.

To make things even worse, physicians who are active in diagnosis and treating tick-borne infections like Lyme are being targeted by insurance companies and medical boards. Some have been forced out of medical practice and driven into bankruptcy. Their personal and professional lives have been ruined.

Lest I end by leaving you depressed and discouraged, let me say that help is available for Lyme and other tick-borne infections and there is reason for hope. Infected people can get better. There are courageous clinicians who are willing to diagnose and treat these patients the right way. But you must take matters into your own hands. Research your condition. Seek out clinicians who have experience. Ask questions and then ask more questions. You need to have a doctor who will spend time with you. The initial visit with a LLMD typically lasts about three hours. Is your doctor spending three hours with you? Probably not. Find one who will, and you'll likely get better, which is what I've found with my daughter Elizabeth, who struggled for many years with Lyme, but who has improved markedly once we figured out what was wrong with her and found her the treatment she needed. Never give up hope!

Joseph A. Annibali, M.D. is Chief Psychiatrist at Amen Clinics, Washington, DC and author of *Reclaim Your Brain—How to Calm Your Thoughts, Heal Your Mind, and Bring Your Life Back Under Control*.