

THE LYME WARS

The Lyme-disease infection rate is growing. So is the battle over how to treat it.

BY MICHAEL SPECTER



Kaleigh Ahern was twelve years old when a tick bit her. She noticed it "perched" on her shoulder when she was taking a shower one morning. "I thought it was your average, everyday bug," Ahern told me recently. But, when she tried to brush it off, the tick wouldn't budge. "The legs wiggled but it was embedded in my skin. I freaked out and started screaming." Kaleigh's mother, Holly Ahern, came running and removed it. "I took the kid and the tick to the doctor," she said. "I told him, Here is my kid, here is the tick, and there is the place where it was attached to her." That was in 2002. The Aherns live near Saratoga Springs, New York, where Lyme disease has been

endemic for years. The infection is transmitted by tick bites, so Ahern assumed that the doctor would prescribe a prophylactic dose of antibiotics. But he said that he wasn't going to treat it. "If a rash develops or she starts to have flulike symptoms, bring her back," he told her. At the time, Ahern, an associate professor of microbiology at SUNY Adirondack, didn't know much about tick-borne illnesses. She took Kaleigh home and watched for the signature symptom of Lyme disease: a rash that begins with a bright-red bull's-eye around the tick bite.

No rash developed, and Kaleigh was fine—strong enough to become an all-American swimmer both in high school

The disease is carried by the black-legged tick, now found as far south as Florida.

and at Union College. There were times during high school when she felt mentally hazy and not quite right physically, which she attributed to allergies or a teen-age bout of mononucleosis. But at the end of her freshman year in college she found herself crippled by anxiety, depression, and insomnia. She was beset by searing headaches, her muscles often felt as though they were on fire, and her brain seemed wrapped in a dense fog. Kaleigh tested positive for Lyme disease. Like most physicians, her doctor followed the standard medical practice, endorsed by public-health officials throughout the United States, and prescribed a three-week course of antibiotics. "I was so happy to know what was wrong with me," Kaleigh said. "For a while, I didn't mind the pain."

The drugs didn't work, though. At her mother's insistence, the doctor extended the prescription three more weeks, but Kaleigh only got sicker. This brought the Aherns to a clinical impasse. The Centers for Disease Control and Prevention has established highly specific criteria for the diagnosis of Lyme disease: an acknowledged tick bite, the appearance of a bull's-eye rash, and, for those who don't live in a region where Lyme is common, laboratory evidence of infection. Most people who fit the profile respond well to antibiotics, even months or years after the initial infection. Many Lyme specialists, however, believe that short-term antibiotic therapy may suppress symptoms but rarely cures the disease. Kaleigh switched doctors and began a course of antibiotics that lasted eight more months.

There was no change. Furthermore, there is no evidence that prolonged antibiotic therapy helps patients with Lyme disease, so insurance companies almost never pay for it. "I realized that my parents were shovelling thousands of dollars into these antibiotics," she said. "After the oral approach failed, I was recommended to go onto I.V. treatment, but I had had enough." Kaleigh's condition had become so grave that she withdrew from school. "I would have episodes where I would just lie on the ground writhing. And my parents could do nothing but watch. I wish they had taken videos and put them online, so people would know."

Kaleigh turned to alternative treat-

ments often recommended by Lyme patients with similar experiences. She took herbs—turmeric and ginger, which are thought by some to strengthen the immune system—and she gave up gluten, grains, refined foods, and sugar. The goal was to reduce inflammation caused by her body's production of insulin and to inhibit the growth of the bacterium that causes Lyme. She also began treatments with a Rife machine, an electromagnetic device invented in the nineteen-twenties which emits radio signals that, some researchers suggest, can destroy harmful bacteria. Although thousands of people are convinced that Rife therapy has helped them with Lyme and other diseases, little empirical evidence exists to demonstrate that it works. Nonetheless, Kaleigh began to feel better. She still has headaches and severe muscular pain at times, but she returned to Union a year ago and graduated this spring. She knows that her approach to Lyme disease is controversial and acknowledges that the improvements might be due to her dietary regimen or to Rife treatments or to a placebo effect. She doesn't mind; after enduring such pain, she has found that fine points don't matter.

