

Congress of the United States
Washington, DC 20515

March 19, 2018

The Honorable Tom Cole
Chairman
Subcommittee on Labor, Health and
Human Services, and Education
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, Health and
Human Services, and Education
U.S. House of Representatives
Washington, D.C. 20515

Dear Chairman Cole and Ranking Member DeLauro,

We write to thank you for your leadership in championing sustained, real growth in medical research funding and urge you to strengthen efforts in research and clinical care for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). We urge you to support FY19 appropriations of \$5.4 million for Chronic Fatigue Syndrome research at the Centers for Disease Control and Prevention (CDC), and to include the attached report language to build upon this progress.

As you know, ME/CFS is a complex, debilitating, and chronic disease afflicting 1 to 2.5 million Americans. It costs individuals, the U.S. health care system, and our economy an estimated \$17-\$24 billion annually as twenty-five percent of patients are bedbound or housebound at some time in their lives and an estimated 69% are unable to work. Additionally, access to medical care is limited and 81-94% of patients are undiagnosed, likely because ME/CFS is only included in 30% of medical curricula and 40% of medical textbooks.

Yet, as the Institute of Medicine noted in its report, "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness," there has been "remarkably little research funding" to date to discover its cause or possible treatments. Given the recent budget prioritization and investment in the National Institutes of Health (NIH), including a \$2 billion increase in Fiscal Year 2018, we believe NIH has the opportunity and ability to increase research funding for ME/CFS to better reflect the extensively documented disease burden and to bring funding in line with other similarly burdensome and prevalent diseases.

We urge you to include the attached Report Language urging the Office of the Secretary of the U.S. Department of Health and Human Services (HHS), National Institutes of Health (NIH), and the Centers for Disease Control and Prevention (CDC) to take the following steps as recommended by the HHS Chronic Fatigue Syndrome Advisory Committee and the National Academies' Institute of Medicine Report:

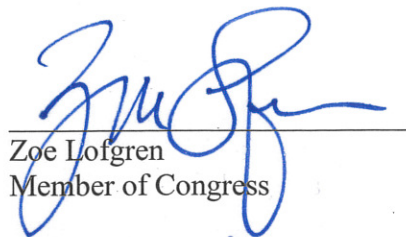
- Encourage CDC to complete the work of its multi-site clinical assessment of ME/CFS, to resolve ME/CFS case definition issues, and to better educate health care providers about the disease and its appropriate management;
- Recommend NIH establish a strategic plan for research to ensure forward progress and to increase the amount and types of research funding and grants used in this effort;

- Urge the Office of the Secretary of HHS to devise a multi-year strategic plan for addressing ME/CFS and fill the vacancies on the HHS Chronic Fatigue Syndrome Advisory Committee.

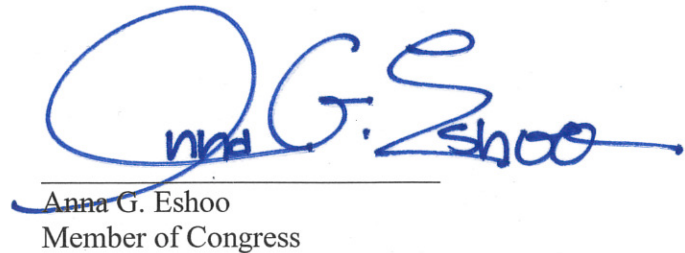
Since 1988, Congress has made similar requests through Appropriations Report Language, and more recently HHS's Chronic Fatigue Syndrome Advisory Committee has made numerous recommendations for increased funding, focused research and improved medical education.

We urge you to support FY19 appropriations of \$5.4 million for Chronic Fatigue Syndrome research at the Centers for Disease Control and Prevention (CDC), and to include the attached report language to build upon this progress and look forward to working with you to strengthen support for ME/CFS research and education programs.

