

# Hundreds rally to protest new Lyme disease treatment guidelines.

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VALHALLA - Hundreds of people rallied yesterday outside Westchester Medical Center to decry new treatment guidelines for Lyme disease that discourage the use of long-term antibiotics to treat lingering symptoms.

The voluntary guidelines were issued last month by the Infectious Diseases Society of America; the lead author was Dr. Gary Wormser, chief of the division of infectious diseases at the hospital.

Protesters from as far away as California and Texas waved a sea of neon-green signs at passing cars at the intersection of Woods and Grasslands roads, some of which personally mocked the doctor with messages like, "Wormser lies ... Patients Die" and "Dr. Wormser - You Make Me Sick!" Others read, "Gross Medical Neglect," and "Stop the Ignorance."

Lyme disease, caused by the bite of a deer tick, can lead to an initial infection including a rash and muscle and joint pain; later it can result in arthritis and neurological symptoms. The new guidelines call for a bite to be treated with a single dose of preventative antibiotics, but say prolonged antibiotic treatment "has not proven to be useful." They also seek to differentiate between patients with "post-Lyme syndrome" and those with just the "aches and pains of daily living."

Patients and advocates yesterday said the study did not take their illnesses, or their efforts to find successful treatment, seriously enough.

"We are here today to fight back," declared Karen Gaudian of Ridgefield, Conn., who decried the new regulations as the result of organizations "corrupted by the quest for financial gain."

Pat Smith, president of the Lyme Disease Association, brought a clock that runs backward to illustrate a study she said was "taking us back in time."

"We cannot and will not allow the IDSA and their followers to take our disease away," she declared.

## **At a glance**

The debate at hand is how to treat patients with long-term symptoms that appear to be caused by Lyme disease.

New guidelines from the Infectious Diseases Society of America say prolonged antibiotic treatment "has not proven to be useful."

A different group, the International Lyme and Associated Diseases Society, supports the use of long-term antibiotics in some of these cases. Patients and advocates at yesterday's rally oppose IDSA and back the ILADS position.

Protesters cheered Dr. Joseph Burrascano, vice president of the International Lyme and Associated Diseases Society, which supports the use of long-term antibiotics in some cases and has called on the IDSA to retract the recommendations.

"If they weren't so seriously flawed, I would say it was a joke," he said of the guidelines. He urged those at the rally to fight back "by uncovering the truth."

Doug Maass, 62, of Sleepy Hollow said he came to the rally because he was concerned he and thousands of other patients would lose insurance coverage or be cut off from treatment for chronic Lyme disease. He believes that he has had the disease since 1988, and that it is the cause of symptoms like his recurring left-side headaches and swollen glands; his wife, who is also ill, has symptoms that are even worse, he said.

"I've been on nine different antibiotics over six years," he said. "When I'm on antibiotics I feel pretty good. I go off for six or seven months, and the symptoms come back."

An attempt to reach Wormser for a response through a Westchester Medical Center spokeswoman was unsuccessful.

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