Congress of the United States
Washington, DC 20515

March 28, 2019

The Honorable Rosa DeLauro
Chairwoman
Subcommittee on Labor-HHS-Education
Appropriations
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Tom Cole
Ranking Member
Subcommittee on Labor-HHS-Education
Appropriations
U.S. House of Representatives
Washington, D.C. 20515

Dear Chairwoman DeLauro and Ranking Member Cole:

As you prepare the Fiscal Year (FY) 2020 Labor, Health and Human Services, Education, and Related Agencies Appropriations Act, we respectfully request that you provide a significant increase in funding for CDC's Lyme disease program to allow the agency to intensify its efforts on developing improved diagnostics, critical surveillance and prevention of Lyme disease. We also request that you include the language we have provided below in your Committee report.

Specifically, we request that you include the following language:

NATIONAL INSTITUTES OF HEALTH (NIH)

Lyme and Other Tick-Borne Diseases: *The Committee strongly encourages NIH to hold within six months of this appropriations report's publication, a workshop on the numerous molecular and functional mechanisms that Borrelia burgdorferi (Bb) employs to evade and subvert the immune system of the human host and the immune responses and consequences and also how these mechanisms and responses can subvert the effectiveness of antibiotics. The Committee supports inclusion of other TBD pathogens to consider shared and unique characteristics of the pathogens as NIH determines practical for the workshop, with participation by researchers who have published peer-reviewed articles describing such mechanisms and immune cell responses, particularly for Bb. It is critical that the multiple, well-documented, defense mechanisms of Bb be evaluated and recognized as understanding these mechanisms and their significance underpins the ability to develop effective diagnostics and treatments.*

The Committee encourages NIH to improve early diagnosis and treatment of Lyme and other TBD to prevent the development of late stage disease and more serious and longer-term disability, but also intensify research on diagnosis and treatment of late stage and chronic disease. Priority should be based on disease burden and should be given to Lyme disease, which has a high public health burden in the U.S., has a significant patient population who are not diagnosed until late stage when treatment is more difficult, and has a significant percentage of patients who relapse and go on to develop chronic symptoms. In addition to development of highly sensitive and specific diagnostics for all stages of disease, a goal should be to develop diagnostics with appropriate sensitivity and specificity for the detection of subclinical or low-level infection for use in disease eradication. Treatments also should be developed for all stages of Lyme and other TBD, determining optimal combinations of new candidate or older drugs and

exploring novel combinations. Although a cure may be defined to include sustained remission, a goal of treatment should be eradication of the pathogen, in which case resurgence is not possible.

The Committee recognizes that community-based physicians, advocates and patients are potential resources who can add value to a broad range of NIH's TBD activities as they are in other diseases, most prominently, HIV. The Committee encourages NIH to establish a Community-Based Participation (CBP) initiative for TBD and to partner with the Office of Extramural Research to identify community-based resources – data and people – and to evaluate how community-based perspectives can add significant value to and be incorporated into the broad range of TBD activities, such as strategic planning, research portfolio design, programs, special Initiatives, grant proposals and peer review.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

Lyme Disease: *In addition to supporting across the board progress in developing innovative solutions to more effectively manage tick-borne diseases, the Committee supports and directs CDC to:*

- o *Apply sufficient resources to develop performance indicators to enable monitoring of program effectiveness for Lyme disease and other priority vector-borne diseases as directed in the Committee report for FY 2018 appropriations.*

- o *Improve surveillance and the problem of underreporting so that disease burden can be more accurately determined. More finely-tuned and accurate assessments of disease burden – utilizing whatever types of clinical data are required (hospital, medical records, laboratory, insurance, etc.) -- are necessary for appropriate establishment of priorities and the application of resources.*

- o *Improve early diagnosis and treatment of Lyme and other TBD to prevent the development of late stage disease and more serious and longer term disability, but also intensify research on diagnosis and treatment of late stage and chronic disease. As noted above, priority should be based on disease burden. We know that Lyme disease has a high public health burden in the U.S., has a significant patient population who are not diagnosed until late stage when treatment is more difficult, and has a significant percentage of patients who relapse and go on to develop chronic symptoms. A goal also should be to develop diagnostics with appropriate sensitivity and specificity for the detection of subclinical or low-level infection for use in disease eradication.*

- o *Identify and validate safe and effective prevention and control methods. Controlling and disabling ticks will require innovative technologies and well-designed studies in communities and ecosystems.*

Thank you very much for your time and attention to this request and we look forward to working with you to assist patients with Lyme and other tick-borne diseases.
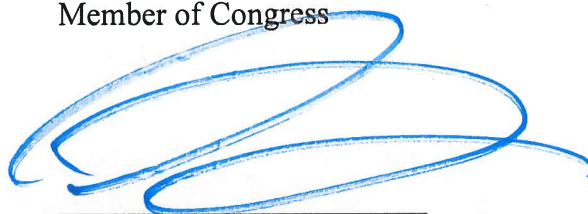
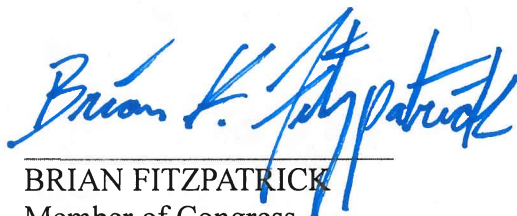Sincerely,

CHRISTOPHER H. SMITH
Member of Congress

COLLIN C. PETERSON
Member of Congress

ANNA G. ESHOO
Member of Congress

ANTONIO DELGADO
Member of Congress

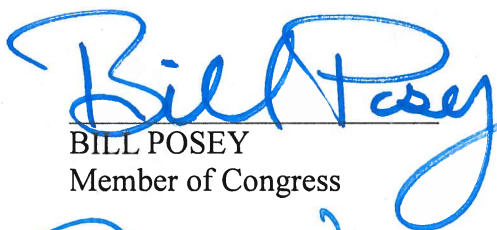BRIAN FITZPATRICK
Member of Congress

WILLIAM R. KEATING
Member of Congress

ELEANOR HOLMES NORTON
Member of Congress

CHELLIE PINGREE
Member of Congress

BILL POSEY
Member of Congress

ELISE M. STEFANIK
Member of Congress

JENNIFER WEXTON
Member of Congress