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Pete Sides and Other Rebels Fight Lyme Disease and the Medical Establishment

By Alison Fromme

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MARCH 2018

The Piano Man's War

Pete Sides and Other Rebels Fight Lyme Disease and the Medical Establishment

By Alison Fromme

When Pete Sides left his house to walk his dog on a crisp fall day in 2015, everything seemed normal at first. But he only made it about fifty yards down the road before he realized something was terribly wrong. Numbness overcame his left foot. He struggled to walk, and he knew he had to turn around. When he reached his driveway, he fell to his knees. He crawled to the house and told his wife, Carol, "We're going to the hospital."

What was going on? Just days earlier, he had played several rounds of golf. All his life, he'd been active. Working eighty-hour weeks at Robert M. Sides, the family music business in Williamsport, Pennsylvania. Spending time with his kids and grandkids. Flying airplanes, racing cars at Watkins Glen. He rarely had aches and pains, and almost never took aspirin.

Now, he thought he might die.

At the hospital, Pete required a wheelchair. Doctors first thought a bone spur in his foot might be the culprit, but that was quickly ruled out. As he waited for answers, the numbness spread up his left leg and down his right. His legs felt weirdly wet, even when he knew they were dry.

Then, a key piece of Pete's health history rose to the surface. Months earlier, in April, he had found a tick embedded in his skin, in an awkward spot on the back of his arm. He knew ticks. He had pulled them off his dog, and he understood the risk. This tick was fat, engorged with blood, and deep in his skin, with only its back end visible. It had clearly been lodged there for a while, probably long enough for the tick to transmit the Lyme disease bacteria. At the time, he went to his regular doctor, who prescribed two days of antibiotics as a precaution. And that was that.

Or maybe not. The hospital doctor, with knowledge of Pete's tick, ordered another Lyme disease test. It came back positive.

Pete soon learned he was one among many in his community. "Everybody knows somebody with Lyme," he says.

Many local people, to their surprise, find their doctors and hospitals don't seem to have an answer for this complicated and elusive disease, and, with other sufferers regionally and nationwide, seek solutions with pioneering doctors operating outside the medical establishment.

The Scope of the Problem

The number of recorded Lyme diseases cases is rapidly rising in Pennsylvania. In 2012, just over four thousand cases in the state were reported to the Centers for Disease Control. In 2016, the number totaled almost nine thousand. The state's Lyme Disease Task Force estimates that as many as 70,000 Pennsylvania residents

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Tiny terror: the deer tick (*Ixodes scapularis*) is a carrier of Lyme disease.

Adult deer tick, Ixodes scapularis, Scott Bauer / CC0 1.0

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Fighting back: Thomas Putnam, whose battle with Lyme disease is ongoing, has helped found a Tioga County (Pennsylvania) support group for fellow suffers.

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could be affected each year by Lyme and other tick-borne diseases. The CDC estimates that 300,000 new infections occur nationwide each year.

"Lyme disease is a big problem in Pennsylvania, for a lot of reasons," says Dr. Stanley Martin, director of infectious diseases for Geisinger Medical Center. The dramatic rise in new cases, he says, is partly due to better awareness of the disease and more testing. It's a very common infection—so common that people can become infected and recover without even realizing it. It's also often over-diagnosed, he says, because common symptoms of Lyme disease—rash, fatigue, fever, muscle and joint pain—overlap with other medical conditions, such as fibromyalgia and autoimmune disorders.

Every week Dr. Martin sees patients who suspect they have the disease. Perhaps they saw a tick and noticed the telltale rash. Or, perhaps they feel unusual pain, weakness, and tingling. The first challenge is accurate diagnosis, he says. To make a diagnosis, doctors use a combination of clinical symptoms and blood serum tests. The tests are not perfect—they cannot detect very early infection—and the results can be tricky to interpret, even for some health care professionals, he says. If blood tests come back positive, then Dr. Martin will likely prescribe antibiotics, usually a course of oral doxycycline for seven to ten days.

