

Congress of the United States
Washington, DC 20515

April 6, 2017

The Honorable Rodney P. Frelinghuysen
Chairman
Committee on Appropriations
U.S. House of Representatives
H-305 The Capitol
Washington, D.C. 20515

The Honorable Nita M. Lowey
Ranking Member
Committee on Appropriations
U.S. House of Representatives
1016 Longworth House Office Building
Washington, D.C. 20515

The Honorable Tom Cole
Chairman
Subcommittee on Labor, Health and Human
Services, and Education
U.S. House of Representatives
2358-B Rayburn House Office Building
Washington, D.C. 20515

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, Health and
Human Services, and Education
U.S. House of Representatives
1016 Longworth House Office Building
Washington, D.C. 20515

Dear Chairmen Cole and Frelinghuysen and Ranking Members DeLauro and Lowey:

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).

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

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.^[vii]

We urge you to include the attached Report Language urging 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:

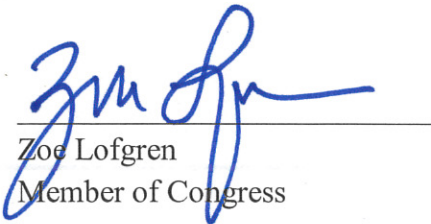
- Encourage HHS to accelerate progress on research, education, and training;

- Encourage CDC to complete the work of its multi-site clinical assessment of ME/CFS, to standardize a ME/CFS case definition, and to implement and expedite a plan to disseminate accurate medical information;
- Urge HHS and CDC to partner with the medical community and other stakeholders to bring new clinicians and researchers into the field and to improve clinical care access;
- 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.

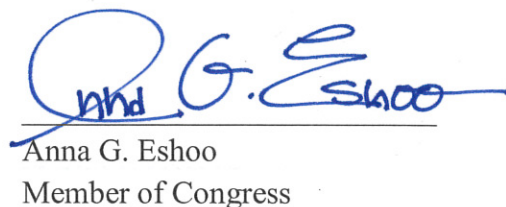
Since 1988, Congress has made similar requests through Appropriations Report Language, and more recently HHS's Chronic Fatigue Syndrome Advisory Committee has made numerous recommendations for increased funding, focused research and improved medical education.^[viii]

We urge you 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.

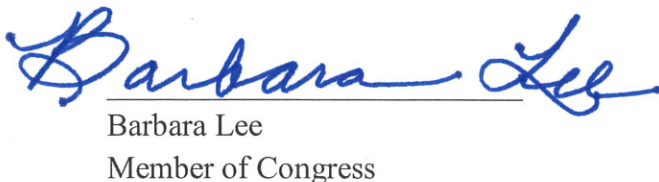
Sincerely,



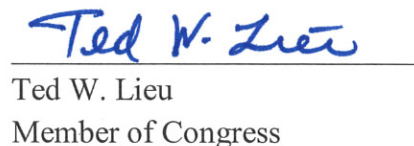
Zoe Lofgren
Member of Congress



Anna G. Eshoo
Member of Congress



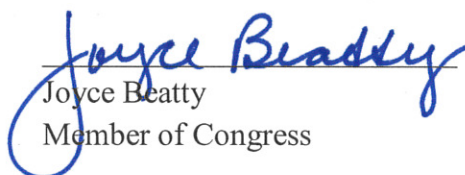
Barbara Lee
Member of Congress



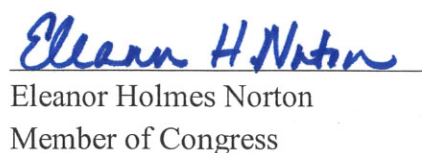
Ted W. Lieu
Member of Congress



Jackie Speier
Member of Congress



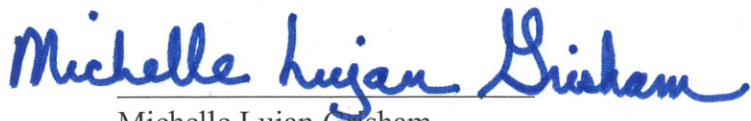
Joyce Beatty
Member of Congress



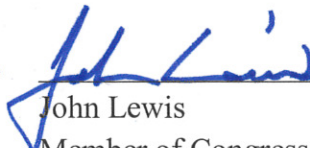
Eleanor Holmes Norton
Member of Congress



