

United States Senate

WASHINGTON, DC 20510

May 14, 2024

The Honorable Tammy Baldwin
Chairwoman
Subcommittee on Labor, Health and Human
Services, Education and Related Agencies
Committee on Appropriations
U.S. Senate
Room S-128, The Capitol
Washington, D.C. 20510

The Honorable Shelley Moore Capito
Ranking Member
Subcommittee on Labor, Health and Human
Services, Education and Related Agencies
Committee on Appropriations
U.S. Senate
Room S-128, The Capitol
Washington, D.C. 20510

Dear Chairwoman Baldwin and Ranking Member Capito:

On behalf of the at least 476,000 people in the United States who contract Lyme disease and other tick-borne diseases each year, we write to express our strong support for expanding Lyme and tick-borne disease research to develop diagnostics, prevention strategies, and treatments funded by the National Institute of Allergies and Infectious Diseases (NIAID) at the National Institutes of Health.

Lyme disease is a potentially debilitating infection caused by *Borrelia* genus bacteria transmitted through the bite of an infected tick to people and pets. If caught early, most cases of Lyme disease can be effectively treated, but the disease can also be misdiagnosed due to lack of education, awareness, and unreliable diagnostic tests. Due to the difficulty in diagnosing and treating Lyme disease, firm statistics on the number of Americans suffering from the impact of persistent Lyme disease are hard to calculate. Researchers estimated that in 2020 nearly 2 million patients suffered from Post-treatment Lyme Disease Syndrome (PTLDS).

Lyme disease is one of the fastest growing vector-borne infectious diseases in the United States. According to the Centers for Disease Control and Prevention, the range of the ticks carrying the *Borrelia* bacteria has also been increasing, bringing more people and habitat into risk of infection. Reported cases in 2019, the last available data year, are more than four times the number reported in 1991. Diagnosed cases increased over 25 percent from 2016 to 2019. In addition, while total confirmed and probable reported cases in 2022 were 62,551, the CDC estimates the actual number of Lyme infections is significantly greater due to insufficient survey methods, despite implementing new surveillance methods.

Lyme disease research has been woefully underfunded. In fact, funding has sometimes decreased even as diagnosed Lyme disease cases have been on the rise. Because cases of tick-borne diseases have substantially increased over two decades, we should increase these investments. Further, many persistent Lyme patients also suffer from other tick-borne infections such as babesia, bartonella, anaplasma, ehrlichia and rickettsia. In FY 2022, NIAID spent \$114 million on all tick-borne disease research. Unfortunately, NIAID is estimated to spend \$100 million in FY 2024. It is concerning that the funding has decreased by \$14 million from recent years as cases rise and we still have no reliable diagnostic or cure for Lyme disease. Therefore, we respectfully request that \$130 million be appropriated for Lyme and tick-borne disease.

The 21st Century Cures Act was intended and designed to promote new health care innovations for addressing an array of public health issues including advancing research on tick-borne

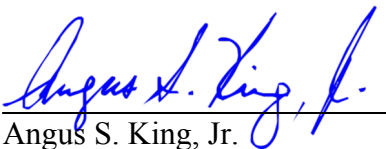
diseases. It required the Secretary of Health and Human Services (HHS) to establish a federal advisory committee to review current research efforts and help identify priorities related to tick-borne disease. The HHS Tick-Borne Disease Working Group was formed to identify gaps in research, education, prevention, and access to care. The most recent, and final, Working Group report (2022, <https://www.hhs.gov/sites/default/files/tbdwg-2022-report-to-congress.pdf>) states:

There is a critical need for increased research funding for basic science investigations and therapeutic trials to reduce the numerous gaps in the scientific evidence related to tick-borne diseases that result in clinical uncertainty. Patients, clinicians, and researchers would benefit from the discovery of accurate diagnostic biomarkers for all tick-borne diseases... This advance would reduce diagnostic uncertainty, thereby decreasing diagnostic delays, and make it easier to design and conduct clinical trials, which could lead to more successful therapeutic regimens. However, because most presentations are treated with generic antibiotics, the pharmaceutical industry, which typically funds therapeutic trials, has few incentives to conduct trials using generic drugs or to develop novel therapeutics. Thus, tick-borne diseases are research-disadvantaged diseases, similar to rare and orphan diseases. Despite this, NIH has historically allocated insufficient funds to investigate this group of diseases. (Page 29).

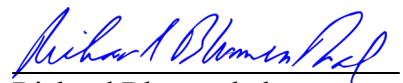
As you make FY2025 appropriations, we respectfully request that you include as much as possible and at least **\$50M for National Institute of Allergies and Infectious Diseases (NIAID)** research to be directed to develop diagnostics, prevention strategies, and treatments for Lyme to a total \$130 million for all tick-borne diseases. We believe this level of funding would be a modest down payment to do the necessary research on Lyme and tick-borne disease diagnostics, prevention strategies, and treatments. Such funding will continue the process of meeting the goals of the Tick-Borne Disease Working Group's 2018, 2020, and 2022 reports to Congress.

Thank you for your attention to this public health matter.

Sincerely,



Angus S. King, Jr.
United States Senator



Richard Blumenthal
United States Senator



Margaret Wood Hassan
United States Senator



Kirsten Gillibrand
United States Senator



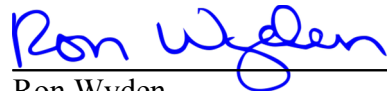
Alex Padilla
United States Senator




Cory A. Booker
United States Senator



Chris Van Hollen
United States Senator



Ron Wyden
United States Senator



Jacky Rosen
United States Senator