Lyme disease is the most commonly reported tick-borne illness in the United States, and the incidence is growing rapidly. In 2009, the C.D.C. reported thirty-eight thousand cases, three times more than in 1991. Most researchers agree that the true number of infections is five to ten times higher. Although some of that increase is due to heightened awareness, transmission is rising in areas, like New England, where the disease is well established, and is spreading to regions as far south as Florida, through changes in climate and the movements of infected animals.

The disease is caused by the bacterium *Borrelia burgdorferi*. In the Northeast and the Midwest, *B. burgdorferi* is transmitted by the bite of a black-legged tick, *Ixodes scapularis*. (In the Western United States, a related tick, *Ixodes pacificus*, prevails, and in Europe the main vector is *Ixodes ricinus*.) Lyme was all but unknown until 1977, when Allen Steere, a rheumatologist at Yale, produced the first definitive account of the infection. The condition was initially thought to have been an outbreak of juvenile rheumatoid

arthritis in and around Lyme, Connecticut. In 1982, Willy Burgdorfer, a medical entomologist at the National Institutes of Health's Rocky Mountain Laboratories, determined that the infection was caused by the previously unknown spirochete borrelia. As is common in scientific practice, the bacterium was named for him: *Borrelia burgdorferi*.

Those facts are undisputed. But nearly everything else about Lyme disease—the symptoms, the diagnosis, the prevalence, the behavior of the borrelia spirochete after it infects the body, and the correct approach to treatment—is contested bitterly and publicly. Even the definition of Lyme disease, and the terminology used to describe it, has fuelled years of acrimonious debate. The conventional medical assessment is straightforward: in most cases, the tick bite causes a skin rash, called erythema migrans, which is easily identified by its bull's-eye. If left untreated, the bacteria can spread to muscles, joints, the heart, and even the brain. Public-health officials say that a few weeks of antibiotic treatment will almost always wipe out the infection, and that relapses are rare. In this view, put forth in guidelines issued by the Infectious Diseases Society of America, Lyme is normally easy to treat and easy to cure.

For many people, though, the clinical situation is far more complicated. Some who have been infected with borrelia don't notice the rash. Others—up to a quarter of those with Lyme, including Kaleigh Ahern—never even get one. Most troubling, some patients who are treated continue to suffer from a variety of symptoms long after their therapy has ended. Nobody really knows why they fail to get better. Infectious-disease experts refer to the phenomenon, which can affect up to twenty per cent of patients, as Post-Treatment Lyme Disease Syndrome. Researchers have attempted to resolve the mystery in experiments with monkeys, mice, and dogs; human studies are also under way. As the number of infections grows, so does the number of people struggling to figure out what is wrong with them.

Many of these patients say that medical officials pay little attention to their persisting symptoms, and that Lyme disease is anything but easy to treat or to cure. They believe that the bacteria can

hide in the body for years, potentially causing harm long after treatment ends. This condition, they say, is pernicious, difficult to diagnose, rarely cured, and widely ignored. Moreover, at least four pathogens, in addition to the Lyme bacterium, can be transmitted by the black-legged tick: *Anaplasma phagocytophili*, which causes anaplasmosis; *Babesia microti*, which causes babesiosis; *Borrelia miyamotoi*, a recently discovered genetic relative of the Lyme spirochete; and Powassan virus. Some of these infections are more dangerous than Lyme, and more than one can infect a person at the same time. Simultaneous infection, scientists suggest, may well enhance the strength of the assault on the immune system, while making the disease itself harder to treat or recognize.

"I am not sure why we act as if we know the answers," Brian Fallon told me. Fallon, a psychiatrist who has studied the neurological impact of Lyme for years, is the director of the Lyme and Tick-Borne Diseases Research Center, at Columbia University. "The evidence that something more complex is going on is tantalizing and substantial."