Dr. Martin also says he spends time cautioning patients that they might not feel better immediately. He explains, for example, when you have strep throat, you get a fever and your throat swells. As you take antibiotics, the inflammation dies down and you start to feel better. With Lyme disease, the inflammation does not subside very quickly. What's usually needed, he says, is "the tincture of time," plus pain relievers like ibuprofen or naproxen.

He emphasizes that most patients respond well to antibiotics and fully recover.

Ongoing Issues

Pete Sides remained at the hospital for almost a week and received additional antibiotics. The numbness in his legs subsided, and although he left the hospital upright, he required the assistance of a walker.

Pete is not the only one in the area to experience lingering symptoms after being treated for Lyme. Between ten and twenty percent of patients continue to suffer after conventional treatment, according to researchers from Johns Hopkins University School of Medicine.

When unusual symptoms struck Thomas Putnam (left) in March of 2017, he turned to his primary care doctor. His fever spiked at 104 degrees, lightheadedness prevented him from walking, and his head throbbed with pressure and heat.

His first test for Lyme disease came back negative. He visited an infectious disease specialist. Still negative. The specialist told him that his body was probably just recovering from a stubborn virus. But his symptoms worsened, and he could barely complete his work at Hamilton-Gibson Productions in Wellsboro. He tried an infectious disease specialist in Rochester. The third test was positive. He took antibiotics for a month, and started to feel better.

But intense fatigue and brain fog returned during the summer, so he returned to his doctors. The Rochester-based infectious disease specialist suggested he should visit his primary care doctor. His primary care doctor suggested seeing the infectious disease specialist.

Thomas adjusted to his ongoing fatigue and brain fog by coming home early from work and napping. This wasn't just stress or burnout, he says. It was distinctly different.

Pete's symptoms persisted as well. For months, he held onto walls or chairs to steady himself while he walked. Determined to get better, he decided to drive two hours away to visit a doctor who offered treatment not covered by insurance: long-term antibiotics, dietary regimens, and supplements.

"I don't care what it costs, I have to do something about this," he recalls saying at the time. After additional testing, he was told he had two other bacterial infections transmitted by ticks, babesiosis and bartonella. Now he reports that, three years and several doctors after the initial tick bite, he is doing much better and tapering off his treatment.

Thomas also sought additional care. "I love my primary care doctor. But because this treatment is so outside the standard protocol, he cautioned me about going to Lyme specialists," Thomas says. But when you're very sick, you have a different perception of risk. "If they're the only ones willing to offer treatment and hope, then why wouldn't someone see them? It's really tough. Do I take my chances on long-term antibiotic treatment and worry about the long-term side effects? Or try something else, when there is little else to try?"

Dr. Martin is one such doctor who strongly warns against unconventional treatment. "A lot of people are convinced that they need more antibiotics," he says. But according to clinical studies published in *The New England Journal of Medicine*, antibiotics don't work. Additionally, a CDC report states that "at least five randomized, placebo-controlled studies have shown that prolonged courses of IV antibiotics in particular do not substantially improve long-term outcome for patients with a diagnosis of chronic Lyme disease and can result in serious harm, including death."

Dr. Martin adds that patients need to consider the possibility that ongoing symptoms might be caused by other health problems, such as fibromyalgia or chronic fatigue/myalgic encephalopathy—not an ongoing infection that could be cured with more antibiotics.

The Biology of Infection

When a tick lodges into a person's skin, it's looking for a meal. It clamps itself onto the skin with a saliva cement, as it slowly sucks blood through a tube held in place with barbs. Some ticks are as small as a poppy seed, and they can secrete an anesthetic that numbs the skin to avoid detection.

