
LIFE WITH A TWIST OF LYME

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I was a Resident Assistant during my senior year at BC. Sitting in a circle during team-building training, my Resident Director encouraged us to get to know one another by responding to questions: "Tell us the story of a trip you took this summer." "Tell us your favorite thing to do in Boston." Then she mentioned the elephant in the room. "Or you can tell us the story of a scar you have." I tried to pull down my t-shirt sleeve to cover it more, but the unusual scar was still visible on my arm. You could see the hole where the tube went in, the four dotted corners where it was sewn into me. I stared at the floor. While I was at BC, I was not ready to tell the story of my scar, my most visible mark of Lyme disease. But now I am.

When I was a junior in the fall of 2002, I lived in 90 St. Thomas More Hall. I woke up one October morning with an inexplicable stabbing pain in the fingers of my left hand, so I popped some Advil to get through that morning's classes. In the days that followed, joint pain became my constant companion. In the span of a minute, the pain moved around, and I could feel joints throbbing in a rhythm. Ankle, ankle, ankle, finger, finger, finger, shoulder, shoulder, shoulder - it was as if I had a new heartbeat. Pangs thumped and pierced through me, each joint an instrument in a symphony of transient pain. At the same time, I felt a little tired. I found myself irritable, crying. I thought it was just stress. When the pain wouldn't go away after a few days, I realized it wasn't just a

cold or the flu. I scheduled an appointment at University Health Services. I remember the physician asked me, "What's your top complaint?" I couldn't name just one; there was this odd arthritis that pulsed through my body, some tiredness, some irritability. I named the joint pain, and the doctor said they would run some tests.

I returned to Health Services a week or so later, still undiagnosed but symptomatic, to be told that all of my tests came back negative. I did not show signs of an autoimmune disease like rheumatoid arthritis; my blood work looked normal. I wasn't sure what was happening but mentioned the possibility of Lyme disease, with which my relative had recently been diagnosed. "Do your knees hurt?" asked the doctor. I shifted in place, the white paper crinkling beneath me. "No," I replied. It was usually a shooting pain in my left hand, my fingers, that kept me awake at night, that stabbed through me when I was studying in Bapst or trying to do genetics research in Dr. O'Connor's lab. "It's just this arthritis that moves around, I've never had it before, it hurts so much," I trailed off, unable to better explain the strange sensations. The doctor shook his head. "If your knees don't hurt, then you don't have Lyme," the doctor said matter-of-factly. "And your Lyme bloodwork was negative." I was happy to hear that. I had never hiked or camped, so I felt that Lyme would be an unlikely

diagnosis for me, anyway. I had no idea what Lyme disease was; I only knew it was caused by a tick bite. Content, but still puzzled as to why I was hurting, I didn't know enough to ask to look at my blood test results at the time.

Had I looked, I would have seen that I had a blood test that wasn't exactly negative for Lyme. Lyme disease was first described in the United States in 1977. The Centers for Disease Control and Prevention (CDC), in conjunction with local and state health departments, began nationwide surveillance for the disease beginning in 1980.¹ In 1991, Lyme disease was designated as a nationally notifiable disease, meaning that physicians were required to report cases to their local health departments for purposes of tracking the infection. Therefore, physicians needed to know what "counted" as a positive Lyme disease case that must be reported. Consequently, the CDC drafted surveillance criteria for Lyme disease based on Western blot testing, which tests for antibodies that the body makes to fight off infection. The surveillance criteria required that physicians report cases to the CDC when the Western blot test showed "diagnostic levels" of antibodies; however, the CDC did not set national guidelines for determining diagnostic levels, and it was up to each state to determine the diagnostic levels for itself.² A test that met a particular state's diagnostic criteria was considered a CDC-positive test. When I was tested in Massachusetts in 2002, a patient needed to have present five out of ten IgG Western blot bands (markers) in order to be CDC-positive for the state's Lyme disease surveillance criteria. I had four bands positive, not five. Therefore, my test was considered negative for Lyme based on the CDC-surveillance criteria, and they would not report my case as positive to the state. Meanwhile, my body was still producing these four antibodies to the bacteria, an indication that infection might be present. Four out of ten Western blot bands did not mean I didn't have Lyme.³ This was the beginning of the intersection of my own experiences with the politics and policies of Lyme disease.

