

Smith Bill to Aid Victims of Chronic Lyme

Lyme Disease Forum Draws Large Crowd

Over 350 local residents attended a Lyme disease forum I recently hosted in Wall Township. The panel discussion featured national public health and medical experts — pioneers in the study and treatment of Lyme — who came to New Jersey to share their expertise about this vexing disease, including detection strategies, best treatments and prevention regimens.

New Jersey, regrettably, ranks fourth in the nation in the number of reported Lyme disease cases, and there has been an increase in other tick-borne pathogens in our state.

Surprisingly, many doctors, public health authorities, and insurance policy makers still do not have a good grasp on the

prevalence of Lyme and best treatment practices. Diagnosis can still be very difficult, particularly in cases presenting only late stage complications. Misdiagnosis leads to mistreatments and medical errors often compounding the suffering for patients. Forums such as the standing-room only crowd hosted in Wall Township are key to public awareness and education — two of the important tools in fighting Lyme.

Prior to the panel presentations, we recognized 10-year-old Myles Hutcherson of Freehold Township who won a second place prize in the Major League Baseball/Scholastic Breaking Barriers Essay Contest for his composition about his experience with Lyme disease. Accompanied by his

family, the West Freehold School fourth-grader read his award-winning essay and relayed the daily struggles he continues to face as a Lyme disease victim. Studies show that children are disproportionately attacked and affected by Lyme disease.

“Now that I know I have Lyme, I have to take lots of medicine everyday and every night,” Myles reported. “It took a long time for doctors to know what was wrong with me. Most doctors don’t believe that Lyme disease is even real or if they do, they think it is no big deal.” He explained that he is often tired and weak and said Lyme “makes you ache all over. My knees and arms always hurt.”

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An upbeat young man, Myles still concluded that "I won't let Lyme disease beat me."

One of our expert presenters at the forum was Dr. Joseph Burrascano, M.D., an internationally recognized Lyme disease clinician and a founding member of the International Lyme and Associated Diseases Society. Dr. Burrascano focused on the clinical diagnosis and treatment of tick-borne diseases and explained that many cases of Lyme are missed because of non-specific symptoms and insensitive tests. He said cases are misdiagnosed because Lyme can mimic many other diseases. "Often patients see literally dozens of doctors and undergo an encyclopedia of tests, Lyme is missed, and they still have no diagnosis." He explained that the problem with incorrect diagnoses is that, "early Lyme if promptly recognized and appropriately treated, can be cured," while "later Lyme may progress, causing a very severe illness and disability."

Also giving presentations were Nick Harris, Ph.D., president of a specialty laboratory and research facility devoted exclusively to patient testing and Ellen Stromdahl, Ph.D., an entomologist with the U.S. Army's Tick-Borne Disease Laboratory for Entomological



Congressman Smith met with Myles Hutcherson, 10, of Freehold Township, a speaker at the forum. They discussed Myles' six-year struggle with Lyme disease. Experts at the forum have said that children are disproportionately attacked and affected by Lyme disease.

Sciences. Dr. Harris discussed his many years researching and developing tests for Lyme, and Dr. Stromdahl provided insightful information on tick species found in the

U.S. and the pathogens they carry, focusing on New Jersey and the Northeast.

New Jersey resident Pat Smith, President of the Lyme Disease Association, used her presentation to focus on the rapid spread of Lyme disease, its impact on patients, and what is being done to fight this disease at the state and federal levels. The LDA has been a leader in sponsoring research on Lyme Disease and providing information about prevention, including how to protect kids from Lyme. Mrs. Smith was instrumental in helping to bring our expert panel to Wall.

As the founding co-chair of the House of Representatives Lyme Disease Caucus, I am pleased that we have made some progress on the federal level targeting needed resources to increase public awareness of Lyme disease and to promote the many prevention techniques needed to combat Lyme. Regrettably, several very serious and far-reaching problems remain including: the lack of knowledge by health professionals in some areas that leads them not to look for the disease or even to tell patients incorrectly that they couldn't have it; a lack of awareness that ticks may carry dozens of pathogens and that co-infections, which can greatly complicate both diagnosis and treatment; unavailability to clinicians of sensitive diagnostics; and exclusive promotion by many public health officials of restrictive treatment guidelines that do not allow for

clinical judgment and do not recognize the complexity of the disease and possible co-infections — leading insurance companies to reject payment for treatments established under other guidelines.

To help address these remaining issues, I continue to push for passage of comprehensive legislation, HR 1179, The Lyme & Tick Borne Diseases Prevention Education & Research Act. In 2009, we did win enactment of some of the provisions found in HR 1179, resulting in the establishment of new grants to examine long term complications related to Lyme, and grants for more sensitive and accurate diagnostic tests. We also won an expansion of epidemiological research, surveillance and reporting, as well as preventative research for tick-borne diseases.

Still, to build on these successes, we need to work to ensure that the broad spectrum of creditable scientific views, unencumbered by financial or professional conflicts of interest, are considered in the development of research portfolios, in the endorsement by public health agencies of treatment guidelines, and in the education of health professionals and patients. That is why it is critical to enact a core provision of HR 1179 which would establish a Tick-borne Diseases Advisory Committee, to provide a broad and expansive means for scientific and public input regarding Lyme.