Fallon is right, yet the medical issues have largely been eclipsed by the attention generated by another faction in the Lyme wars. These people—patients, advocates, politicians, and "Lyme literate" physicians, led by the International Lyme and Associated Diseases Society—refer to the illness as "chronic Lyme," and argue that the traditional approach to diagnosis and treatment, put forth by most American physicians, all but guarantees failure. The Lyme Action Network, one of many political groups that have formed to increase awareness and raise funds, recently released a pamphlet called "It Might Be Lyme." The group lists dozens of possible symptoms, including headache, joint pain, neck stiffness, chest pain, bladder dysfunction, hypersensitive skin, unexplained fevers, weight loss, sweats, chills, fatigue, blurry vision, heart murmurs, sleep disturbances (including too little or too much), difficulty with concentration, lightheadedness, and mood swings. Physicians associated with the network argue that a cure requires not weeks but months or years of strong antibiotics, and that relapses are common.

"There are two standards of care

when it comes to Lyme," Holly Ahern said. "One in which patients are diagnosed and treated until they get better, and the other where people are treated for three weeks with antibiotics—and, if you don't get better, then there must be something else wrong with you, or perhaps you are making it up." Ahern is a scientist, and hers is a measured critique. But emotion and despair are often the driving forces behind Lyme activism. The documentary "Under Our Skin: The Untold Story of Lyme Disease" essentially accused organized medicine of ignoring the illness. Scores of highly read blogs—Lyme Policy Wonk, Touched by Lyme, Living the Lyme Life—regularly overflow with fury.

Nobody disagrees that more research into the long-term effects of Lyme is needed. But most doctors reject the term "chronic Lyme," in part because many people who say they have it are not infected with borrelia. Without biological proof—a positive blood test or the telltale skin rash—the symptoms are vague and varied and could apply to many conditions. Infectious-disease experts say that the lingering symptoms might be an autoimmune response to the original illness or residual damage to tissues caused by the infection. "There is no doubt that people can have symptoms after being treated for Lyme disease," Roy Gulick told me when I visited him recently in his office at the Weill Cornell Medical College, where he is a professor of medicine and the chief of infectious diseases. "They can hang on for weeks or months. But you have to be specific about whether it's plausibly related to Lyme."

"I am sympathetic to people who are suffering," he continued. "And I have no doubt that they are. But if you have not been infected with borrelia you can't have Lyme disease. We don't have all the answers. We never do. These people are true believers. But I'm an infectious-disease doctor. I understand pathogens that cause disease and I understand the manifestations of those infections. Believing or not believing is not part of the process."

I grew up in Connecticut, attended college in the Hudson Valley, and graduated in 1977, the year Lyme was first identified. I don't recall hearing about the disease. I do remember going

to a professor's house for dinner one night that year and having him urge me to arrive before dusk, so that we might look for deer. We drove around for an hour without luck, and I wondered whether to believe him when he said he had seen one just the day before.

Today, deer are no longer exotic in the Hudson Valley, and the area has the highest rate of Lyme disease in the country. If you drive the back roads of Columbia County at dusk, deer are nearly



impossible to avoid, and accidents are common. Ticks are constantly on residents' minds, and watching children run barefoot to the edge of the bucolic woods is no longer a carefree delight. Deer are not *Ixodes*'s most important host, but they have come to symbolize the spread of Lyme, and represent an ecology that has changed dramatically in the past thirty-five years. "Once you have Lyme disease in the area, and once you start to carve up the forest into little bits, and especially when the fragmentation is done by suburban development, you get an increase in Lyme risk," Richard Ostfeld told me recently when I met with him at the Cary Institute of Ecosystem Studies, in Millbrook, New York. Ostfeld, a senior scientist there, has studied *Ixodes* for more than a decade. "The best host for the tick and pathogens is not deer but white-footed mice," he said. "And they do beautifully when you chop the forest into bits. They thrive. And competitors do not."

Ixodes scapularis is surprisingly sophisticated for an organism that, until it is engorged with blood, is less than half the size of a pea. "These ticks are nimble, durable, and adaptable," Ostfeld said. The black-legged tick passes through three distinct phases—larva, nymph, and adult—and females require a blood meal at each stage. They usually pick up the spirochete, which under the microscope looks like a spiral French fry, in their first meal, and pass the disease to the host—

small mammals, birds, deer, and sometimes humans—during the second or the third. To insure that it becomes engorged, the tick can attach its barbed mouth to a host for up to a week. First, though, the tick releases a series of anti-inflammatory chemicals and antihistamines to numb the skin and make a bite difficult to notice. It then secretes a compound called cementum, a kind of glue that helps the tick adhere to its prey. With those tasks accomplished, the tick bores its mouthparts into its host. While it feeds, the tick can inject borrelia, and other pathogens, into the bloodstream.

