

For Immediate Release

Lyme Patients Protest

House Health Committee & Congressman Pallone Bowing to Powerful Medical Society

Long Branch, New Jersey, May 7, 2008 – Patients from across the country mobilized in New Jersey today under the Lyme Rights banner to demand action on HR 741, the Lyme bill sponsored by Congressman Chris Smith (NJ-4). Congressman Frank Pallone (NJ-6), Chairman of the Energy & Commerce Health Subcommittee, has direct control over the fate of this health legislation in the House. Senator Edward Kennedy has control in the Senate (S-1708/Dodd CT).

The Jersey Shore has been an endemic area for Lyme disease for years. In 2006, the Garden State ranked 3rd in reported cases in the US, and Monmouth County, the site of the protest, ranked 2nd in case numbers in NJ. Children ages 5-9 are most at risk, yet according to protestors today, Mr. Pallone continues to ignore the problem and the patients.

In an action which influenced today's rally, Attorney General Richard Blumenthal announced on May 1 that he had concluded his investigation of the Infectious Diseases Society of America (IDSA) and reached a settlement which forces IDSA to re-examine its Lyme disease guidelines. The settlement shows the patients are right; the IDSA is biased against chronic Lyme. The IDSA panel which created Lyme disease treatment guidelines said there is NO chronic Lyme and NO treatment should be given to patients. This settlement makes IDSA go back to the drawing board with an unbiased panel in a public manner, and the ramifications are enormous to Lyme patient care everywhere.

Despite the historic decision by the Attorney General, the federal Lyme bills have not been placed on either the Senate or House Health Committee agendas. Patients are angry and frustrated at this stonewalling by Congress who, they believe, has listened to the IDSA lobbying intensely against the bill. Today's protest reflected that mood. "Congressman Pallone who chairs the House Health subcommittee has not listened to the patients," said attendee and activist Joan Wire, a New Jersey resident whose 15 year old son has been wheel chair bound for 2 years due to Lyme disease. "Other diseases have money and a federal focus, and other diseases allow patients to be part of the process to find a cure for their disease. Mr. Pallone has outright ignored our sick children. "

Colleen Nicholson of Military Lyme Support, who traveled to the rally from New York, said "I talk with military Lyme patients throughout the country who describe the personal devastation of chronic Lyme disease. Why, they ask, has Congress abandoned them when they risk their lives fighting for their country? I do not have the answers for them but came today to try to make Congress accountable for its slight of the military."

New Jersey is also home to the national Lyme organization which represents the most patients nationwide, Lyme Disease Association (LDA). LDA has been in the forefront of developing the federal Lyme bill since 1997. Pat Smith, a Monmouth County resident, rallied the crowd of 150 representing at least 8 states, with the history of Lyme in Monmouth County, which goes back to the late 70s and early 80s. Many of the first cases in NJ were documented on Earle Naval Weapons Station, nearby the rally. She discussed the personal impact on two of her daughters, both diagnosed in the 80s, one who missed more than four years of school, had seizures, and now has heart damage as a result of her chronic Lyme disease. Because of extended treatment, she is able to live and work independently, something many patients are unable to achieve, due, in part, to their delayed diagnosis and delayed or inadequate treatment.

Ms. Smith said, "The time has come for Lyme patients to be heard and seen. They need to provide a face for this invisible epidemic sweeping this great country of ours. Lyme patients have no more patience

for being told, 'you are not sick, you never had Lyme disease, you need psychiatric help,' or even worse. Mothers do not want to be told, 'you are making your child sick,' or hear insulting questions from doctors like 'does she **really** have Lyme, or do you just **think** she does?' Twenty years have gone by since I heard that line right here in Monmouth County, and yet mothers today are having their children taken away by family service agencies, all for the crime of having them treated by a licensed medical doctor for Lyme disease."

"Research and education," she continued, "hold the key to unraveling this disease, yet Congress will not even allow our voices or the voices of our treating physicians to be heard." Ms. Smith's comment here alludes to HR 741, The Lyme and Tick-Borne Diseases Prevention, Education & Research Act of 2007, which the rally spotlighted. It creates an advisory committee on Lyme and other tick-borne diseases where patients and treating physicians alike have a voice in Lyme disease for the first time. The IDSA, who has been lobbying against the bill, wants that voice to be removed. (Ms. Smith can be reached at Lymeliter@aol.com or 888 366 6611)

About the bill: Besides establishing the advisory committee, the bill authorizes to appropriate \$100 million for tick-borne diseases research over five years. Goals include improving diagnostic testing & outcomes research, enhancing public health surveillance systems, and improving public education to prevent new cases of Lyme and other tick-borne diseases.

About Lyme disease: Lyme is the most prevalent vector-borne disease in the country, and it has been joined by other tick-borne infections including babesiosis (very prevalent in NJ), anaplasmosis/ehrlichiosis, and tick-borne Bartonella, transmitted by the bite of the same deer ticks that carry the Lyme disease bacteria. Lyme has been reported in all 50 states and is found in 65 countries worldwide. It is often misdiagnosed as MS, ALS, chronic fatigue, fibromyalgia, Alzheimer's, and lupus, and if it goes undiagnosed or improperly treated, it may cause many patients to suffer persistent health problems, including arthritic, musculo-skeletal, cardiac, neurologic, and psychiatric manifestations, and may even cause death.

About Lyme Rights: Lyme Rights is a grass roots group of Lyme patients who mobilize when needed nationally to take their message directly to those individuals who are responsible for shaping public policy or those responsible for violating their rights.

Informative websites:

www.LymeRights.org for information and pictures on the protest

www.LymeDiseaseAssociation.org for information on Lyme disease and HR 741, the Lyme bill.

<http://www.ct.gov/ag/cwp/view.asp?a=2795&q=414284> for CT Attorney General Press Release

www.ILADS.org for information from treating physicians

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