

SCIENCE, FEAR, AND THE REALITIES OF LYME DISEASE IN CANADA

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I am a scientist and a Lyme disease sufferer, and I am writing to warn you about the realities of Lyme disease, and the failure of our governments to acknowledge its prevalence in Canada. This story is filled with controversy, I am one of its victims, and I am far from alone.

First, let me introduce the culprit. Lyme disease is caused by *Borrelia burgdorferi*, a bacterium transmitted by the bite of an infected tick. Contrary to popular belief, you don't have to have a large insect attached to your skin for 24 hours to get infected. These ticks can actually be difficult to spot as they are often smaller than a poppy seed and they tend to climb inside clothing before they feed. When infected, the first sign is often an expanding bull's eye shaped rash accompanied by flu-like symptoms. Without immediate antibiotic treatment, the infection disseminates throughout the body and the bacterium, which is shaped like a corkscrew, can literally drill its way through cells, and ultimately reach every organ, including the brain. Once the rash has disappeared, Lyme becomes very difficult to diagnose. It has been called the "master mimic" because it can imitate many other illnesses: multiple sclerosis, fibromyalgia, lupus, chronic fatigue syndrome, rheumatoid arthritis, psychiatric disorders, and the list goes on. In short, these are all chronic conditions, for which there are no cures. Without adequate treatment, many if not most of those who have Lyme eventually become unable to work or take care of themselves. Some become confined to wheelchairs, and some bed ridden. As you can see, this is a very serious illness.

The good news is that, unlike these other medical conditions, many patients recover from Lyme with antibiotic therapy. The bad news, as many Lyme sufferers will tell you, is that it is virtually impossible to get it diagnosed and treated in Canada. Here is my experience.

I had the characteristic bull's eye shaped rash in 2006. I didn't recognize it, or the flu-like symptoms that I had at the time, as telltale signs of early Lyme disease. Over the next few months, I began to develop neuromuscular problems: shoulder pain, cramps in my forearms, numbness in both hands, joint swelling, clumsiness. Over time, my neck and back became increasingly tight and painful.

These symptoms continued to worsen, and, in spite of physiotherapy, I became unable to write, cook, hold the phone, or even wash my hair. I saw many doctors - none could explain my condition. "There is no physiological reason, you should try to meditate", said one. After a year and a half of increasing disability, I had to put my PhD dissertation on hold, not knowing if I would be ever be able to return to work. I underwent extensive medical tests; MRI, EMG, etc. Nothing. One doctor advised me to "stop looking for the cause, and simply accept the fact that I had become disabled."

Then I saw a TV special about Lyme disease. I recognized the bull's eye rash immediately. Sure enough, all of my symptoms had appeared after this strange rash. Furthermore, by then I had also developed a ringing in my ears, bouts of dizziness, confusion, migraines, and night vision problems. All of these symptoms, as it turns out, were typical of untreated Lyme.

I was shocked, however, when my doctor told me that the results of my Lyme test was negative, which meant that I did not have Lyme. He still could not explain any of my symptoms, and, shrugging, he offered me sleeping pills and antidepressant medication, due to their supposed tertiary benefits for sufferers of chronic pain such as that caused by fibromyalgia. Unconvinced, I

consulted an Infectious Diseases specialist, who told me that Lyme disease seemed to have turned into some sort of ‘disease-du-jour’ and that my negative test was definitive.

I went home in disbelief. Being a scientist, and armed with the ability to read scientific literature, I began to conduct the sort of critical research that I had been trained to perform. In the process, I discovered that there is a good deal of disagreement within the medical community over the nature of Lyme infection, as well as over the accuracy of the serological tests relied upon by physicians.

I decided to seek the help of a US physician who treats Lyme based upon patients’ clinical symptoms, regardless of their serological results - as recommended by the US CDC. That physician not only treated me for Lyme, he suspected that I, like many others, was also suffering from a co-infection acquired at the same time that I was infected with Lyme. Further testing for tick-borne co-infections, which no other physician had ever recommended, revealed that I was also infected with a tick-borne malaria-like blood infection called babesia. When I shared these results with my previous physician, he was suitably chastened, and he acknowledged, in writing, that my specialist had been “very helpful in finding the diagnosis.” I have now been in treatment for these infections for a few years and I have made tremendous progress. I have slowly regained the use of my hands, and my neuromuscular symptoms are virtually gone! After years of hell, I can now once again sit at a computer and type, which has enabled me to resume and my doctoral program.