Ostfeld is a thoughtful, soft-spoken man, not unduly excitable. But when he talks about the Lyme bacterium he sounds like a proud parent. "Borrelia is a remarkable creature," he told me. "It has all my respect." He went on to explain that the bacterium, after slipping through the tick's mouthparts, can change its form, cloaking itself in the surface proteins of the tick's saliva. Then, much like H.I.V., the bacterium hijacks the immune system. "It doesn't stay in the bloodstream for long," he said. "Instead, borrelia manages to insinuate itself into parts of the body that have fewer circulating antibodies, where it is harder for antibiotics to reach."

The relationship between the tick and borrelia can be compared to the deadly, symbiotic partnership of *Plasmodium falciparum* parasites and the anopheles mosquitoes that transmit malaria, which have evolved together for thousands of years. Genetically, the bacteria are so adaptable that it is possible to find different strains of borrelia in the same tick. "Some of these infections are really very worrying," Ostfeld said, as we sat, one sunny morning, in his green, airy office at the institute. "We can't even know yet how big a problem a bacterium like miyamotoi will become. But it is possible that Lyme will turn out to be among the least threatening of the pathogens carried by *Ixodes*."

Ostfeld, a field biologist, received his Ph.D. from the University of California at Berkeley, and studies the ecology of small mammals—skunks, possums, chipmunks, and white-footed mice—which are found in large numbers in the Hudson Valley. Soon after he arrived at the institute, in 1990, he noticed something striking about the

thousands of mice he had trapped: their ears were often covered in ticks the size of poppy seeds. Those ticks, Ixodes nymphs and larvae, were feeding on the mice. "That was the beginning of my interest in Lyme disease," he said. His 2010 book, "Lyme Disease: The Ecology of a Complex System," describes the environmental relationship in detail. Before European colonists arrived in America, ninety per cent of New England and New York was covered in forest. Lyme was unknown. In the next century, forested areas were cut by half. "But it was a shitty life here," Ostfeld said. "Colonists had a rough go of it. The rocky soil was infertile and difficult for agriculture." In the eighteen-thirties, when the Erie Canal opened the Ohio Valley to agricultural development, the farms of the Northeast were abandoned. The forests returned, along with deer. Mice and other small mammals accompanied them.

Diagnostic failures cause much of the confusion associated with Lyme disease. It takes the tick at least thirty-six hours to transmit borrelia. If ticks are removed immediately, the threat of infection falls dramatically. But it takes weeks, and sometimes longer, for blood tests to detect antibodies; a test taken too soon will produce negative results. Even then, many people who become infected will test negative in error, while others who aren't infected will test positive.

"You get people all the time who have Lyme but who do not know it," Ostfeld said. "Their doctors don't know it." The basic blood tests look for antibodies but are not always sensitive enough to pick out the right ones. Another test for Lyme disease involves PCR, a technique that allows scientists to amplify the number of copies of a specific region of DNA. When done properly, that test can detect the Lyme spirochete directly. Yet it is prone to contamination, and it often produces positive results for people who are not infected. The situation is similar to one in India, where tens of millions of people test positive for tuberculosis. Few of them will actually get sick, but many are mistakenly treated with highly toxic drugs. A relatively new, but expensive, diagnostic machine can differentiate between latent and active t.b. infections. "We badly need that kind of diagnostic

certainty with Lyme," Ostfeld told me. "And we do not have it."

Public-health officials stress that if doctors see a bull's-eye rash they should assume that the patient has Lyme and prescribe antibiotics. The advice is often ignored. Nor do many doctors or patients consider the potential impact of simultaneous infection with several pathogens. "This is not resolved science," Ostfeld said. "Clearly, not everyone claiming to have Lyme disease is sick, particularly those who have never tested positive for borrelia. But there are just too many questions we still have to answer about those who are infected: Does the bacterium persist after treatment? If so, is it capable of harm? What is the impact of co-infections, and what is really the best way to treat advanced stages of Lyme?

