

Support Myalgic Encephalomyelitis (Chronic Fatigue Syndrome) Research at HHS, CDC, and NIH

Deadline: Tuesday, April 4, 2017 COB

Dear Colleague:

Please join us in sending a letter to the Labor, Health and Human Services, and Education Appropriations Subcommittee requesting report language in support of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) research at the U.S. Department of Health and Human Services (HHS), Centers for Disease Control and Prevention, and the National Institutes of Health.

The National Academies' Institute of Medicine issued a report in 2015 concluding that ME/CFS is both under-funded and under-researched even though it affects 1-2.5 million Americans (more than other chronic medical conditions such as Multiple Sclerosis and Lupus).

The attached FY18 Report Language request includes recommendations from the HHS Chronic Fatigue Syndrome Advisory Committee and the National Academies' Institute of Medicine, and builds upon language included in the Senate FY17 Labor, Health and Human Services, and Education Appropriations bill.

Please contact Angela.Ebiner@mail.house.gov (Congresswoman Lofgren) to sign onto the letter.

Sincerely,

Zoe Lofgren
Member of Congress

Anna G. Eshoo
Member of Congress

April xx, 2017

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

The Honorable Nita M. Lowey
Ranking Member
Committee on Appropriations
U.S. House of Representatives
1016 Longworth HOB
Washington, DC 20515

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

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

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.

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