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NARRATIVE MATTERS



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Chronic Lyme Disease: It's Time To Solve The Medical Mystery Inside An Enigma

Scientists and doctors disagree about whether there is such a condition as "chronic" Lyme disease or "post-Lyme disease syndrome." Americans need the National Institutes of Health and basic science research to help determine the answer.

BY LAURIE MCCLELLAN

I don't believe in the Loch Ness monster. I don't think a cabal of government scientists are autopsying aliens right now somewhere deep in Area 51, or plotting a vast conspiracy from a bunker at the North Pole. But in the past two years, I've lived through an experience that has felt, at times, like a real-life epi-

sode of *The X-Files*—that long-running TV show about a government conspiracy hiding the existence of intelligent extraterrestrials.

What happened is this: My husband, Pat, who's now fifty-one, became frighteningly, mysteriously ill. And when two doctors finally fit the puzzle pieces of his symptoms together, we discovered that

according to medical authorities, his disease does not officially exist.

A Backpacker Gets Sidelined

Pat's symptoms came on gradually—so gradually, it took us years to realize he was sick. Longtime hikers, in 2008 we backpacked through Washington State for five days, lugging forty-five-pound packs over rugged mountain passes rippling with wildflowers. "This seems a lot harder than it usually does," Pat remarked one day, taking an uncharacteristic rest break halfway up a hill. Then his muscles began to stiffen up after long car rides.

In 2009 Pat's usual runs on the treadmill became too taxing. By June of 2010 he couldn't make it to the gym at all. He was so tired that he needed a two-hour nap every night after work. One night he got home an hour late. He'd forgotten the name of our subway stop and had kept riding the trains back and forth until he remembered.

Guessing that his problem might be hormonal—Pat was forty-nine at the time—he made an appointment with an endocrinologist. While he waited six weeks for the appointment to roll around, he started wearing wool socks to bed: His feet were now inexplicably freezing. He began to stumble when walking, occasionally bumping into walls.

The joint pain started up a few weeks later: a feeling like electric shocks shooting through his knees and elbows. Numbness in his hands began making it hard to type. He'd sometimes choke while drinking or stumble over words. Pat finally saw the endocrinologist in July, but the doctor confidently dismissed the odd array of symptoms as impossible. "The mind is very powerful," he explained.

Pat's next stop was my internist, Kate Lemmerman, whom I respected and trusted. She talked to him for an hour and gave him a quick exam. "Based on your symptoms," she said, "I think you might have chronic Lyme disease."

I was surprised. It seemed like an ob-

scure disease, even though I'd read that ticks carrying Lyme disease were thriving in northern Virginia, where we live. Pat could have picked up a tick while hiking in the woods or simply from a bush while walking through our front yard. The Lyme test came back negative, but Dr. Lemmerman started him on antibiotics anyway. The tests weren't always accurate, she explained, and Pat's symptoms were spot-on. He would need to see a specialist in chronic Lyme disease to confirm the diagnosis.

Then she continued, "I have a friend in New York with chronic Lyme, and she has to drive to Connecticut to see a doctor. The politics...they're just terrible."

Terrible politics? In retrospect, when I think of that moment, I picture myself stepping through the looking glass like Alice, entering the topsy-turvy world beyond.

Through The Looking Glass

Pat called the Lyme clinic. The practice was so busy, it took eight weeks—until November—to get an appointment, and in the meantime I started researching.

A science writer by profession, I'm comfortable doing research: pulling studies out of databases, interviewing experts, delving into a topic until I can explain it to others. I expected to find out more about what Dr. Lemmerman had told us: that Pat had possibly had Lyme disease for years, which could explain his gradually worsening symptoms. This long-term version of the disease was called "chronic" Lyme disease by some doctors, "post-Lyme disease syndrome" by others.

Pat's case was different from the typical patient who gets diagnosed with Lyme disease immediately after becoming infected. These people often spot the tick that carries the disease on their skin or develop a telltale rash within a few days and are diagnosed quickly. Infected with Lyme disease bacteria only for a week or two, such patients recover completely after taking fourteen to twenty-one days of antibiotics.

