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NJ-04 Resident and Expert Named to Nat'l Panel

New Federal Lyme Disease Working Group Gets to Work

The U.S. Department of Health and Human Services (HHS) recently announced the appointment of 14 members to its new HHS Tick-Borne Disease Working Group, which expects to issue its first comprehensive report to Congress by December 2018.

It was a long time coming.

The idea for a working group was hatched nearly 20 years ago when it was included in my comprehensive *Lyme Disease Initiative of 1998*. The legislation mapped out a multi-year blueprint to focus resources of the federal government in a new battle against Lyme Disease—still one of the fastest-growing infectious diseases in the nation and the most common tick-borne disease in America today.

One of the provisions of the legislation called for a Lyme Disease Task Force—and I have continued throughout the years to advocate for the creation of this task force as a forum that would include doc-

tors, researchers and on-the-ground officials from state and county health organizations. More importantly, the Task Force was to include patients and their advocates, ensuring that individuals impacted by federal policies would have a seat at the table when the decisions about treatments and coverage were made.

It was evident then, as it remains now, that the medical field and federal medical agencies—the Centers for Disease Control (CDC), the National Institutes of Health (NIH) and HHS—were missing the threat of Lyme Disease and the best ways to detect and treat it.

It has taken many years, some steps forward and several reintroductions of the bill, but thankfully when Congress adopted the *21st Century Cures Act* last year it incorporated provisions to address Lyme. The wide-ranging health care reform package included the establishment of a forum similar to the Lyme Disease Task Force—

the Tick-Borne Disease Working Group—that will begin the process of addressing the great unmet needs in the Lyme community in an open and transparent manner.

Bringing great credit and credibility to the national Working Group is the appointment to the panel of Pat Smith (no relation), a Wall resident and president of the Ocean County, NJ-based Lyme Disease Association (LDA). Pat, who has been an integral advisor on many legislative projects including my first and several subsequent Lyme bills, is a nationally-known expert who has fought for Lyme Disease patients with tenacity, expertise, empathy and skill. She will be a force for good on the Working Group.

The Working Group's Mission

In accordance with its mandate, the Working Group represents: a diverse set of stakeholders, including doctors and

other medical providers and scientists and researchers; patients and family members; and Lyme patient advocates. Far too many have suffered for decades with this debilitating disease, only to be told that their illness does not exist. The public representatives on the panel, including Pat Smith, bring hope to Americans suffering from chronic Lyme.

The Working Group is tasked to review all HHS efforts on tick-borne diseases to provide a wide-range of perspectives and experience to foster interagency coordination and minimize overlap, examine research priorities and identify unmet needs.

Equally divided between federal and non-federal officials, the Working Group held its inaugural public meetings on Dec. 11, 2017.

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Congressman Christopher
Smith (R-NJ) Reports Home.
2017-2018.**

LYME DISEASE

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Lyme cases across the US & NJ

The CDC has estimated that while over 300,000 Americans are diagnosed with Lyme annually, a mere 30,000 of the cases are reported, leaving many people untreated and chronically ill. The Garden State has the third-highest number of confirmed

Lyme cases in the nation.

According to HHS, while some cases of Lyme disease can be treated successfully with courses of antibiotics, especially when caught early, other individuals who contract this illness may develop debilitating long-lasting health problems. Among its many tasks, the Working Group will hopefully help better identify chronic Lyme and best practices for successful treatment of this crippling disease.



Congressman Smith addressed the LDA-Columbia University 18th Annual Conference in Philadelphia last fall, sharing the work he has done in Congress to advance funding and research in the fight against Lyme Disease. LDA President Pat Smith of New Jersey (left) was one of the seven public members appointed in November to the new national Tick-Borne Disease Working Group.