

FOR IMMEDIATE RELEASE November 14, 2018 Contact: Matt Hadro (202) 225-3765 http://chrissmith.house.gov

First biennial report to Congress gives blueprint for federal response

2018 Tick-Borne Disease Working Group Report Confirms Lyme is Spreading, Time for Action is Now

WASHINGTON, D.C.— The <u>2018 Tick-Borne Disease Working Group Report to Congress</u>—the very first report by the new HHS Working Group—confirms what Rep. Chris Smith (R-NJ) and other advocates have long warned of, that incidents of Lyme disease and other tick-borne diseases are increasing and that more federal attention to the problem is needed, Smith said on Wednesday.

"As this report clearly shows, Lyme disease is spreading—in the overall number of cases, in the geographic area of occurrences, and in the number of disease agents. We have been working for years—the Lyme Disease Caucus and other advocates—to enhance awareness of Lyme disease and push for a coordinated, comprehensive federal response, including more funding of research," said Rep. Smith, who is founder and co-chair of the Congressional Lyme Disease Caucus. Smith and the caucus have successfully pushed for more federal funding of Lyme research, and Smith recently authored legislation to create a new national strategy on Lyme disease.

"This report is a first step, the beginning of our response. The spread of tick-borne diseases should concern all states, not just high-incidence states," Smith said.

Released on Wednesday, the report is the first biennial report to Congress of the new HHS Tick-Borne Disease Working Group, created to serve as a Federal Advisory Committee by the *21st Century Cures Act*, which Smith helped shepherd through Congress in 2016. The Working Group is tasked with reviewing federal research of tick-borne diseases, any advances in detection and treatment of tick-borne diseases, and identifying any research gaps, along with submitting a report to Congress every two years on its findings.

Nationally-known expert and advisor Pat Smith, a Wall resident and President of the Ocean County, NJ-based Lyme Disease Association (LDA), is on the HHS Tick-Borne Disease Working Group.

"We cannot underestimate the significance of the release of this Working Group report, considering the CDC just announced the latest case numbers for Lyme and other tick-borne diseases. The numbers show over 42,000 reported cases—due to underreporting, that means over 420,000 cases probably occurred in the US in 2017 alone," Pat Smith, President of the Lyme Disease Association, said of the report.

"The Working Group report was produced to inform Congress, using expert input from scientists, physicians, federal officials, advocates, patients and their family members, who each provided a

perspective to paint the picture of this devastating disease. The report is a first step to unlocking the political gridlock surrounding tick-borne diseases, particularly Lyme. Now it is the job of Congress to provide the necessary resources to stop the spread of Lyme and tick-borne diseases so that patients can get properly diagnosed and treated."

Wednesday's report says that Lyme disease has steadily increased over the last 25 years in the number of estimated cases and in the geographic areas, but as the accuracy of diagnoses is still a challenge for many physicians, the current state of treatment is insufficient.

New Jersey is a high-incidence state for Lyme disease and other tick-borne diseases. According to 2017 data from the U.S. Centers for Disease Control (CDC), there were 3,629 confirmed cases of Lyme disease in New Jersey. The state ranks seventh overall among "high-incidence states" for Lyme and third overall in the number of reported Lyme cases for 2017, according to the Lyme Disease Association.

"Lyme disease is having a direct, devasting impact on my constituents, and through countless meetings, advocacy, and pieces of legislation, I have been working to address the needs of the Lyme disease community," Rep. Smith said.

The idea for a working group on Lyme disease originated in Smith's comprehensive *Lyme Disease Initiative of 1998*. Smith has continued to repeatedly call for the creation of a Lyme disease task force that includes patients and patient advocates, doctors, researchers and on-the-ground officials from state and county health organizations, to ensure everyone had a part in the conversation about a federal response to tick-borne diseases.

The Congressional Lyme Disease Caucus, which Smith co-chairs, successfully pushed for the inclusion of \$5 million in FY 2016 funding of tick-borne disease research in the DOD's Congressionally Directed Medical Research Program (CDMRP).

Smith also introduced legislation earlier this year—the <u>National Lyme and Tick-Borne Diseases Control</u> <u>and Accountability Act of 2018</u> (HR 5900)—that would call for a new national strategy on Lyme disease and help coordinate federal efforts across departments and agencies into one comprehensive federal response to tick-borne diseases.

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