Pat never spotted a tick or a rash. He didn't get sick right away. Instead, it was possible that he had graciously hosted his Lyme bacteria for years, giving his unwelcome guests plenty of time to re-



produce and deeply infiltrate his organs, muscles, and nervous system. If this were the case, Pat would need to take antibiotics for six months or longer to recover.

Dr. Lemmerman's explanation echoed what I'd learned a few years earlier, when a friend's teenage daughter became suddenly and strangely ill. An honor-roll student who took several dance classes each week, she became so fatigued that she had to sit out much of her senior year of high school. She suffered from joint pain so severe that she sometimes just lay on the sofa and wept, and she lost her ability to read. One neurologist declared that she was merely anxious, but another doctor diagnosed chronic Lyme disease. After a year of antibiotics, she was well enough to start college.

I began my research on the website of the National Institutes of Health (NIH). "Lyme disease can usually be successfully treated with 3 to 4 weeks of antibiotic therapy," it stated. "After being treated for Lyme disease, some patients still report nonspecific symptoms, including persistent pain, fatigue, impaired cognitive function....[T]hese patients...may be diagnosed with post-Lyme disease syndrome....[S]tudies have shown that more antibiotic therapy is not beneficial and the risks outweigh the benefits."

I was puzzled. Why did the NIH say long-term antibiotic therapy was not effective? Although it was only one case, I knew someone who'd apparently been cured by it. And at this point, Pat had been taking the single antibiotic prescribed by Dr. Lemmerman for about six weeks. After a week on the drug,

the numbness in his hands started to recede. After a month, he stopped gagging while he drank. It was clear that Pat was getting better, but it also seemed clear that stopping the treatment would be a disaster. He was still extremely sick.

When I got to the websites written by Lyme disease patients and advocacy groups, the news was worse than puzzling. I learned that some doctors who treat chronic Lyme disease had been investigated by state medical boards, and many had even lost their medical licenses. Why? According to the guidelines put together by the Infectious Diseases Society of America—the acknowledged medical experts in this case—chronic Lyme disease doesn't exist.

I'm not comfortable coloring outside the lines. If credible authorities tell me that a diagnosis is bogus, I believe them. I might have told Pat to cancel his appointment with the Lyme specialist, except for two things: I knew someone who'd had the same symptoms as Pat, and she'd apparently been cured by a year of antibiotics. Although doctors consider one case anecdotal information, not proof, I'd found dozens of strangely similar stories in my research that were hard to ignore.

Also, I trusted my internist. She, too, was an MD, just like the doctors at the Infectious Diseases Society, and she'd diagnosed Pat with what she called chronic Lyme disease. She'd even referred him to another doctor in our area who treated the disease.

I felt like we'd landed in the middle of a war. Pat, who'd been climbing mountains a few years ago, now struggled to walk a city block. Two doctors were telling us that he had a certain disease, that it was treatable, and that he could recover. But the standard medical authorities were telling me that this condition didn't exist and that the proposed treatment was ineffective and harmful.

What were we supposed to do?

Given the choice between doing nothing and pursuing a possible cure, we did what I think almost anyone would. In November 2010 I accompanied Pat to his first appointment at a Lyme disease clinic.

During my research, I'd discovered that a state medical board once had suspended this doctor's license for pre-

scribing long-term antibiotics. I felt like an outlaw entering that office—and also like someone desperate for help. Staff members ordered more tests to screen out look-alike diseases. Blood tests ruled out a host of conditions, and a brain scan showed that Pat didn't have multiple sclerosis (MS). Chronic Lyme disease seemed to be the diagnosis that fit.

Pat was given prescriptions for a sophisticated regimen of drugs to control his symptoms, plus multiple antibiotics to fight the infection. He would need to take the drugs for the next year or so. He started swallowing some twenty-five pills a day, and the pace of his recovery picked up.