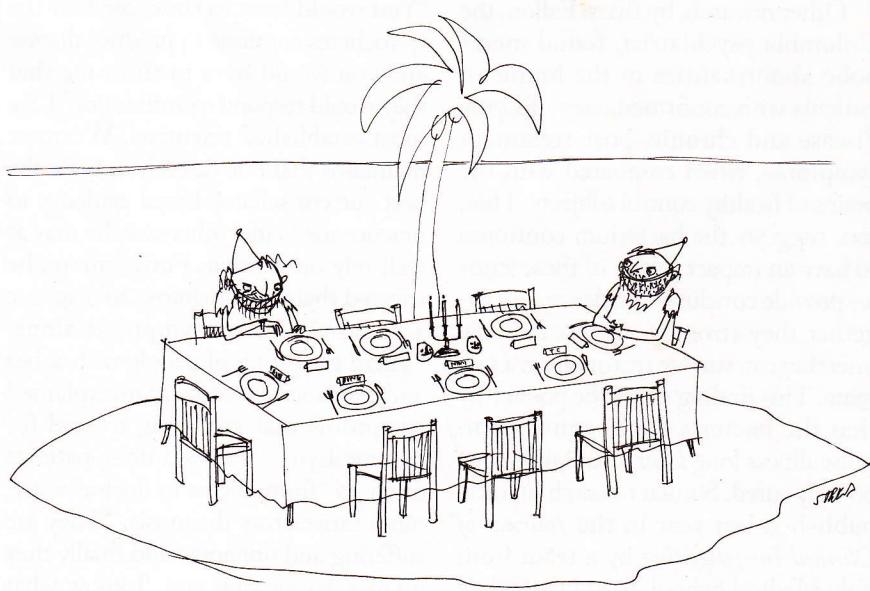
"The conventional view is that several studies have answered the most important questions about persistence and treatment," Ostfeld went on. "But look at heart disease. How many thousands of studies were conducted on the relationship between cholesterol and heart disease? Over how many decades? And we still go back and forth. When it comes to Lyme, we have a long way to go."

The controversy over Lyme disease is unlikely to diminish until scientists resolve at least two critical, but related, questions. Can the bacteria persist in the body, causing harm and illness months

or even years after treatment has ended? And can prolonged antibiotic therapy destroy the remaining bacteria? Here, as with nearly every issue related to Lyme and its treatment, there is disagreement not only about the answers but also about the questions.

Determining whether Lyme spirochetes cause illness after treatment is difficult in part because the symptoms are so diverse. Moreover, it is nearly impossible, with current tests, to know whether the infection has been cured. Recent studies with mice and macaques provide interesting clues. In a study published last year in the online journal Plos One, a team of scientists led by Monica E. Embers, of the Tulane National Primate Research Center, and Stephen W. Barthold, the director of the Center of Comparative Medicine at the University of California at Davis, carried out two experiments on rhesus macaques to determine whether borrelia persists after antibiotic treatments.

First, twenty-four rhesus macaques were infected with the Lyme bacteria in the laboratory. After four to six months, half the macaques received aggressive antibiotic therapy, which, in theory, should have cured them, but the bacteria persisted in some of the animals. Then the scientists used a method called xenodiagnosis to determine if treatment worked in three other monkeys. They planted ticks that had been



"I'm starting to think that no one else is coming."



"Would you rather be attacked by a horse-size duck or fifty duck-size horses?"

reared in the lab under sterile conditions on macaques that had received antibiotics, and let them feed for four days. When the ticks were removed and examined, the scientists found small numbers of intact, functioning spirochetes in two of them, which could have come only from the blood of the macaques. A team of scientists led by Adriana Marques, of the National Institute of Allergy and Infectious Diseases, and Linden Hu, of Tufts University School of Medicine, is conducting a similar study in humans. (The scientists have obtained permission from patients to permit ticks to feed on them.)

