

## **Harvey: Lyme disease is unrecognized but real**

*By Andrea Harvey*

Too many Lyme disease patients are not receiving timely and affordable treatment due to the Infectious Diseases Society of America's strict guidelines. "Everybody should have the right to be a healthy person, but I don't get that right," University of Oregon junior Sofia Webster said.

Sofia was 14 when she was bitten by a tick while camping with her Girl Scout troop in California. After it was removed, however, she forgot about it. Months later, she was experiencing chronic fatigue and pain in her feet, muscles, head and joints. She began using a wheelchair.

Four years, twelve doctors and several different misdiagnoses later, no one had any idea what was wrong.

Through an online search, Sofia's mother discovered Lyme disease, a tick-born illness explaining Sofia's symptoms almost perfectly. Remembering the tick bite, she made another appointment to get tested. But her doctor refused and said Lyme doesn't exist in California.

Frustrated, Sofia went to a doctor outside her health insurance and paid out-of-pocket to get tested. It was positive.

She then began intensive antibiotic treatment from a Lyme Literate Medical Doctor, one of the few types of professionals who treat Lyme patients in the area.

In June of 2012, Sofia visited a specialist within her insurance company to seek affordable treatment. But the positive blood test wasn't enough proof. She was told she didn't have Lyme disease because she was bitten outside the East Coast, she never developed a rash and her test was not done according to the Centers for Disease Control and Prevention's standards.

Yet in 2012, the [CDC](#) recorded 61 confirmed Lyme cases in California, and says 20-30 percent of patients won't get the rash. They even mention evidence supportive of post-Lyme disease syndrome, a condition that Sofia is experiencing, but is unrecognized by the IDSA.

“Bullshit,” Sofia wrote in her personal blog. “I did not understand the injustice.”

The IDSA’s [Clinical Practice Guidelines](#) includes an overly meticulous definition of Lyme disease. For example, the tick must have been embedded in the skin for more than 36 hours and the bite must have occurred in an area with an infection rate exceeding 20 percent, which is the East Coast and parts of Minnesota and Wisconsin.

Many Lyme patients pay hundreds of thousands of dollars on treatment because their insurance providers won’t cover it. And often, their disease has left them unable to work. If they had been diagnosed sooner, one bottle of antibiotics might have cured them and allowed them to live a normal life.

Dr. J. Stone Doggett is a researcher and assistant professor of medicine at the Oregon Health and Science University’s Division of Infectious Diseases. Like most doctors, he believes the science behind Lyme is well established; however, the expansion of potential symptoms unverified by medical evidence leads to many misdiagnoses and unnecessary antibiotic treatment.

“When you perform any test in a population with a low prevalence of disease there is a risk for false positive results,” Doggett said. “There are significant risks from taking antibiotics. These risks increase when people take antibiotics for a long time or through an IV.”

Undoubtedly, the guidelines are meant to prevent these risks. But the presence of Lyme disease in the Northwest, as rare as it may be, has been confirmed. Clearly a misdiagnosis poses a risk, but does that risk deserve more attention than the risk of an undiagnosed case of Lyme disease? Are they forgetting that people can die because of this?

Or does the problem stem from the way doctors and health insurance providers approach these guidelines? Richard Whitley, the IDSA president, addressed this in an online video, “I want to emphasize one point. The guidelines are just as they say they are. They’re guidelines. They’re not rules. They’re not laws.”

Meanwhile, hundreds of Americans infected with Lyme disease continue to suffer. Something needs to be done.

Today, Sofia is receiving homeopathic treatment and feeling better. She recently became president of the UO AccessABILITY Student Union. Her struggle has inspired her to fight for social justice in any way she can.