Searching For Answers

I'm not a scientist. I don't know exactly what's causing Pat's symptoms, or how they're related to the bacteria carried by a tick. In some ways I'm not surprised that doctors don't have ready answers, because Lyme disease was pinpointed only thirty-five years ago (it's named for Lyme, Connecticut, where a cluster of cases was first identified), and it's still considered an emerging disease.

Here's what I do know: Just because scientists don't understand the cause of a disease doesn't mean that it doesn't exist. Back when patient-reported symptoms were all doctors had to go on, MS was known as "faker's disease." Then magnetic resonance imaging was invented, and doctors could suddenly see detailed high-resolution images of the brain lesions that explained the symptoms patients complained about.

Like those MS patients who were once called fakers, chronic Lyme disease patients are trapped in a nightmare. I see only one solution: research and new knowledge.

We need to pick apart the tangled causes of this disease and find the most effective treatments. The NIH recently took a first step in this direction, directing the Institute of Medicine (IOM) to hold a workshop on Lyme disease. (It took place in October 2010; the report now is posted on the IOM website.) Researchers and doctors on

many sides of the debate spoke, including some who treat patients for that "nonexistent" chronic Lyme disease that Pat was diagnosed with. In his closing remarks, IOM committee chair Lonnie King, dean of the College of Veterinary Medicine at Ohio State University, talked of the need for a national research agenda.

I believe the NIH should create that research agenda and, in the process, set up long-term clinical trials with Lyme disease patients. Lyme research is still in its early stages, and funding could have a tremendous effect, breaking through the controversy that has stifled progress. Researching Lyme disease fits with the NIH's history of focusing on specific diseases (such as cancer), emerging diseases (such as HIV), and diseases that lack a clear explanation (such as those being studied in the NIH's Undiagnosed Diseases Program).

It's important not only that the NIH begin funding and organizing Lyme disease research; it's also important that it do so now. The number of confused, ill patients is growing.

In 2010 the Centers for Disease Control and Prevention reported 30,000 new and suspected cases of Lyme disease. For people living along the East Coast, the situation is urgent. Just twelve states accounted for 94 percent of all Lyme cases reported in 2010, including all of the coastal states from Virginia to Maine.

The governor of Virginia recently created a Lyme Disease Task Force to address the problem—a step that, according to one newspaper article, is "calling for a more open-minded approach by the medical community."

"We don't want people freaking out inappropriately," said task force chair Michael Farris, an attorney whose wife and children have been diagnosed with Lyme disease, "but a certain amount of freaking out is warranted here."

As frightening as the numbers are, some researchers believe that Lyme disease cases might be underreported by a factor of ten. If 10 percent of those cases turn chronic, as studies suggest might happen, that could mean 30,000 Amer-

icans every year sidelined by a debilitating disease—one that we've failed, so far, to truly investigate.

Escape From The Underworld

Sometime in the spring of 2011, Pat made a joke. I couldn't remember the last time he'd done that, despite the fact that before he got sick, someone we'd once met on vacation asked him, "Are you a stand-up comic?"

Hearing Pat's joke was like seeing the first spring crocus poke through the patchy snow. He was making his way back from the underworld of illness. Today, fifteen months after starting antibiotic treatment at the Lyme clinic, Pat says he's about 75 percent better. He still can't go running, but we recently took a three-mile hike together.

Western medicine has never been good at dealing with the unknown. Our system loves tests, clinical data, yes-or-no answers. Solving a medical mystery like Lyme disease is quite a bit trickier.

Thinking about the Lyme wars raging today, my mind circles back to Dr. McCoy on the classic *Star Trek* TV show. He could cure nearly any disease in the universe with what appeared to be a handheld scanner, but when faced with the unknown, McCoy blurts out, "I'm not a magician, Spock, just an old country doctor!"

Like Dr. McCoy, we possess the most advanced medical technology ever seen on the planet, yet the unknown, in the form of an emerging disease—such as Lyme disease in all its forms—still has the power to baffle us. It's time to harness the power of our labs, researchers, and government agencies and start looking for answers. ■

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