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Patients from throughout US Protest Guidelines in New York Hundreds Carry Signs & Cheer Actions of Connecticut Attorney General

New York, December 4— Three hundred patients from New York, Connecticut, New Jersey, Pennsylvania, Delaware, Massachusetts, Maine, Rhode Island, New Hampshire, Vermont, Maryland and even as far away as Texas, Florida, California and Washington gathered outside Westchester Medical Center/NY Medical College in Valhalla, NY on November 30 protesting the latest changes to what were already inadequate and restrictive diagnostic and treatment protocols by the Infectious Diseases Society of America. Westchester Medical Center/New York Medical College is home to three IDSA committee members, including guidelines chair Dr. Gary Wormser.

Nationally known speakers from the Lyme community were joined by several officials concerned about the guidelines impact upon patients: Dr. Joseph Burrascano, Jr. a world renowned Lyme expert from East Hampton, Long Island, who also serves as vice president of the International Lyme and Associated Diseases Society (ILADS), Pat Smith, president of the national Lyme Disease Association (LDA), and New York officials Assemblyman Joel Miller, and Yorktown Congressman Jim Martorano of Yorktown Heights. Several patients also spoke, and the Lyme disease Association's online petition against the guidelines, which has over 18,000 signatures to date, was read to the assembled patients, some of whom already were experiencing problems due to the guidelines.

Ms. Smith announced at the rally that there is now an electronic Member Letter circulating (by Congressman Christopher Smith NJ-4) in the US House of Representatives directed to the Centers for Disease Control & Prevention's Director Dr. Julie Gerberding, expressing concern with the CDC's placement of these guidelines on their website. Patients were urged to contact their Congressman to sign onto the letter.

Dr. Burrascano discussed the implications of the guidelines to practicing physicians and Assemblyman Miller stated his strong concern about the implications for chronic patients who would not be able to continue treatment. Commissioner Martorano expressed patient support from himself and also from Congressman-elect Jim Hall (NY-19) who takes office in January.

Protestors cheered the actions of the Connecticut State Attorney General (AG), Richard Blumenthal, who last month issued a Civil Investigative Demand to the IDSA, initiating an investigation into the guidelines development process for possible exclusionary practices. The IDSA refused to allow the LDA (representing patients) or ILADS (chronic disease-treating physicians) input into the guidelines' process despite formal requests to do so.

Patients have mobilized to insist that the medical community recognize that Lyme disease can be a chronic disease that is helped by antibiotic treatment. It is known to lead to nervous system, heart and brain problems if the illness goes undetected or is inadequately treated. The new IDSA guidelines recommend any clinical diagnosis be supported by a positive test or a bulls' eye rash, despite the fact that the tests are unreliable and the bulls' eye does not occur in up to half of the cases. Long-term treatment and many kinds of antibiotics prescribed by Lyme treating physicians are listed

as “not recommended,” as are alternatives and even supplements. The IDSA is a powerful organization whose guidelines are adopted by medical and governmental authorities and by insurance companies, and often patients are denied treatment and doctors are charged with malpractice for treating outside such guidelines.

Lyme disease, the most common vector-borne disease in the United States, is caused by the bite from a bacteria-infected tick. Symptoms of early Lyme disease vary for each individual patient, but may include fever, chills, headache, backaches, fatigue, and a bull’s eye rash. The Centers for Disease Control and Prevention estimates that Lyme is vastly underreported—220,000 to 240,000 Americans are probably infected with Lyme disease each year. While Lyme disease is often considered a Northeastern disease, it has been reported in 49 states, and increases have been reported in Maryland and in other southern and central states.