As a scientist, however, my research on the controversy concerning Lyme is not over.

According to the British Columbia Center for Disease Control, Lyme is extremely rare in BC. The number of cases, however, is much higher in the states just south of us. The US Center for Disease Control estimates that the number of new cases in the US may be as high as 200,000 annually, i.e. more than AIDS and West Nile combined! In Canada, however, the number remains extremely low.

So... what's going on?

In the US, there are two sides to the Lyme debate. On the mainstream side is the Infectious Diseases Society of America (IDSA), who advocate the use of a two-tier antibody Lyme test, and who claim that Lyme can be cured with a few weeks of antibiotics. When symptoms remain beyond their recommended treatment, they are usually attributed to “post-Lyme syndrome”, an auto-immune condition that has no cure. On the other side, is the International Lyme and Associated Diseases Society (ILADS), a smaller group of doctors who are in strong disagreement with the IDSA over Lyme. ILADS argues that the antibody tests for Lyme are unreliable, and emphasizes that Lyme should be diagnosed clinically. ILADS also recommends a more aggressive treatment, in which months or years of antibiotics may be required if the infection is not diagnosed early. Many people, like me, find much better results with ILADS’ approach than that of the IDSA. However, most US insurance companies will only cover the short IDSA treatment, leaving Lyme patients with medical bills sometimes totaling hundreds of thousands of dollars. It is therefore no surprise that advocacy groups are becoming increasingly vocal. Interestingly, the IDSA has recently agreed to reconsider its Lyme guidelines, after a lengthy investigation of its Lyme Panel members by the Connecticut Attorney General, for having undisclosed conflicts of interests.

The difference between Canada and the US on the matter of Lyme is that Canadian authorities have basically adopted the IDSA guidelines, and there is simply no other option available to the

public. As a response to the growing number of Canadians who have raised questions about false-negative Lyme test results, some hospitals have actually forbidden their physicians from diagnosing Lyme without positive serological evidence, fearing that individuals who are not genuinely infected would be given antibiotics unnecessarily. This practice of turning away seronegative patients is not only flawed, it is outright dangerous! The reason is that many seronegative patients are in fact infected. My research has revealed that the company that manufactures the test kits in question, MarDX, states in its test kit literature (a copy of which I possess) that "A negative western blot does not exclude the possibility of infection with *B. burgdorferi*." According to the data in the test kit literature, false negative test results are in fact not rare at all - MarDX reports a test sensitivity of only 52% two months after infection, and 81% a year after infection. The categorical refusal by some hospitals to treat seronegative patients, despite the explicit admission in the test kit literature that false negatives results do indeed occur, condemns some who truly have Lyme to a life of serious disability. Canadian laboratories, meanwhile, which are well aware of the limitations of this test, are not conveying this information to doctors, and what's more, they do not relay the details of the test results to our physicians. Unlike US physicians who receive detailed reports, Canadian physicians receive only a "positive" or "negative" interpretation from the laboratory based on predetermined cutoffs, which are not universally accepted. That is, Canadian laboratories, rather than our physicians, are calling the shots. Many physicians are fearful of diagnosing Lyme based upon patients' clinical symptoms, despite repeated claims by the BCCDC and the Public Health Agency of Canada, that physicians are free to diagnose and treat Lyme even with a negative blood test. Lyme has become a spectre, and those patients who claim to have it are being shunned by our medical practitioners, who fear censure by the College of Physicians. Many Canadian patients have been forced to seek treatment in the US.

I have written many letters to our health authorities about my experience and my concerns regarding this problem. Unfortunately, the answers that I have received thus far have been few, vague, and contradictory, and have not demonstrated willingness to remedy this problem. This refusal to acknowledge the failure of the current diagnostic tests is both scientifically and intellectually dishonest. Canada's scientific and medical communities should not stand idly by in the face of such flawed diagnostic policy. Ill patients should be treated clinically, and physicians must not fear retribution when seronegative patients present with very clear symptoms of Lyme infection.

It is my sad conclusion that the likelihood of getting diagnosed accurately with Lyme disease in Canada is slim. But I am pleased to see more stories about this in the media, which brings me much hope that others, like me, will recognize this infection, and that they will find the help that they desperately need.