

health

Tick Wars

For those suffering with persistent Lyme disease, the treatments are few, and the controversies are many. By Christianna McCausland

Perhaps it's not surprising that Carol Siegmeister got Lyme disease. The 71-year-old Pikesville resident is an avid gardener and she sees deer in her neighborhood often enough: "Donner and Blitzen live in my backyard," she says. What is surprising is that Siegmeister went through an approved treatment for the disease but never got well.

When first bitten, she thought the bumps on her ankle were poison ivy. Two weeks later, she developed a rash on her abdomen, a fever, and fatigue. She immediately went to her doctor and was diagnosed with Lyme disease. After treatment, she only got sicker.

"I am a triple type-A personality and I was hit with exhausting fatigue to the point that I was in bed a good bit of the day, which was terrible for me," she explains. In addition, she suffered such severe cognitive dysfunction that she couldn't run her interior-design business.

"New symptoms would emerge daily and I had no idea what was happening to me. I began to get lost in my own neighborhood, I had digestive problems, there was the chronic fatigue, I was unable to eat normally, I had flashing lights behind my eyes."

While most people who are diagnosed and treated early for Lyme disease are cured, there is a small but terribly debilitated population that never gets well. It took almost two years for Siegmeister to feel better. A doctor carefully monitored her individualized care. Only in the past two months has she felt well enough to play golf again and eat properly, although she still tires easily.

Experts cannot even agree on what to call this persistent ailment, much less how to treat it. And the division between two distinct groups of long-term sufferers is so vitriolic that many experts fear research of the disease is getting bogged down by the controversy. But a small number of Baltimore-area physicians who specialize in Lyme disease are soldiering on anyway, trying to find help for the lingering form of the affliction.

LYME DISEASE IS CAUSED BY AN INFECTION WITH A bacterium called *Borrelia burgdorferi*, which is usually transmitted by a deer tick bite. There are about 20,000 reported cases of Lyme disease in America annually and there were 1,248 reported cases of Lyme disease in Maryland in 2006, but experts agree that cases are vastly under-reported. Most people who get Lyme disease—though not all—develop a bull's-eye-shaped rash around the bite area. The disease—which can strike people of any age—is treated with oral antibiotics and, for most people, that's the end of the story.

Depending on who you ask, however, anywhere from 5 to 25 percent of people who have a well-defined Lyme disease diagnosis will develop the chronic form. These people receive treatment for Lyme disease but have symptoms that won't give up. The lingering Lyme can be completely debilitating, imprisoning people in their homes, confining them to their beds. And there is no FDA-approved treatment for these patients.

But there's no shortage of opinions as to what's behind this disease and how to treat it. Although the Internet is full of snake-oil salesmen willing to capitalize on the desperation of sufferers with a host of unproven remedies, two recognized schools of thought exist. One side of the debate, which includes some patients and so-called "Lyme-literate" doctors, calls the disease "chronic Lyme disease." The other side, occupied primarily by researchers, the Centers for Disease Control (CDC), and the Infectious Disease Society of America (IDSA), calls it "post-Lyme syndrome."

"People that call it chronic Lyme disease believe strongly that the cause is due to persis-

tent, ongoing infection despite the initial antibiotic treatment, so their approach is to treat it with longer courses of antibiotics," explains Dr. John Aucott, founder of the nonprofit Lyme Disease Research Foundation of Maryland. Aucott also runs a referral clinic for the care of patients with Lyme disease and its complications. He cared for Carol Siegmeister. "The post-Lyme group, which is often represented by the CDC and the Infectious Disease Society, believe that the infection is gone and the symptoms are a by-product of having been infected."

Aucott firmly places himself on neither side of the debate but rather in the middle, struggling to help his patients with the information and treatments available (or lack thereof). It's no wonder he doesn't want to pick a side—the debate between the two dogmas is so ugly it rivals the Hatfields and McCoys. When the IDSA published its practice guidelines for Lyme disease—which clearly state that long-term antibiotic treatment is ineffective against post-Lyme syndrome—the Attorney General of Connecticut sued IDSA.

Insurance companies hopped onboard with the IDSA guidelines and used them to justify denying Lyme sufferers long-term antibiotic treatment. (Lyme-literate doctors often treat chronic Lyme disease with months, if not years, of oral and IV antibiotics.) Proponents of the chronic-Lyme theory believe IDSA and the CDC have a stranglehold over research and funding, are pushing Lyme-literate doctors out of practice, and are denying sick people access to treatment. For their part, the post-Lyme syndrome folks don't think anyone has a hard-and-fast answer yet, and

anyone who says he does is selling patients promises he might not be able to keep.

