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A Call to Action to Combat Lyme and Other Tick-Borne Diseases

WALL, NJ— *Below are excerpts of Rep. Chris Smith's (R-NJ) remarks at a Congressional town meeting on Lyme disease that he hosted at Wall Township Municipal Building, on Wednesday:*

Welcome to tonight's town meeting on Lyme and tick-borne diseases—with expert analysis on the exploding health risk—especially to children—and the latest on prevalence, prevention, diagnosis and treatment.

More must be done to mitigate and over time eradicate this catastrophic disease.

That's why we meet tonight. To enhance our understanding of the huge risk posed by Lyme and other tick-borne diseases while pursuing sustainable solutions.

Special thanks to Mayor Kevin Orender for his deep commitment to combatting Lyme disease and for his remarks.

And allow me to extend a special welcome and thanks to our expert panelists:

- Dr. Benjamin Beard, Deputy Director, Division of Vector-Borne Diseases, of the Centers for Disease Control and Prevention (CDC) who will focus on the disease burden, trends and what you can do to protect yourself;
- Dr. Richard Horowitz, an accomplished internist from Hyde Park, New York who will provide updates in the diagnosis and treatment of Lyme and chronic disease;
- Pat Smith, President of the Lyme Disease Association who will speak to the massive spread of ticks and infection and government activity.

Twenty-seven years ago—in 1992—it was Pat Smith who asked me to help push federal health policy leaders to more effectively combat Lyme and tick-borne diseases. I've been all in ever since.

I arranged meetings in Washington first in 1992—and several times since— with the top public health officials of CDC, NIH and the Department of Health and Human Services.

Everyone was civil at that first meeting in 1992 but our well-founded assertion that chronic Lyme exists and is devastating the lives of many whose plight is marginalized and trivialized and that one month of the antibiotic doxycycline doesn't cure chronic Lyme was rejected by the top public health officials even though Pat pointed to the experience of her own daughters and Assemblywomen Claire Farragher—a chronic Lyme sufferer too—made a persuasive case.

Since the 1990s, I've authored more than a dozen comprehensive bills—focusing on the need for a national strategy which includes more accurate prevalence studies, world class affordable diagnostic tools, more aggressive prevention initiatives and effective treatment options.

At the core of each bill was the establishment of an advisory commission or working group that would include Lyme-literate physicians, researchers and patients—a group of people who have been systematically excluded for years from the policy debate.

When the 21st Century Cures Act was under consideration by the House, we successfully added the [Tick-Borne Disease Working Group to the Act](#). The Senate had no such provision and to my disappointment—but not surprise—was determined to strip it from the bill.

Both Pat Smith and I contacted Majority Leader Kevin McCarthy—whose daughter has suffered from chronic Lyme. Kevin made it absolutely clear that if the Senate kills the Tick-Borne Disease Working Group, the entire 21st Century Cures Act would not be brought back for a final vote in the House. The Senate backed off their misguided opposition and accepted the Tick-Borne Disease Working Group and the bill became law.

The [Working Group's first report—the 2018 Report to Congress](#)—is historic, comprehensive and transformative—and is an urgent call for action.

Of significance, all three of our panelists tonight—Pat Smith, Dr. Benjamin Beard and Dr. Richard Horowitz served with distinction on the Working Group.

Much of what we have argued for more than a quarter of a century has now been scientifically validated by the Working Group including the fact that massive numbers of people are getting seriously ill from ticks and the federal response to date has been woefully inadequate.

Some of the important findings of the Working Group Report include:

- "...Americans need help. Yet progress has been hampered by a lack of attention at the Federal level and by divisions within the field..."
- "Tick-Borne Diseases have rapidly become a serious and growing threat to public health in the United States. Despite many scientific unknowns, experts agree that the incidence and distribution of tick-borne diseases are increasing.... Over the past 25 years, reports of Lyme disease have increased steadily with estimated annual (new) cases approximating 300,000."
- And the Report notes that the number may even be higher: in 2016, the number of new cases was estimated to be between 291,430 to 437,150;
- "The number of U.S. counties now considered to be of high incidence for Lyme disease has increased by more than 300% in the Northeastern states and by 250% in the North-Central states."
- "CDC currently recognizes 18 tick-borne pathogens in the United States (and) researchers and health care practitioners continue to discover emerging disease agents..."

- “...10-20 % of patients suffer from persistent symptoms which for some are chronic and disabling.”
- “Today, available diagnostics tests can be inaccurate and complex to interpret...”
- “There are currently no uniformly accepted or validated treatment options for patients with these chronic symptoms. As a result, uncertainty surrounding appropriate clinical care has led to polarization within the medical community, and patients are often left suffering in limbo without a clear path to illness resolution or even symptom management.
- “need exists for the transparent development of a safe, effective human vaccine to prevent Lyme disease...”
- “...immediate changes are also required to help patients already suffering from tick-borne diseases; to protect them from discrimination; and to address the inflexible, inconsistent and often unaffordable care that patients frequently encounter in the current health care system...”
- “Federal funding for tick-borne diseases is less per new surveillance case than that of any other disease...”
- CDC spent only \$11 million on Lyme in 2017; NIH only \$28 million.
- “All research, prevention and education programs should be inclusive of special populations such as children, who suffer disproportionately from tick-borne diseases.”

Finally, In January I introduced [legislation designed to establish a bold new Lyme and tick-borne national strategy](#).

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