In Pennsylvania, about fifty percent of blacklegged ticks carry the Lyme disease-causing bacteria *Borrelia burgdorferi* in their guts. When ticks feed on people or animals, the spiral-shaped bacteria can travel from the tick's cool belly into the hot skin of a mammal. It's something

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Don't Get Ticked

"In this part of the country, there are lots of people who like to do things outdoors, and that means they come in contact with ticks," says Dr. Lee Meyers, of Guthrie Family Practice in Wellsboro. "And we still want people to enjoy the outdoors and lead active lifestyles."

The most important way to avoid contracting Lyme disease, she says, is to be vigilant about checking for ticks when you return from outdoor activities. She suggests changing clothes, bathing, looking and feeling all over your body, and asking a friend or family member to help check hard to reach places, like in your hair and on your back.

In the first few hours, ticks will likely just brush off. But if you find a tick attached to your skin, there's no need to panic, she says.

Many people are worried about Lyme disease because they have a friend or family member with the disease. Many see their doctor for tick removal. At Guthrie's walk-in clinic, a doctor or nurse practitioner will use a special removal device, ask for the patient's medical history, and plan next steps.

For example, if the patient just gardened that morning and hadn't been outside for the previous week, then it's likely no further treatment would be needed, Dr. Meyers says. A tick needs to be attached for about forty-eight hours before the bacteria that causes Lyme disease can be transmitted.

In contrast, if the person had a rash and fever, she would prescribe antibiotics, usually a twenty-one-day course of doxycycline. Alternative antibiotics are available for kids under eight years old, pregnant or nursing women, and people who are allergic to doxycycline.

If no tick was discovered, but Dr. Meyers suspects that a patient's symptoms might be caused by Lyme disease, she will order a blood serum test. This test doesn't detect the Lyme disease bacteria itself. Instead, it searches for antibodies that the person's body creates to fight the infection. Antibodies don't show up right away because the person's immune system takes time to respond to the infection—and that means the test works best a few weeks after infection.

The test is performed in two stages. If the first (ELISA) comes back positive, a second test (the Western Blot) is completed. A Lyme disease diagnosis is only made if both tests are positive. Testing isn't recommended for people who have no symptoms.

Usually twenty-one days of antibiotics are also prescribed for the later stages of the disease, she says. If a patient experiences facial paralysis, cardiac, or other severe problems, they'll be referred to specialists.

"Most patients are better within twenty days," Dr. Meyers says. This is not, she cautions, the kind of treatment that works in a couple days.

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of a shape-shifter, changing which genes are turned on or off to accommodate the change of environment.

When *Borrelia burgdorferi* enters a person, the infection triggers the immune system. The first line of defense is inflammation. Next, generalized immune cells arrive to gobble up anything foreign. Then, specialized immune cells target and kill the bacteria—these cells are made after the infection specifically to recognize molecules on the bacteria's surface.

For many people, the infection stops right there at the surface, evidenced only by an inflammation-induced rash.

If *Borrelia burgdorferi* evades these immune system defenses, though, it multiplies at the tick bite site and can travel throughout the body, corkscrewing its way between cells, attaching to human-made molecules, and lodging itself in different tissues, including muscles, joints, nerves, and even the heart. The bacteria can hardly make any of its own components needed for life—like sugars, fats, amino acids—and absorbs these things from its surroundings.

The person's immune system keeps attacking as the infection spreads, and *Borrelia burgdorferi* can continue to change its surface molecules to avoid detection or hide out in lymph nodes or dense tissue like tendons. Prescribed antibiotics can aid the body's defenses and help eliminate the bacteria.

Borrelia burgdorferi doesn't produce any known toxins that sicken people. Instead, it's the body's response—the inflammation and the immune processes that show up in stages—that makes people sick. It starts out as some combination of a skin rash, fatigue, headache, muscle and joint pain, fever, and swollen lymph nodes, and sometimes progresses to more alarming symptoms like memory problems, facial paralysis, an irregular heartbeat, or debilitating arthritis.

