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# Local residents rally for rights

“Let us live!” was the opening cry from Coming, N.Y., resident Dr. Elisabeth Heininger as she spoke at a Lyme (disease) Rights protest rally on Thursday, Nov. 30 at the Westchester Medical Center/NY Medical College in Valhalla, NY. Heininger was one of several speakers at the rally held to protest new guidelines for diagnosis and treatment of Lyme disease written by a committee of the Infectious Diseases Society of America. Lead author of the guidelines is Gary Wormser, MD, infectious disease specialist at the center where the rally was held.

Other key speakers included Joseph Burrascano, Jr., M.D., one of the world’s leading authorities on Lyme disease and vice president of the International Lyme and Associated Diseases Society; Pat Smith, president of the Lyme Disease Association and past chair of the New Jersey Governor’s Lyme Disease Advisory Council; and Joel M. Miller, NY State Assemblyman (R-Poughkeepsie).

Lyme disease is a bacterial infection caused by the bite of an infected tick. Children ages 5-9 are at highest risk of contracting Lyme although anyone can be affected. The disease is systemic and variable. It may include flu-like symptoms as well as neurological, cardiac, and central nervous system involvement. Early treatment is critical to avoid the more serious, long-term effects.

According to Lyme Rights, the group that organized the protest, use of IDSA guidelines “guarantees people will not be treated in time, empowers insurance companies to deny treatment coverage, and threatens physicians’ ability to treat.” Some physicians treating people for chronic Lyme disease and common co-infections have been investigated by state medical boards and a few have lost their licenses. Both patients and health care providers are victims of restrictive guidelines, according to a press release.

More than 300 people from 16 US. states including Florida, California, Texas, and Washington protested IDSA guidelines. Other local residents at the rally with Heininger were Dr. Suzanne Maschmeyer, also of Coming, and NYPENN Lyme Disease Support Group founder and leader Linda Wales of Millerton. They represented more than 60 Twin Tiers residents who have been clinically diagnosed with Lyme disease.

Protestors carried signs bearing many important messages, one of the most poignant being that they were there not only for themselves but also for the thousands of other Lyme sufferers who were far too ill to participate. A 19-ft long scroll was displayed remembering hundreds who have died from Lyme disease.

Use of the new IDSA guidelines (published November 8, 2006) has already proved

detrimental. They have been used to deny health insurance coverage for treatment validated by the International Lyme and Associated Diseases Society, a professional organization composed of physicians and other health care providers who have treated thousands of people with the disease and produced scientifically sound research on diagnosis and treatment. ILADS has also published treatment guidelines but it is IDSA guidelines that appear on the website of the national Centers for Disease Control and Prevention.

Burrascano, referring to IDSA guidelines stated that, "If they weren't so seriously flawed, I'd say It was a joke.' Protestors cheered, knowing first-hand how difficult it is to find physicians who recognize Lyme and use long-term antibiotics-when necessary. Such treatment is what allowed many to attend.



LYME DISEASE can be transmitted from mother to child across the placenta. Since symptoms may not occur for weeks to years after the bite of an Infected tick, the mother may be unaware of her infection. Some researchers believe that Lyme may also be sexually transmitted (the bacterium is a spirochete as is syphilis).