

Friday, December 1, 2006  
Dozens from Dutchess join Lyme treatment rally

**Liz Anderson**

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

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."

About 40 people from Dutchess County, including patients, prominent tick-borne disease advocates and doctors, and Assemblyman Joel Miller, R-Poughkeepsie, traveled to Westchester County for the rally.

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.

Nowhere in the country do residents have as high a risk for Lyme disease as in the Hudson Valley. That has made the valley an epicenter not only for disease, but for controversy over its treatment. Advocates allege that doctors have been targeted by insurers and state regulators for aggressively treating Lyme symptoms with long courses of intravenous antibiotics.

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, neurological symptoms, heart trouble and a variety of other ailments.

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

Patients describe a litany of debilitating symptoms that they and their doctors attribute to Lyme. Difficulty concentrating, severe joint pain and other ailments only begin to describe the list.

Many argue vehemently that the only reason they can function after Lyme is that they have received long, and expensive, courses of antibiotics. Sometimes only intravenous antibiotics - a particularly expensive form of treatment - is the only thing that works. Patients often travel 50

miles or more to reach the handful of doctors who treat the disease aggressively.

Patients and doctors have had difficulty at times getting insurance companies to pay for the treatment, and the guideline could be used to deny the treatments they say they need.

This is only the latest battle in a long war. The debate has also been waged in Albany, where an alleged crackdown on doctors that aggressively treat Lyme led to reform of the state's regulation of professional medical conduct.

"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.

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."

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Courtesy Lynn McCabe  
Residents of Dutchess County carried protest signs to Westchester for a rally in support of aggressive Lyme disease treatment Thursday.

### 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.