But disease progression is not always straightforward. Different strains of *Borrelia burgdorferi* can cause different problems. For example, the European strain, if left untreated, can cause a lesion that alters the texture of the skin. Each person's immune system varies in unique ways, and symptoms may be compounded by underlying and coexisting health issues. Studies show that animals respond to infection in very different ways—mice can remain infected but don't usually exhibit any symptoms, for example, whereas dogs develop arthritis. Nor is *Borrelia burgdorferi* the only bacteria transmitted by ticks. Other rare but problematic tick-borne diseases can further complicate the patient experience.

At the 2011 meeting of the Committee on Lyme Disease and Other Tick Borne Diseases at the National Institutes of Health, scientists called for better diagnostic testing and more research—and research continues today, with attempts to develop improved diagnostic tools, treat persistent symptoms, understand the bacteria's biology, and control tick populations.

Many questions remain. For example, no one knows for certain if long-lasting, unresolved symptoms are caused by ongoing infection, or continued immune response to dead bacterial fragments, or tissue damage remaining after a long-gone infection. Two recent studies in the peer-reviewed journals *PLOS ONE* and the *American Journal of Pathology* found that monkeys who were infected with *Borrelia burgdorferii* and treated with antibiotics still harbored live bacteria that could be transmitted back to ticks—a finding that conflicts with previous evidence.

"We're not where we want to be [in terms of understanding all aspects of the disease]," says Dr. Martin. "We're going to solve the Lyme disease problem with medicine, and more science."

What Next?

For those ten to twenty percent of patients still suffering after Lyme treatment, the pace of science is excruciatingly slow. And the lack of treatment options offered by conventional medicine is maddening. Fatigue, brain fog, neuropathy, arthritis, and other symptoms can seriously disrupt daily life. Depression often follows. Many patients report that their doctors dismiss their pain.

The 2016 Pennsylvania Lyme Disease Task Force report acknowledged that patients experience "delays in diagnosis, confusion, frustration, limited treatment options, ongoing illness, with, in many cases poor outcomes, disability, and a significant financial burden."

"Doctors had me thinking I was lazy and crazy," says Linda Wales, of Millerton, Pennsylvania, who first became sick in 1995 with severe pain migrating through her body, fatigue, and Alzheimer's-like confusion. After several episodes of remission and relapses, she saw twenty doctors and then turned to prayer. She was diagnosed in 2001 and says she's been symptom-free since 2011.

Along her journey, a doctor suggested that Linda devote time and energy toward raising awareness of Lyme disease. She organized her first event at the local high school, then started a support group and co-founded the nonprofit A Hope For Lyme. That nonprofit now runs support groups in two Southern Tier communities, Horseheads and Addison, fields phone calls and emails from people concerned about Lyme, and organizes events in the area. Last year, the group partnered with Arnot Health graduate medical education to provide a symposium for students and healthcare professionals, and the event is slated to repeat again this year, with an additional presentation for the public.

"Helping others helped me not focus so much on how bad I felt," Linda says. "It's very rewarding."

Now, Thomas Putnam is following Linda's lead in starting a Tioga County (Pennsylvania) Lyme disease support group, along with another resident. The goal at each monthly meeting is to offer an educational component, a question and answer period, and time to socialize.

About forty adults of all ages, including locals and neighboring county residents, attended the first meeting in January. People shared their stories and offered empathy and encouragement.

"When people get together, they are just so grateful to be around others who understand," says Thomas, who reports that he's feeling much better, although he still experiences relapses. "Often you can't tell a person is suffering."

During the few weeks following the meeting, Thomas says he received about twenty phone calls from people searching for direction. "It's really hard that there are no clear answers, and people are desperate. People are really suffering."

Alison Fromme is a writer living, Ithaca, New York. She contributed to The Science Writers' Handbook *(DaCapo Press 2013), and was the recipient of a National Association of Science Writers Career Development Grant and a Saltonstall Foundation for the Arts fellowship.*

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