Other research, by Brian Fallon, the Columbia psychiatrist, found metabolic abnormalities in the brains of patients with confirmed cases of Lyme disease and chronic, post-treatment symptoms, when compared with the brains of healthy control subjects. That, too, suggests the bacterium continues to have an impact. None of these studies provide conclusive evidence, but together they strongly suggest that the infection can survive treatment in a primate. This finding raises the possibility that the bacteria could continue to cause illness long after a patient is supposedly cured. Similar research in mice, published last year in the *Journal of Clinical Investigation* by a team from Yale Medical School, found that while antibiotics stopped the infection, spirochete antigens persisted in areas ad-

jacent to cartilage—a condition that could produce swelling.

None of these studies have swayed Gary Wormser, the chief of the division of infectious diseases at New York Medical College, and the lead author of the often criticized Infectious Diseases Society of America guidelines for Lyme. He says that, in the absence of new data, doctors should continue to treat Lyme with courses of oral antibiotics that generally take no more than thirty days.

"Right now, in the published literature, there is no evidence of persistence in humans, and if there were I would say, 'So what?'" he told me recently. "You would have to show me that the spirochetes continue to produce disease and you would have to show me that they would respond to antibiotics." Like most established scientists, Wormser maintains that one can rely only on the best current science-based evidence to practice medicine; otherwise, he may as well rely on voodoo. Furthermore, he stressed that it is dangerous to diagnose a disease based on symptoms alone. "There is a group of people with aches and pains and medically unexplained symptoms that are being treated for chronic Lyme." He said these patients often go "from doctor to doctor" without a satisfactory diagnosis. "They are suffering and unhappy, and finally they go to a doctor who says, 'I know what you have, it's chronic Lyme.' Then they get treated and treated and treated for

chronic Lyme. And patients are happy because somebody has finally taken interest in them."

Wormser continued, "If you had Lyme and nobody disputes it and you don't feel back to normal, it's logical to ask, 'Does the antibiotic work?' Or maybe the organism is still there. Those questions have been explored, and we continue to explore them." Yet he added that the majority of people who are being treated as if they had post-Lyme symptoms have never had the disease. "Never had the test, the rash, swelling, not the slightest credible evidence of Lyme. If somebody walked into your office and said, 'I have renal failure, I need dialysis,' you would do a test. If it was negative, nobody in his right mind would give the patient dialysis."

Wormser's many critics regard his view of the disease as willfully limited. In response, he and others cite four double-blind, placebo-controlled trials funded by the N.I.H. over the past fifteen years. Each attempted to determine whether prolonged antibiotic treatment, given after the initial courses were completed, helps eliminate persistent symptoms of Lyme disease. The two largest studies reported no evidence of improvement; the results of the other two studies were equivocal. But none of the researchers concluded that the theoretical benefits outweighed the tangible risks of extended intravenous therapy, which included severe infections. In a separate case, a woman on intravenous antibiotics died after a blood clot.

Physicians who regularly see people with Lyme symptoms say that the conventional methods simply don't work. "I think a lot of these people who are set in their ways need to see more patients," Richard Horowitz told me when I called him at his office in Hyde Park, New York. Horowitz is one of the most prominent "Lyme literate" physicians: he is board certified in internal medicine and has practiced in the Hudson Valley for more than twenty-five years. Officials who endorse the Infectious Diseases Society of America's approach to Lyme disease consider Horowitz a pariah, but patients wait for months to see him, and several told me that he had essentially cured them of a disease that nobody else seemed able to treat.

Horowitz told me that he has seen more than twelve thousand patients, all of whom have a tick-borne ailment. Whenever possible, he avoids antibiotics. "Most of my patients do not present simply with Lyme," he told me. "They almost always have multiple co-infections. That means they have a suppressed immune system with complex symptomatology. Thirty days of doxycycline"—the most common drug used to treat Lyme—"just isn't going to cure this. Each of these pathogens requires different regimens."

Horowitz offers a complex combination of dietary restrictions and supplements to help "detoxify" the body and starve the bacteria. He argues that organized medicine, by relying on a few double-blind trials, focusses only on borrelia and Lyme. "But we know the ticks can spread many pathogens. More than half of my patients present with babesiosis," he told me. (It causes symptoms similar to those of Lyme, though it more frequently begins with fevers and chills.) The incidence of babesiosis, which is caused by microscopic parasites that infect red blood cells, has been increasing dramatically in the Hudson Valley, according to research done by Wormser. "That infection has to be treated in an entirely different way from Lyme, and together they cause far more harm than either one does alone," Horowitz said. "I have never understood why that is a controversial assertion."

