

## The Fight on Behalf of Lyme Disease Patients Continues

# Smith Legislation Aims to Broaden Scientific Community Base Represented in Public Health Policy

**T**ragically, there is much we do not know about Lyme and other tick-borne diseases.

The gaps in the science of Lyme disease leave patients vulnerable to serious and prolonged illness and constrains the ability of physicians to appropriately treat the disease. Patients with Lyme disease need a research agenda that reflects outcomes that will have a real impact on patients, namely effective diagnostic tools and treatments that restore them to health. I and others have been fighting for such a research agenda for over two decades.

We do know, however, that Lyme disease is a global problem, a U.S. problem, and, most certainly, a New Jersey problem. There are over 850 recognized species of ticks worldwide, and ticks rank second only to mosquitoes in the number of life-threatening and debilitating diseases they transmit to humans. In the U.S., Lyme disease is the most prevalent vector-borne disease, causing 90 percent of all vector-borne infections.

According to the Centers for Disease Control & Prevention (CDC), 22,561 new cases of Lyme were confirmed in 2010, and another 7,597 probable new cases were reported. However, it has been estimated that only 10 percent of the cases that would meet CDC's stringent criteria are reported. That means that 225,000-300,000 people actually contracted the disease in 2010. New Jersey ranked first in the country in the number of confirmed reported cases of Lyme in 2010. When probable cases are included, New Jersey, with 3,712 cases,

ranked second behind Pennsylvania in the number of confirmed and probable reported cases of Lyme in 2010. It is, therefore, estimated that there were 37,120 new cases of Lyme disease in N.J. in a single year.

If not diagnosed and treated early, Lyme disease can lead to chronic illness and can affect every system in the body, including the central nervous system. Later symptoms of Lyme disease include arthritis of weight-bearing joints; neurological problems, such as facial paralysis, encephalopathy, memory problems and weakness of the extremities; and heart symptoms, such as heart block and inflammation of the heart muscle.

In addition to Lyme, tick-borne diseases in the U.S. include Rocky Mountain spotted fever, southern tick-associated rash illness (STAR), Colorado tick fever, anaplasmosis, babesiosis, ehrlichiosis, rickettsiosis, tick-borne relapsing fever, and tularemia. Crimean-Congo hemorrhagic fever and tick-borne encephalitis are widespread on multiple continents. One tick bite can result in simultaneous co-infections with different types of disease-causing germs (spirochetes, other bacteria, viruses, protozoa, mycoplasmas). We do not have a good grasp on Lyme, much less the myriad co-infections that greatly complicate both diagnosis and treatment.

To address the inadequate state of the science and the threat of Lyme and other tick-borne diseases in N.J. and across our country, I authored the "Tick-Borne Diseases Advisory Committee Act" (H.R. 2557). This bill establishes an advisory committee within the Office of the

Secretary of the U.S. Department of Health and Human Services (HHS) to enhance coordination and communication among federal agencies, medical professionals, and patients/patient advocates. It will ensure that a broad spectrum of creditable scientific viewpoints are represented in public health policy decisions and that information disseminated to the public and physicians is balanced.

The bill directs the Secretary of HHS to ensure that members of the advisory committee, as a group, represent a diversity of scientific perspectives relevant to the committee's duties. In addition to members from relevant federal agencies, members of the committee are to include individuals representing the scientific community, voluntary organizations, health care providers, individuals or family members of individuals who have been diagnosed with a tick-borne disease, and state and local health departments.

As chairman of a House subcommittee which includes global health and global human rights within its jurisdiction, I plan to convene a hearing within the next couple of months on the global health problem of Lyme and other tick-borne diseases and their impact especially and including right here in N.J. It is anticipated the hearing will examine the scope of the worldwide problem of tick-borne diseases, current and emerging science and technologies, and impacts on patients.

Creditable scientists doing valuable work who have long been marginalized, and most importantly the sick patients and their families, need our help. I plan to continue to fight on their behalf for as long as it takes.