

United States Senate

WASHINGTON, DC 20510

January 10, 2020

The Honorable Alex Azar
Secretary
U.S. Department of Health and Human Services
Washington, D.C. 20201

Dear Secretary Azar:

On December 21, 2019, the Kay Hagan Tick Act was signed into law, as part of the Further Consolidated Appropriations Act of 2020 (PL 116-94). The new law is named after the late Senator Kay Hagan, who tragically died from Powassan virus, a tick-borne disease this past October. The law provides a unified approach with leadership at the federal level and resources at the local level to combat the escalating burden of tick and vector-borne diseases and disorders in the United States. As authors of this bipartisan legislation, we request that you prioritize its implementation to better protect Americans from the significant and growing threat of tick-borne diseases.

The incidence of Lyme and other tick-borne diseases has increased significantly since the Centers for Disease Control and Prevention (CDC) reporting began in 1991. From 2004 to 2018, reported cases of tick-borne diseases more than doubled from 22,527 to 47,743 cases.¹ Furthermore, CDC tracking of Nationally Notifiable Infectious Diseases shows that Lyme disease is the most common tick-borne disease and the most common vector-borne disease.²

Maine alone reported more than 1,400 confirmed cases in 2018, the highest incidence of Lyme disease in the nation.³ Minnesota is also vulnerable with 950 confirmed cases of Lyme diseases in 2018. These data, however, capture only about one-tenth of the estimated number of disease cases, and a full understanding of the economic and societal cost remains unknown. Studies so far indicate that Lyme disease alone costs approximately \$1.3 billion each year in direct medical costs, and overall costs, including indirect costs, average \$75 billion.⁴

With the national effort that the Tick Act establishes, we can slow the spread of these devastating tick-borne diseases, and better protect our health. The Kay Hagan Tick Act applies a three-pronged approach to address Lyme and other tick and vector-borne diseases:

¹ "Tickborne Disease Surveillance Data Summary." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 4 Nov. 2019, <https://www.cdc.gov/ticks/data-summary/index.html>.

² "TABLE 1. Annual Reported Cases of Notifiable Diseases and Rates per 100,000, Excluding U.S. Territories - - United States, 2018." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, <https://wonder.cdc.gov/nndss/static/2018/annual/2018-table1.html>.

³ "Lyme Disease Data Tables: Historical Data." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 22 Nov. 2019, <https://www.cdc.gov/lyme/stats/tables.html>.

⁴ Berger, James J, and B Kaye Hayes. Tick-Borne Disease Working Group 2018 Report to Congress. 2018, <https://www.hhs.gov/sites/default/files/tbdwg-report-to-congress-2018.pdf>.

1. **National Strategy.** The law requires the Department of Health and Human Services (HHS) to develop a National Strategy to expand research, improve testing and treatment, and coordinate common efforts for tick-borne diseases across federal agencies, including Department of Defense, the U.S. Department of Agriculture, the Environmental Protection Agency, the Veterans Administration, the Department of Interior, and Homeland Security.
2. **Regional Centers of Excellence.** The law reauthorizes Regional Centers of Excellence in Vector-Borne Disease for five years at \$10 million per year. These centers have led the scientific response against tick-borne diseases, which now make up 75 percent of vector-borne diseases in the U.S. Lyme disease alone accounts for 70 percent of all tick-borne disease in the nation.
3. **Support to States.** The law authorizes \$20 million per year in grants to state and other health departments to improve data collection and analysis, support early detection and diagnosis, improve treatment, and raise awareness. These awards will help build a public health infrastructure for Lyme and other tick and vector-borne diseases, and amplify initiatives through public-private partnerships.

At the core of the Tick Act, to ensure that resources are appropriately allocated, is data. The Centers for Disease Control and Prevention (CDC) last released estimates of Lyme disease prevalence in 2015 using 2010 data. At that time, CDC estimated that although 30,000 cases of Lyme disease are reported annually, the actual number of estimated cases is approximately 10 times higher at 300,000 cases. Researchers and policy makers continue to rely on this estimate, although it is now a decade old. Further, the reported number of confirmed and probable cases can take months to compile each year, resulting in serious delays. Even less is known about the prevalence of Post-Treatment Lyme Disease Syndrome, also known as chronic Lyme disease – a recent Brown University study estimated that the prevalence may reach 1.9 million Americans in 2020.⁵ Outdated, delayed, and incomplete data serve as a barrier to ensuring that the Tick Act reaches Americans who need it the most.

We request, therefore, that in addition to providing an update on implementation steps and timeline for the Kay Hagan Tick Act, that HHS address the following critical questions by February 7, 2020:

1. When will HHS, in coordination with CDC, plan to update the 2010 estimates of Lyme diseases prevalence?
2. What steps will HHS take towards the development of real-time data of Lyme and other tick-borne diseases?
3. What steps will HHS take to estimate annual prevalence of Post-Treatment Lyme Disease Syndrome?

⁵ DeLong, Hsu A, and H Kotsoris. "Estimation of Cumulative Number of Post-Treatment Lyme Disease Cases in the US, 2016 and 2020." *BMC Public Health*, no. 19, 2019, p. 352.

If you have any questions, please do not hesitate to contact us or have your staff contact Sarah Khasawinah with Senator Collins at [REDACTED] or Adam Schiff with Senator Tina Smith at [REDACTED].

Thank you for your work in protecting communities from tick-borne diseases. We look forward to working with you.

Sincerely,



Susan M. Collins
United States Senator



Tina Smith
United States Senator