The CDC surveillance criteria were developed for tracking and monitoring Lyme disease, and they were never intended to be used for clinical diagnosis.⁴ My Western blot lab results, which reported, "Lyme disease negative; A Western blot IgG result is positive ONLY if five (5) of the IgG bands are detected," were based on the surveillance criteria, which meant that my case did not meet the threshold level for reporting.⁵ However, these lab results definitely did not mean that I wasn't infected. The CDC surveillance criteria, often interchangeably used by health care providers as diagnostic criteria, led my physicians to the inaccurate conclusion that I did not have Lyme. Typical diagnostic tests for Lyme are highly insensitive, so "... a negative test result does not mean you don't have Lyme. There are many reasons why someone who actually has Lyme may have a negative test result. There may not have been time for antibodies to develop; the immune system may be suppressed; or the person may be infected with a strain the test doesn't measure."⁶ Days passed, and my condition deteriorated, yet I continued believing I was not infected. Meanwhile, the spiral-shaped bacteria that cause Lyme disease were burrowing deeper into my tissues, squeezing into my joints and synovial fluid, and crossing my blood-brain barrier.

Throughout the fall, I continued visiting Health Services and pressing with questions. A biology major, I searched my textbooks for answers. I was still in pain, and now a puzzling new symptom had appeared: I was reading and rereading the same pages from textbooks, but I could not remember what I had read. There are notes in my medical chart like "exacerbation of arthralgias and myalgias, fatigue" and "? Lyme diagnosis - not supported by labs - after long discussion . . . have decided to retest in 4 weeks if symptoms persist."⁷ My relative who was diagnosed with Lyme saw in me the symptoms he had experienced, and he insisted I come back home to New Jersey to see a Lyme literate medical doctor (LLMD). It was not until I visited an LLMD, whose

practice specialized in the diagnosis and treatment of tick-borne illnesses, that I began to get answers. The first answer came after running a polymerase chain reaction (PCR) blood test. Whereas the Western blot testing looks for antibodies made in response to the Lyme bacteria, a PCR test looks directly for the presence of the bacteria's actual DNA. When we checked my blood for the DNA of the Lyme bacteria, the results were unequivocally positive. The second thing I learned was that my experience with inaccurate test results was common with Lyme. Some studies indicate that up to 50% of the patients tested for Lyme receive false negative results.⁸ Third, I learned that not only did I have Lyme disease, but I also had several other infections that were transmitted by ticks. Without memory of a tick bite, without the hallmark bull's-eye rash, without any known exposure to a tick, this whole illness seemed impossible and foreign. The thought of being bitten by a tick felt violent and violating. I now inhabited a foreign land; I was deep in the woods, living the land of Lyme.

The morning I woke up in pain sent me traveling into a land I knew nothing about, down paths I never intended to travel, paths that out of necessity I learned to navigate. My course changed, not by my choosing, and I learned to inhabit this new land. The topography was deep and dark, like the woods in Grimms' fairy tales. It was filled with dangers, physical and psychological. The space in which I found myself was like the woods after dark, where danger lurked and what seemed uncomplicated and beautiful—like nature or unremarkable lab results—could not be trusted. The rules about entering the land of Lyme were simple: one only had to be bitten.

I was treated with oral antibiotics throughout junior year, but my symptoms did not consistently improve. With my neurological symptoms increasing, my LLMD determined that I needed IV treatment so that we could get antibiotics across the blood-brain barrier. I was still in the woods, but at least now I had a map: a course of treatment that we thought would work well.

The summer after my junior year at BC, I lay on an X-ray table in a hospital's operating room, my left arm out to the side. A doctor numbed the inside of my arm, then found the vein in my upper arm a few inches above my elbow. I watched the X-ray screen like a television as it captured everything in live motion. I watched as a clear tube was inserted into that vein, then up through my arm, then down into my chest. When the tube had reached its resting place near the largest vein in my heart, the doctor secured the tube into my skin with some small black stitches. He had given me a peripherally inserted central catheter, or PICC line. Each day for the next 8 weeks, I would hook myself up to a portable IV pump, which would push cold, potent antibiotics into that tube in my arm, dumping the medicine in the vein. Those weeks I would cross my fingers that the medicine would do its job, that it would cure my illness or at least abate my symptoms, would give me my life back. The day before I returned to BC for senior year, a nurse pulled out the two feet of tubing. An angry-looking scar was left in its wake, just visible under the sleeve of my t-shirt.