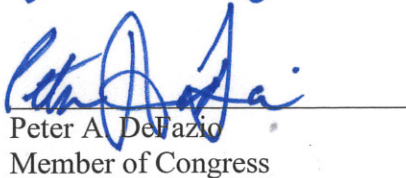
Sincerely,



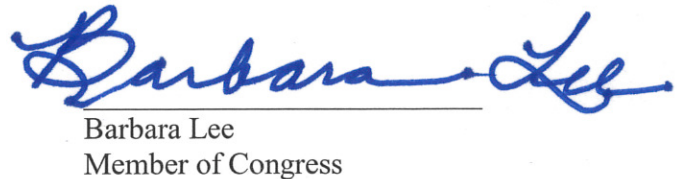
Zoe Lofgren
Member of Congress



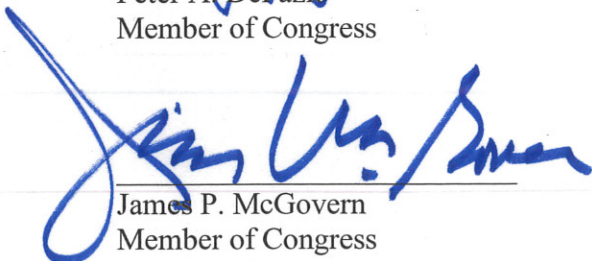
Anna G. Eshoo
Member of Congress



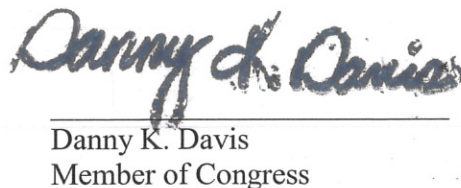
Peter A. DeFazio
Member of Congress



Barbara Lee
Member of Congress



James P. McGovern
Member of Congress



Danny K. Davis
Member of Congress



Susan A. Davis
Member of Congress



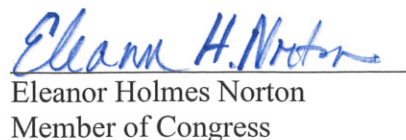
Michael E. Capuano
Member of Congress



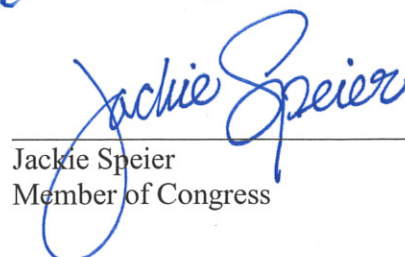
Jamie Raskin
Member of Congress



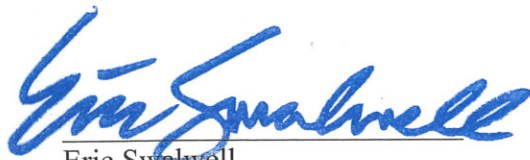
Steve Cohen
Member of Congress



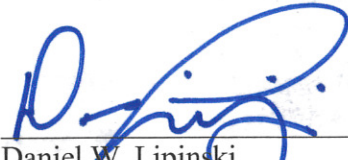
Eleanor Holmes Norton
Member of Congress



Jackie Speier
Member of Congress



Eric Swalwell
Member of Congress



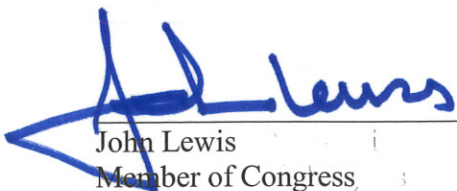
Daniel W. Lipinski
Member of Congress



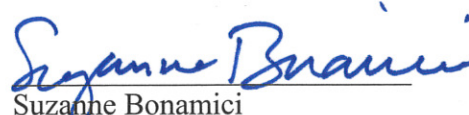
André Carson
Member of Congress



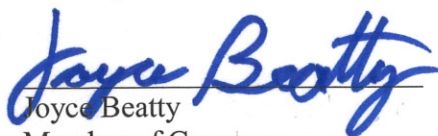
Bonnie Watson Coleman
Member of Congress



