

Lyme disease activists to protest

By Robert Miller

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Area Lyme disease activists, dismayed by recently released treatment guidelines for the illness, will go public with their protest Thursday, rallying at Westchester Medical Center/New York Medical College in Valhalla, N.Y., where the lead author of the guidelines works.

"They're highly restrictive," said Dr. Steven Phillips, a Ridgefield physician who is the former president of the International Lyme and Associated Diseases Society. "I just cannot understand why they've chosen to ignore all the data on this."

"They were worse than we expected," said Maggie Shaw of the Newtown Lyme Disease Task Force.

"In a word, I think they're a disgrace," said Dr. Raphael Stricker of San Francisco, who is the current president of ILADS. "They're not relying on best science. They're relying on their opinion."

The guidelines are so controversial that Attorney General Richard Blumenthal has intervened. His office is now investigating whether the group that wrote the guidelines, the Infectious Diseases Society of America, is a monopolistic organization trying to shape treatment of the tick-borne disease without allowing other treatment options to emerge.

"It's a medical issue but also a patient issue," Blumenthal said. "Their guidelines limit very severely the types of diagnosis and treatment available to patients. In a way, that's anti-competitive."

The national guidelines issued by the Infectious Diseases Society of America recommend that doctors give patients with Lyme disease 10 to 28 days of oral antibiotics to treat the disease, with another month allowed for persistent symptoms.

But the guidelines -- now posted on the Web site of the Centers for Disease Control and Prevention -- deny the existence of chronic Lyme disease, saying there's no medical evidence that the bacteria that causes Lyme survives antibiotic treatment.

It also emphasizes using either the characteristic bull's-eye rash or blood tests to help correctly diagnose the disease -- two methods Lyme activists say can lead to Lyme cases being missed.

Diana Olson, spokeswoman for the infectious diseases society, said the 14 doctors who worked on the guidelines -- led by Dr. Gary Wormser, an infectious disease specialist at Westchester Medical Center/New York Medical College -- studied more than 400 published medical reports on Lyme disease before coming to their conclusions.

"This is the best science has to offer," she said.

Olson said the society could not take into account things like patients' anecdotal accounts of their Lyme disease treatment in writing the guidelines. Nor, she said, did it concern itself with whether insurance companies would pay for treatment outside those guidelines.

She also said that guidelines are just that, and that patients and doctors are free to find different treatments that work best for them.

She also said the society is cooperating fully with Blumenthal's office.

"In our experience, we've never heard of this kind of investigation," she said. "But we stand behind our methods and our recommendations."

But Lyme activists and doctors who support a more liberal approach to treating the disease said the new guidelines are highly restrictive, not allowing doctors any latitude in treatment.

Perhaps the most contentious point is whether chronic Lyme disease even exists.

Many Lyme patients and their doctors contend the standard treatment for Lyme disease sometimes fails, or never gets administered to begin with.

When that happens, they say, the bacterial spirochete that causes the disease can re-emerge in the body, causing a bewildering array of symptoms -- including arthritis, chronic fatigue, heart problems, memory loss, depression, and neurological disorders including loss of sight and hearing.

To treat these symptoms -- and those of several other tick-borne illnesses, which can overlap -- these doctors recommend several months or even years of antibiotics, often using a mix of drugs.

The infectious disease society, however, said that these symptoms are "nonspecific" and associated with many other illnesses, not Lyme infection. They also caution that there are medical problems -- including the development of drug resistance -- that should lead patients to avoid long-term antibiotic care whenever possible.

But Phillips of Ridgefield and Stricker of San Francisco said this approach ignores the hundreds of studies that now show the Lyme bacteria can bury itself in muscle tissue, lie dormant, then re-emerge.

"There (have) been 18,000 papers published on Lyme disease," Stricker said. "So saying you're looking at 400 means you've only looked at 5 percent of the research."

"The evidence just continues to grow and grow on this," Phillips said. "To ignore a whole section of this research, as if it doesn't exist, raises questions for me."

Because of the prestige the infectious disease society carries, Lyme activists say insurance companies will now be even more adamant about refusing coverage beyond 28 days of antibiotics -- something, they say, that has already begun.

They also say the new guidelines will stifle new treatments, because doctors will fear they'll be disciplined if they step beyond the guidelines.

"This isn't theoretical," Blumenthal said. "It will come down to a matter of dollars and cents."

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