David Roth is not a scientist, but he believes that only science can end the Lyme wars. I met with him one gray, cloudy day on the forty-third floor of the Blackstone Investment Group building in Manhattan, where he is a managing director. Roth was dressed in pinstripes, a crisp white shirt, a yellow tie, and spit-shined brogues. He has an air of distinguished nonchalance, and his brown hair is tousled in the manner of a Kennedy. Three years ago, Roth became very sick, and while it has been difficult for him, and for his family, his illness may be the best thing that has happened for people infected with tick-borne ailments.

"I started working on this problem because I was shocked by the approach of the medical community," he told me. "I felt there was a real social injustice."

Roth's story was similar to those of others I had heard. His illness began with flulike symptoms, enlarged lymph nodes, and insomnia. Doctors found no apparent cause. His symptoms worsened; full-body shakes, numbness in his feet and hands, pain in his tendons, and immense fatigue. "I went up and down this city seeing doctors," he said. "I had CAT scans and PET scans and M.R.I.s." Those tests also turned up nothing, but eventually—about four months after falling ill—he tested positive for both Lyme disease and babesiosis. He was treated with antibiotics as well as with malaria medication; they helped, but only for a while. "When I stopped, things got worse," he told me. The more he looked into the treatment of Lyme, the angrier he became. "Here is what I don't understand," he said. "Somebody can get ill and not know what it is and the symptoms get worse and worse. Two years or more later, they can learn that they have Lyme. They take antibiotics for a month. And then, according to their doctors and insurance companies, they are done. Cured. Sometimes that is enough. But many people continue to be sick, and the government's position, in a world where there are ten times as many bacterial cells as human cells in our body, is that this particular bacteria has been removed forever and the problem must be due to something else."

Roth is forty-six, goes to the gym several times a week, and looks robust. ("One of the problems with Lyme is that people tend to look better than they are," he said.) He has received treatment—dietary supplements and dietary changes—from Horowitz, and his health has improved greatly. Like Kaleigh Ahern, he has difficult days, but they are less frequent. Recently, he was appointed to a federal advisory committee that is working on ways to improve Lyme diagnostics. He was one of the hosts of a gala, held by the Tick-Borne Disease Alliance, earlier this year, which raised eight hundred thousand dollars. "I try to act rationally and work with rational people," he went on. "Sometimes that is hard to do."

For Lyme activists to be taken seriously, they will have to be led more by

people like Roth than by those who foster dark conspiracies. I was told by several Lyme activists that the government created the infection on Plum Island, that reporters at the *Times* have been "muzzled" and prevented from reporting honestly about Lyme, and that the N.I.H. has made a pact with pharmaceutical companies to ignore chronic Lyme. There is now a bill before the legislature in New York that would require insurance companies to reimburse long-term treatment with antibiotics—even though no study has proved their effectiveness, and treatment with I.V. antibiotics can cause serious, and sometimes fatal, complications.

Meanwhile, the scientists sometimes seem to respond more comfortably to data than to people. Researchers at the N.I.H. are pursuing several lines of inquiry, including the possibility of bacterial persistence. The atmosphere resembles that of the early days of AIDS activism, when many of the individuals most at risk lost confidence in their doctors and sought their own medical answers. In the end, organizers of ACT UP and the Gay Men's Health Crisis became well known for their public protests, but they succeeded for another reason: they did their homework. Nobody was more knowledgeable about the course of H.I.V. infection than the best-informed activists.

Lyme-advocacy organizations need to rely on similarly well-informed people. Kaleigh Ahern is one of them. She

recently presented a paper on the behavior of black-legged ticks at the annual meeting of the Federation of American Societies for Experimental Biology. "It was my thesis at Union," she explained. "I looked at the effects of soil pH on molting success. I wanted to know the ecological factors

that make Lyme increase so steadily in this region." She has applied to graduate school, where she hopes to help develop more useful diagnostics for Lyme.

I asked if her parents were surprised that she has chosen to work with Lyme ticks. "They are horrified," she told me, laughing. "But, if I don't do it, who will?" ♦