The IV antibiotic helped, but I would get better and then relapse. My Lyme disease case was complicated by the presence of three other tick-borne infections: Bartonella (a rod-shaped bacteria that causes fever and lymph node swelling, among other symptoms), Babesia (a red blood cell parasite, much like the one that causes malaria), and Mycoplasma (a small bacteria that causes arthritis and fatigue). I am not alone; it is estimated that about 32% of Lyme patients also have Babesia, 28% have Bartonella, and 15% have Mycoplasma.⁹ These were words I had never heard of before my diagnosis, but in navigating this new terrain of Lyme disease, I learned to speak a new language. There are other tick-borne co-infections for which I have, thankfully, never shown signs. The process of finding all of these co-infections took several years, and Lyme patients with co-infections experience more severe illness, more symptoms, and a longer recovery.¹⁰ Fitting with that picture, my road to recovery has been a

long one, and unlike some people whose symptoms vanish after a few weeks of basic antibiotics, my experience with Lyme and co-infections has been persistent and chronic. The presence of multiple co-infections partially explained why I felt so ill, and why new symptoms continued to appear over the course of my time at BC and soon afterward.

I have lived with tick-borne illness for the last thirteen years. Like many patients with chronic Lyme disease, I have become an expert in living in this forest. I have experienced hypothyroidism, skin rashes, excruciating migraines, herniated discs and degenerative disc disease in my spine caused by Lyme arthritis, sensitivity to sound and visual patterns, muscle aches and pains, difficulty breathing (a symptom of Babesia known as air hunger), neurological difficulties (like having difficulty finding words or feeling lost in places I know well), cognitive symptoms (like difficulty reading and focusing), psychiatric symptoms (like sleep disturbances and obsessive-compulsive behavior), and that mysteriously moving joint pain.

After years of intensive treatment, and under the guidance of a world-renowned LLMD, my body is now on the road to healing. Lyme disease has been killed off and quelled, but the places in which it lived in my body are like a war zone after a battle. Devastation lies in its wake. I try to rebuild. Although most of my symptoms are alleviated, I sometimes feel aftershocks; some symptoms still linger on.

My body—post-Lyme and its co-infections—is not the same. I face ongoing headaches and anxiety. I face a bone-weary fatigue that settles over me, my constant companion, like the hazy smog over a city. I never experienced these symptoms before Lyme. There are little reminders of my illness everywhere. For example, whenever someplace holds a blood drive, I am not allowed to give blood. The Red Cross will not take my blood donation. I speak with

them on the phone and am told that I am “deferred indefinitely,” my red blood cells infected with Babesia, permanently overtaken with little ring forms or tetrads of parasites. Grass and the woods terrify me now, triggering traumatic flashbacks to the days when I was sickest, when I wondered how I could have been infected. I can remember the two-thirds of my life that was before Lyme, but it feels so far away. In my physical exam before I was admitted to Boston College, my pediatrician examined my 18-year old body and wrote “Well Adolescent” on my college physical form. That was true for a short time while I was at BC.

At my worst, Lyme disease and my three other tick-borne infections have had me on a gurney in an ER, hooked up to an IV, morphine the only way to relieve the agony of my head and neck. At my worst, Lyme disease has cost me and my family tens of thousands of dollars and left me a shell of myself, my brain and body overtaken. At my worst, Lyme has left me bedridden, sleeping for 18 hours at a clip, bone-weary and barely able to move.

At my best, I feel like I did before that October day in 2002. At my best, I am pain-free. At my best, in quiet mornings or in calm evenings, I swallow vitamins and herbal supplements to try to keep my immune system up, and except for those vitamins I forget I ever was sick.

Most days during the last twelve years have been somewhere between the best and worst. The days are like a game of whack-a-mole, the bacteria and parasites living symbiotically within me, my immune system or medicines and herbs knocking them down one at a time before the others pop up. If I have drenching night sweats, or difficulty breathing (air hunger), the whack-a-mole infection to take down is Babesia. I will share this with my LLMD, who might prescribe thick, paint-like yellow Mepron and little pink azithromycin tablets, or a Chinese herbal product called artemisinin, or some other combination of Western and integrative

medicine, and after several weeks or months we will knock that mole back into hiding. But it's not long before another mole pops up, with foot pain and a red, striped rash across my chest, belly, and back that looks like I was clawed by a raptor. These are symptoms of Bartonella, which lives in epithelial skin cells. We can knock it down with Rifampin, an antibiotic whose side effects I hate but whose killing effects are worth it. Living in daily whack-a-mole, I am constantly monitoring symptoms and trying to stay on top of them before they get out of control.

