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.\[1\] It costs individuals, the U.S. health care system, and our economy an estimated $17-$24 billion annually\[2\] as twenty-five percent of patients are bedbound or housebound at some time in their lives\[3\] and an estimated 69% are unable to work.\[4\] Additionally, access to medical care is limited and 81-94% of patients are undiagnosed\[5\] likely because ME/CFS is only included in 30% of medical curricula and 40% of medical textbooks.\[6\]

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.\[7\]

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;

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• 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