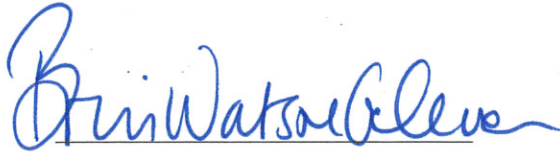
Eric Swalwell
Member of Congress



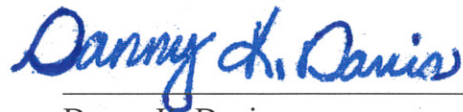
Michelle Lujan Grisham
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John Lewis
Member of Congress



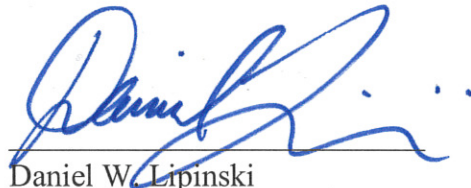
Bonnie Watson Coleman
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Danny K. Davis
Member of Congress



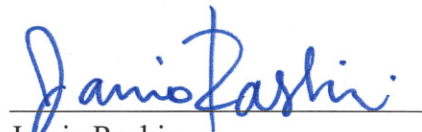
James P. McGovern
Member of Congress



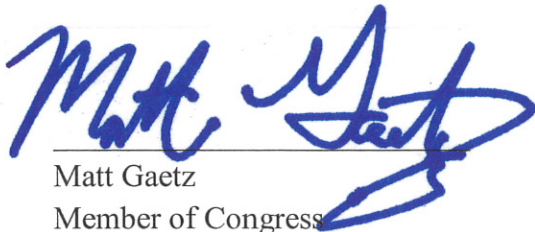
Daniel W. Lipinski
Member of Congress



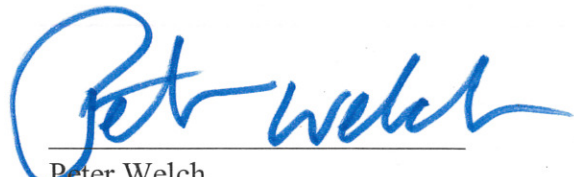
Steve Cohen
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Jamie Raskin
Member of Congress



Matt Gaetz
Member of Congress



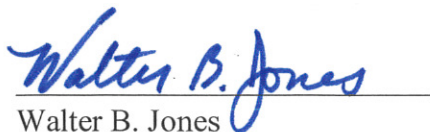
Peter Welch
Member of Congress



Ro Khanna
Member of Congress



Alma Adams
Member of Congress



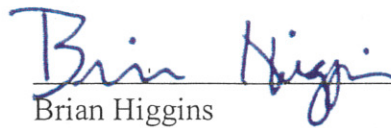
Walter B. Jones
Member of Congress



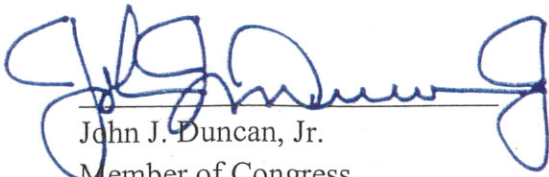
Elizabeth H. Esty
Member of Congress



Peter A. DeFazio
Member of Congress



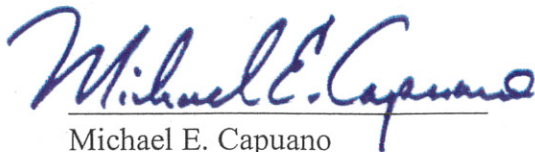
Brian Higgins
Member of Congress



John J. Duncan, Jr.
Member of Congress



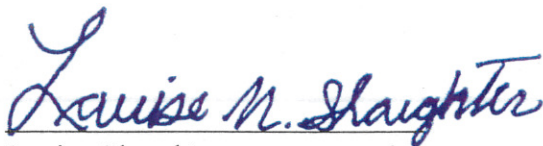
Suzanne Bonamici
Member of Congress



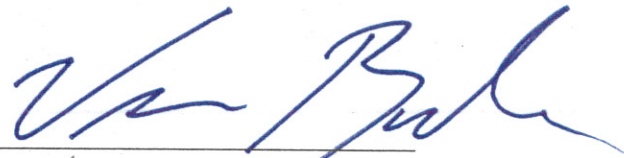
Michael E. Capuano
Member of Congress



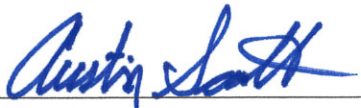
Ted Deutch
Member of Congress



Louise Slaughter
Member of Congress



Vern Buchanan
Member of Congress



Austin Scott
Member of Congress