John Lewis
Member of Congress



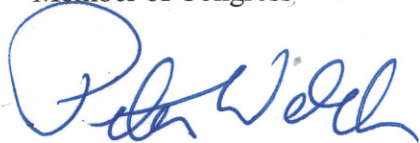
Suzanne Bonamici
Member of Congress



Joyce Beatty
Member of Congress



C.A. Dutch Ruppersberger
Member of Congress



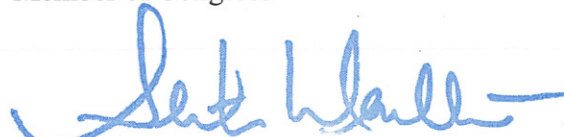
Peter Welch
Member of Congress



Al Lawson
Member of Congress



Adriano Espaillat
Member of Congress



Seth Moulton
Member of Congress



Robert C. "Bobby" Scott
Member of Congress



Scott H. Peters
Member of Congress



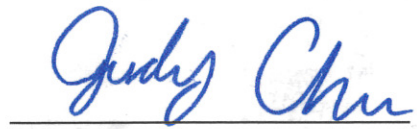
Beto O'Rourke
Member of Congress



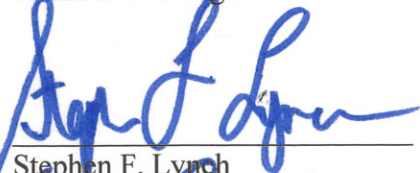
Nanette Barragán
Member of Congress



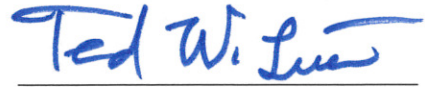
Lisa Blunt Rochester
Member of Congress



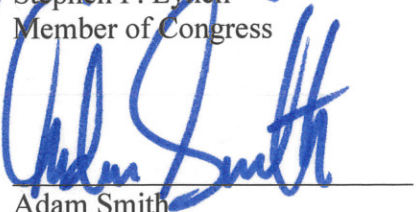
Judy Chu
Member of Congress



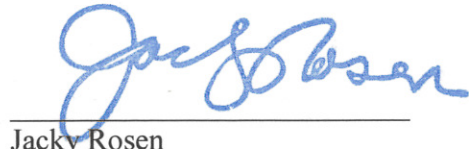
Stephen F. Lynch
Member of Congress



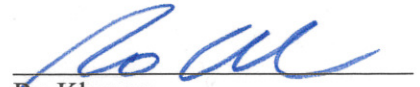
Ted Lieu
Member of Congress



Adam Smith
Member of Congress



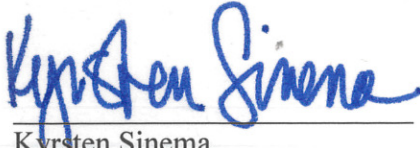
Jacky Rosen
Member of Congress



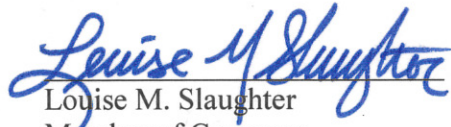
Ro Khanna
Member of Congress



Donald Norcross
Member of Congress



Kyrsten Sinema
Member of Congress



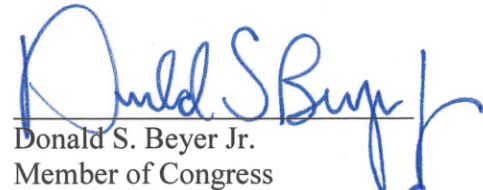
Louise M. Slaughter
Member of Congress



Ann McLane Kuster
Member of Congress



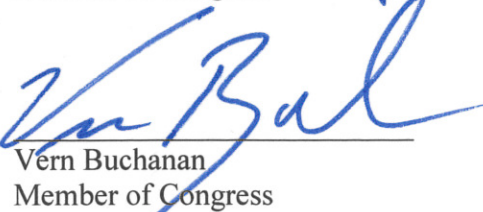
William R. Keating
Member of Congress



Donald S. Beyer Jr.
Member of Congress



Tom O'Halleran
Member of Congress



Vern Buchanan
Member of Congress

Enclosure: Proposed Language for FY 2019 Labor, HHS, Education, and Related Agencies Appropriations Committee Report

1. Centers for Disease Control

Chronic Disease Prevention and Health Promotion: Chronic Fatigue Syndrome [ME/CFS] — The Committee recommends that CDC maintain level funding of \$5.4M to cover critical activities. The Committee applauds CDC's efforts to collaborate with disease experts in its multi-site study to resolve the case definition issues and urges CDC to complete that effort. The Committee also commends the CDC's recent update of its website informing the public about ME/CFS and encourages CDC to work with disease experts and patients to continue to better educate healthcare providers about the disease and its appropriate management. However, the Committee is concerned that neither the website updates nor CDC's current plans will address the continued medical stigma and misinformation about ME/CFS and the critical lack of medical providers. We are very concerned that there are fewer than twelve experts in the country and that the vast majority of patients have no access to knowledgeable physicians. We urge the CDC to partner with other HHS agencies, disease experts, and key medical societies to implement a proactive plan to address these issues and find creative ways to bring additional clinicians into the field.

2. National Institutes of Health

Office of the Director: Chronic Fatigue Syndrome [ME/CFS]—The Committee is pleased that NIH has begun to expedite research into ME/CFS. However, NIH itself has acknowledged that there are too few centers and that 10 to 20 times more funding is required to make progress in the field. The Committee is concerned that NIH's current plans to increase research activities and funding will take too long to produce the FDA-approved treatments and diagnostic tests critically needed by patients and their doctors. The Committee urges NIH to collaborate with disease experts and the patient community to identify additional opportunities to expedite progress on this understudied disease. Specifically, the Committee recommends that NIH increase research funding to better reflect the disease burden and use that funding to further accelerate the research field through a set of intramural and extramural investments such as: (1) RFAs for biomarkers and treatment trials, (2) additional funding for investigator-initiated studies and early stage investigator awards, (3) additional funding for each collaborative research center (CRC) and for additional centers of excellence, (5) an initiative to reach consensus on the case definition and methods of selecting patients for trials, and (6) mechanisms to incentivize researchers to enter the field.

3. Office of the Secretary

General Department Management: Chronic Fatigue Syndrome [ME/CFS]—The Committee is concerned that Americans afflicted with ME/CFS have very limited access to clinical care, that there is no diagnostic test for ME/CFS, and there are no FDA-approved treatments for them. HHS is encouraged to (1) utilize the ME/CFS Advisory Committee [CFSAC] to accelerate progress on research, education, training, clinical care, and services to better address the needs of over one million Americans suffering from ME/CFS and (2) fill the existing vacancies on CSFAC. We also encourage HHS to take advantage of the Assistant Secretary of Health's expanded role defined in the CFSAC charter to accelerate progress on research, education, training, care, and services to better address the needs of over one million Americans suffering from ME/CFS. The Committee also suggests that HHS devise a multi-year strategic plan for addressing ME/CFS as was done for HIV/AIDS.