There have been days, months, and years during which I am asymptomatic and feel great. There have been days, months, and years that are worse than I can describe. I have wondered if I was exaggerating the effect of Lyme on my life, but I felt validated when I read a recent study showing that chronic Lyme patients suffer worse quality of life compared with those who face other lifelong diseases, such as congestive heart failure, diabetes, lupus, liver failure, and multiple sclerosis.¹¹ Although I have reached remission in the past, and although I work toward remission again, I have learned these infections are something I will continually battle.. Lyme and its co-infections have become part of my identity. Being someone who lives with chronic illness has become a sociocultural identifier for me, the same as my gender or race. It is an identity that I never imagined I would hold.

It is also an identity that some do not believe exists. The Infectious Disease Society of America (IDSA), which created guidelines for Lyme treatment in 2000 and revised them in 2006, argues that short courses of antibiotics cure Lyme patients and that a so-called "chronic" Lyme or post-Lyme disease syndrome does not exist. They cite a lack of evidence for persistent infection in Lyme patients who have been treated with antibiotics.¹² If and when symptoms persist after following an IDSA-recommended treatment regimen (usually a short course of doxycycline), the Lyme patient is encouraged to seek other diagnoses or reasons for symptoms. In contrast to the

federally-funded IDSA, there exists a nonprofit, international, multidisciplinary medical society named International Lyme and Associated Diseases Society (ILADS) that is dedicated to the diagnosis and appropriate treatment of tick borne diseases.¹³ ILADS holds that Lyme is a clinical diagnosis, especially when considering that current screening tests are unreliable.¹⁴ ILADS believes that not only does chronic Lyme disease indeed exist, but also that most cases of chronic Lyme require long courses of antibiotics to relieve symptoms, as there is no test available to prove that the bacteria are eradicated or that the Lyme patient is cured.¹⁵

When I did not get well after a year of oral antibiotics and eight weeks of IV antibiotics, I was frustrated and exhausted, only to hear from IDSA physicians that this was all in my head or that my Lyme had been treated, so there must be something else wrong with me. Those physicians were wrong in my case. My Lyme case has been persistent and tricky to cure, but with longer courses of antibiotics, I have gotten better. It has been ILADS-affiliated or ILADS-trained physicians that have treated my illnesses and brought me symptomatic relief, although I am not yet fully out of the woods.

Beginning during my time at BC, I found myself caught in the crossfire of infectious disease policy and my own reality, caught between the IDSA and ILADS, stuck between falsely negative test results and positive ones, caught up in an illness that infectious disease doctors said I couldn't possibly have. I have heard Lyme patients say, "You don't get it until you get it." That is, until you or your relatives are caught up by one of these mysterious tick-borne illnesses, you don't understand the magnitude of their impact across every domain of your life, the difficulties that come with inaccurate diagnostic testing, and the frustration that you feel when you know something is wrong but testing shows otherwise. I share the story of my Lyme scar now because an increas-

ingly alarming number of people are facing this illness, with about 300,000 new diagnoses each year.¹⁶ Still others are inexplicably sick but remain in the shadows, due to the unreliability and invalidity of testing, scarcity of LLMDs, and soaring treatment costs.

As I learn to live right on the edge of the woods of Lyme, I know others suffer or are misdiagnosed due to policy and politics, insufficient testing methods, and the guidelines proposed by the IDSA that deny patients like me treatment. The so-called Lyme Wars between the IDSA and ILADS rage on, while patients like me seek a way out of the darkness, out of the land of Lyme.

Time in the woods of Lyme disease is measured not in hours or minutes, days or months, but by those plastic, brightly colored weekly pill organizers. Years into my illness, I would quickly outgrow the standard sized ones they sell at the pharmacy; not every medication, herbal supplement, or vitamin will fit in one of those standard ones. My husband, for a gift, would buy me a bigger pill container set that was easier to open. Each week I take about twenty minutes to fill my pill organizer; each day I gulp down handfuls, morning and night. I get good at taking them two or three at a time, so I can get all fifteen or twenty into me with just a few gulps of water. The idea is that if my immune system stays strong, the bacteria and parasites will be kept quiet, kept at bay.

I am grateful that overall, I do feel better now than I ever imagined I would feel when I was first diagnosed. I have lived a third of my life with Lyme, but I have not always been trapped in its woods. When I have felt well, I have been lucky enough to go on safari in Africa, hike the Grand Canyon, and walk the cobblestone streets of Venice. I was able not only to graduate with a biology degree from Boston College, but also to put myself through graduate school, marry, and pursue a teaching career that I love. When I have felt unwell, I have remembered my doctor's words. He has said that the last chapter of my Lyme story has not yet been writ-

ten, but we will keep writing until we get the ending that we want.

ENDNOTES

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