

# Spotlighting Lyme Disease Treatments

**O**n July 17, I chaired the first congressional hearing on Lyme disease in 19 years and the first ever hearing addressing global challenges in diagnosing, treating and managing this vexing disease. Physicians and researchers, as well as patients, families and advocates, were pleased that many of the obstacles to effectively managing Lyme disease were brought out in a public, national forum.

My commitment to those suffering from Lyme disease goes back 20 years. At that time Patricia Smith, a constituent from Wall, N.J. and President of the national Lyme Disease Association (LDA) based in Jackson Twp. N.J. (and one of the witnesses at the July 2012 hearing), along with others, shared with me the problems associated with Lyme disease and receiving proper medical treatment. They requested

my assistance in receiving promising treatments for patients who suffer from chronic Lyme disease. Ever since, we have been working together to continue the fight on behalf of patients and their physicians who are laboring with inadequate clinical tools to manage the disease.

We have had some successes. In 1993, my amendment to establish a Lyme disease program to concentrate on Lyme prevention techniques and treatments for servicemembers was enacted. We have also had some incremental gains for enhanced research in Lyme. Yet the larger challenge — establishing a coordinated federal Lyme treatment and research program—remains unmet. In May 1998, I introduced a broad, bipartisan Lyme disease bill (H.R. 3795)—which among other provisions would have established an advisory committee to comprehensively investigate Lyme. I

reintroduced this Lyme disease legislation in subsequent Congresses. Unfortunately this legislation was met with formidable opposition, which evidence indicates was at least partially motivated by financial conflicts of interest by some of the parties.

Still our efforts on behalf of Lyme disease patients must and do continue. We recognize that there is unwillingness of some to take a fresh, comprehensive look at this insidious disease. Few diseases have aroused such a high level of emotion and controversy among the public, physicians, and researchers as Lyme disease. There are two distinct views of Lyme disease, each citing scientific evidence to support its claims. One view — promoted by the Infectious Diseases Society of America (IDSA) — is that the disease is “hard to catch and easy to cure,” and denies the

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existence of chronic Lyme disease or persistent infection with the Lyme bacteria.

The other view—promoted by the International Lyme and Associated Diseases Society (ILADS) and also by numerous academic researchers in the U.S. and around the globe—asserts that the science is too unsettled to be definitive and there can be one or more causes of persistent symptoms after initial treatment in an individual who has been infected with the agent of Lyme disease. These causes include the possibility of persistent infection, or a post-infectious process, or a combination of both.

Among those testifying at the July 17 global health hearing on Lyme disease, Dr. Stephen Barthold, Ph.D., a Professor of Medical Pathology at the University of California, noted that Lyme disease is exceedingly

complex in humans, posing major challenges to diagnosis and treatment. He also stated that firmly entrenched opinion and prejudicial peer review are standing in the way of needed research. Ms. Smith testified about the problems of patients getting diagnosed and treated and physicians being allowed to practice clinical judgment in the treatment of Lyme patients, citing disturbing examples of patients being abandoned by the medical community.

Other witnesses who provided powerful testimony were: Dr. Raphael Stricker, M.D., Vice President, ILADS; Dr. Mark Eshoo, Ph.D., Director of New Technology Development at Ibis Biosciences, Inc.; Mr. Evan White, an attorney and former Lyme patient; and Ms. Stella Huyshe-Shires, Chairwoman of Lyme Disease Action, a non-profit in the United Kingdom.

It is hoped that this hearing (all of the testimony can be viewed or read at <http://foreignaffairs.house.gov/hearings/view/?1455>) will

help lead to an open dialogue and development of a national strategy for addressing Lyme disease. We must remain committed to ensuring that the interests of patients are put first and that we follow the best science rather than having the pursuit of science and the dialogue manipulated by dogmatism and entrenched interests—as hearing witnesses described.

To assist in those goals, my current bill—H.R. 2557—establishes a Tick-Borne Diseases Advisory Committee with the requirement of ensuring diversity of valid scientific opinion—a “broad spectrum of viewpoints”—on the committee.

Once established the committee will work to ensure coordination among federal agencies and private organizations on Lyme and other tick-borne disease activities, advise federal agencies on priorities related to such diseases, hold public meetings to ensure transparency, and produce an annual report of its activities and recommendations.

## Background on Lyme Disease

**In 2010—the most recent year data is available—New Jersey ranked first in the number of confirmed cases of Lyme disease reported to Centers for Disease Control and Prevention (CDC).**

Lyme disease was not recognized in the U.S. until the early 1970s when a statistically improbable cluster of pediatric arthritis occurred in the region around Lyme, Conn. Then, a researcher at the National Institutes of Health identified the spiral-shaped bacteria (or spirochetes) causing Lyme disease and made the connection to the deer tick.

Today, Lyme disease is the most common vector-borne (transmitted by an infected host) illness in the U.S., where it has been reported in 49 states and is most common in the northeastern and north central states, and in northern California into Oregon. Over 30,000 confirmed cases were

reported to the CDC in 2010, making it the 6th most common reportable disease in the U.S. and the 2nd most reportable in the Northeast. CDC has estimated that actual new cases may be 10 times more than the reported number—indicating roughly 300,000 new cases in 2010 alone.

Clinical manifestations can include profound fatigue, fever, chills, headache, sore throat, sore and aching muscles and joints, and swollen glands. More serious stages can be marked by migratory musculoskeletal pain, and in some patients, neurological complications and heart inflammation or heart block, causing severe headache and stiff neck, facial paralysis, weakness and/or pain of the chest or extremities, as well as arthritis characteristic of rheumatoid arthritis, affecting primarily the knees and other large joints.