United States Senate WASHINGTON, DC 20510

April 20, 2017

The Honorable Thomas E. Price Secretary U.S. Department of Health & Human Services 200 Independence Avenue, Southwest Washington, D.C. 20201

Dear Secretary Price:

Last year, we were pleased to see Congress take real steps to address tick-borne diseases through the bipartisan passage of the 21st Century Cures Act. This landmark legislation included language based on a bill we authored called the Lyme and Tick-Borne Disease Prevention, Education, and Research Act. Sec. 2062 of the 21st Century Cures Act requires the Secretary of Health and Human Services (HHS) to support research related to tick-borne diseases and establishes a Tick-Borne Disease Working Group comprised of representatives of federal agencies, physicians, researchers, and, importantly, patients, their family members, and organizations that advocate on patients' behalf. Given the urgency around this growing public health threat, we ask that you provide us with an update on your efforts to implement the tick-borne disease provisions required by the 21st Century Cures Act.

Lyme and other tick-borne diseases continue to plague communities in states across the country. Reported cases of Lyme disease have tripled over the past several decades, to about 30,000 cases each year. In the past fifty years, experts have discovered at least a dozen tick-borne illnesses in addition to Lyme disease. While Lyme disease is still the most commonly reported vector-borne illness in the United States, scientific experts have identified various species of tick that carry entirely new vector-borne diseases. Historically, this public health threat has had a disproportionate impact on states in the Northeast and upper Midwest, including states like Connecticut and New York, which together reported nearly 65,000 confirmed cases of Lyme disease between 2005 and 2015. However, these diseases are now found across the entire country in virtually every state. In fact, nationally, the Centers of Disease Control and Prevention (CDC) reports that there were nearly 29,000 confirmed cases of Lyme disease in 2015 alone. Perhaps even more alarming, the agency estimates that the total number of people diagnosed with Lyme disease each year is actually about *ten times* higher than the number of reported cases. At over 300,000 cases per year, Lyme and other tick-borne diseases represent a severe threat to public health and wellbeing.

The proliferation of Lyme and other tick-borne diseases in our country is undeniable and underscores the need for strong diagnostic tools, better data collection and subsequent research,

Doucleff M., & Greenhalgh J. (2017). "Forbidding Forecast For Lyme Disease In The Northeast." NPR.

² Center for Disease Control and Prevention. (2016). [Data table on reported cases of Lyme disease by state or locality, 2005-2015]. Retrieved: https://www.cdc.gov/lyme/stats/tables.html#modalIdString_CDCTable_1

and robust public awareness and educational efforts nationwide. The tick-borne disease provisions within the 21st Century Cures Act represents a critical opportunity to combat this growing threat to public health. As you know, the statute requires the Secretary of HHS to support ongoing research related to tick-borne diseases directed in part by a newly established working group on the topic. We must stress that any working group on tick-borne diseases brings together patients, advocates, researchers, medical professionals, and government officials to ensure a coordinated and inclusive approach in response to Lyme and other tick-borne diseases. The working group will be required to submit a report to Congress summarizing its activities and recommendations, and we would like to emphasize the importance of reflecting the diverse views of all members of the scientific and advocacy community in the working group that will prepare this report.

With the right support and coordination, the innovative research underway today could create the cures of tomorrow for these debilitating and sometimes irreversible diseases. The steady rise of Lyme and other tick-borne disease cases in our nation can no longer be ignored. Therefore, we respectfully request that you provide us with an update on your efforts to implement the Lyme and tick-borne disease provisions in the 21st Century Cures Act. In addition, we look forward to working with you to ensure that diverse patient and medical perspectives are represented in federal efforts to address Lyme and other tick-borne diseases.

Sincerely,

RICHARD BLUMENTHAL

United States Senate

KIRSTEN GILLIBRAND

United States Senate

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