Dr. Paul Auwaerter is the clinical director for the division of infectious diseases at Johns Hopkins University School of Medicine. He participated in the review of the IDSA guidelines and also helped author an article on the debate over post-Lyme syndrome that appeared in the *New England Journal of Medicine* last fall (and that raised no small amount of contention from the chronic Lyme set).

“We really don’t know what the best treatment strategies are and this is where, unfortunately, the science has lagged behind,” says Auwaerter. “We end up clearly falling more into the art of medicine.” Because there is no FDA-approved treatment for persistent Lyme disease, it falls to doctors to treat the symptoms affecting patients, using anything from cognitive-behavioral therapy to pain medication.

As if the waters needed to become muddier, the means of diagnosing the disease can be inaccurate and a lot is left to interpretation. Many people with persistent Lyme disease are mislabeled with fibromyalgia or chronic fatigue syndrome, or vice versa. The chronic Lyme advocates believe the illness is underdiagnosed by doctors. Physicians like Auwaerter think the chronic Lyme folks are too loose in their diagnosis criteria.

“A lot of times, these poor patients basically get told they’re crazy, which is tragic,” adds Aucott. “They usually get told they are depressed and that’s just a way for the physician to get them out of their office.”

Auwaerter is emphatic that he does not believe these patients are crazy and he does not believe the IDSA guidelines state that either. But there are doctors who routinely dismiss subjective symptoms as psychosomatic, and it’s that mentality that really lights a fire under Pat Smith.

Smith is the president of the Lyme Disease Association (LDA), a national nonprofit that provides funding for research, education, and prevention of Lyme disease and also some patient support. LDA is on the side of the chronic Lyme disease label.

“The problem comes into play because there’s a segment of mainstream medicine

that says there’s no such thing as chronic Lyme disease—they say it’s all an autoimmune reaction,” she states. “They say there’s no disease and they feel, unfortunately, that these patients should not get any treatment.”

The IDSA states on its website that “an extensive review of scientifically rigorous studies and papers available to date has determined that there is no convincing biological evidence to support a diagnosis of chronic Lyme disease after completion of the recommended treatment.”

To Smith and those on her side, the IDSA guidelines are fundamentally flawed by bias.

“Because the guideline’s committees were composed of physicians who belong to the IDSA, they were all of the same mind,” says Smith. “They did not include any input from patients . . . they did not include any input from ILADS, the International Lyme and Associated Disease Society, or even from their own members who said, ‘We don’t agree with this position.’”

The IDSA states that long-term antibiotic use can have harmful side effects. While Smith doesn’t know that long-term antibiotic treatment is the absolute answer to chronic Lyme disease, she feels it is the best option available right now, one where the benefits outweigh the risks.

“We’re talking about people who have lost their useful lives, people who may be in their house for 10 years,” she explains. “Antibiotics give them the ability to have a life.”

One thing both sides can agree on is that more research needs to be done—and that their own infighting might be hindering that process.

“When I look here in academics and I train infectious disease fellows, fellows don’t want to see Lyme patients,” says Auwaerter. “They don’t want to enter this controversial area because it seems like it’s just a recipe for headaches. I think the debate, as it were, has gotten to such a level that it may stifle research.”

Ironically, both sides want many of the same things: research into the long-term nature of Lyme disease and how to treat it, and the development of better diagnostic tools.

“We desperately need more research,” Smith agrees. LDA currently is backing two

bills in Congress to get \$100 million over five years for research, education, and prevention of Lyme disease. But she fears the political climate swings to the side of the IDSA. “I don’t know what the answers are, but I know they need to be found, but they need to be found in a free scientific way, not in a way where a few people are controlling what comes out of this,” says Smith.

Whether the two sides can lay down their arms and work together remains to be seen, but persistent Lyme sufferers face many more hurdles.

Both researchers and pharmaceutical companies follow the money and there’s not much to be made either in the research of Lyme disease or the creation of pharmaceuticals for its treatment.

Aucott formed his foundation to support research when he tried to develop a research program for Lyme disease at Johns Hopkins and failed to get any CDC funding. This June, he’s embarking on a prospective trial of 100-200 patients with well-defined, early Lyme disease and tracking them for two years to evaluate their risk for developing the persistent form of the disease. But in the competitive world of grant money, Lyme disease simply lacks the doomsday cache needed to attract big bucks.

“When you put it next to bird flu, where people have scares of pandemics killing millions of people, or you put it next to bioterrorism, where you could have mass casualties, it doesn’t look as scary,” he laments.

Ultimately, it’s the patients who fall between the cracks. “No one wants to see these patients because there’s nothing you can do to help them that’s FDA-approved,” says Aucott. “For traditional guys like me, it’s hard to sit in front of a patient and tell them you don’t know why they still feel bad after you’ve treated them, and you don’t have anything else that’s obviously going to make them better. And it’s tragic. The poor patients get caught in the middle, and they just want to get better.”