

Congress of the United States
Washington, DC 20515

Dr. Francis Collins
Director
National Institutes of Health
One Center Drive
Bethesda, Maryland 20892

March 19, 2014

Dear Dr. Collins,

We write to thank you for your attention to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), and to encourage you to continue and strengthen this effort.

As you know ME/CFS is a debilitating, complex condition affecting millions of patients. It causes major suffering and costs individuals, the health care system and the economy greatly in both treatment and loss of productivity. It afflicts more people than many other diseases, including MS, AIDS, and Lyme disease that get much more funding and attention.

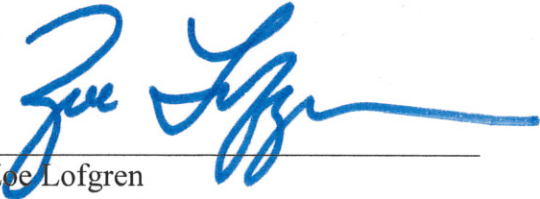
As you may also know, this disease has not been taken as seriously as it should be, in part due to its name and the mistaken impression that the symptoms are psychosomatic. This lack of understanding has harmed patients who are sometimes mistreated or told their symptoms are not real. We understand it has hindered research by discouraging scientists from pursuing investigations in an area where they may not be taken seriously. It is an ongoing problem and we encourage you as Director of NIH to help raise awareness and attention among clinicians and researchers.

We applaud your efforts to support the Trans-NIH ME/CFS Research Working Group, and in hosting the ME/CFS Research Workshop in April 2011. The Workshop concluded that there continues to be a need for additional interdisciplinary research, coordination of research, centralized data sharing, and recruitment of additional qualified investigators. These suggestions are in line with the recommendations of the HHS CFS Advisory Committee, including an NIH RFA in the range of \$7-10 million.

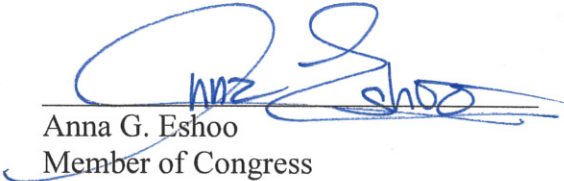
We encourage you to act decisively on these recommendations. We also ask that you provide us with the current status of the effort to meet the need in ME/CFS research, as well as plans for moving forward with a strong and fully supported research program.

Thank you in advance for your attention to this issue. We look forward to working with you to raise awareness, understand this disease and find a cure.

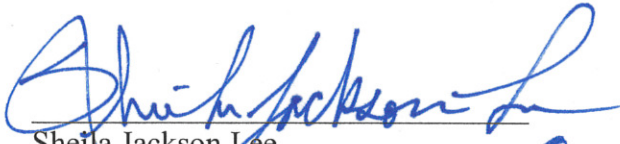
Sincerely,




Zoe Lofgren
Member of Congress



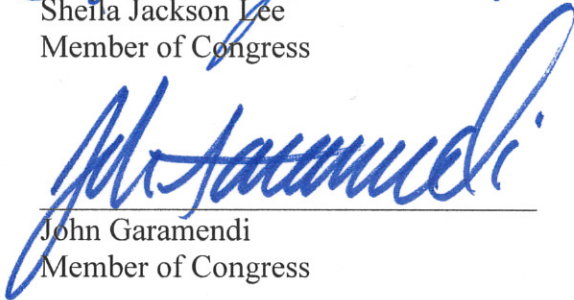
Anna G. Eshoo
Member of Congress



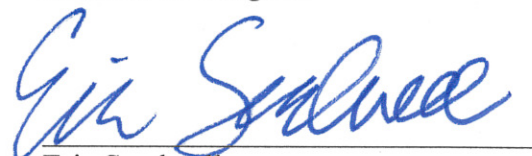
Sheila Jackson Lee
Member of Congress



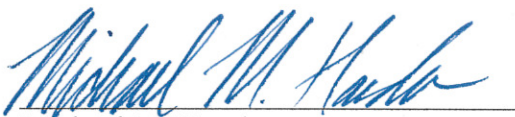
Suzan K. DelBene
Member of Congress



John Garamendi
Member of Congress



Eric Swalwell
Member of Congress



Michael M. Honda
Member of Congress



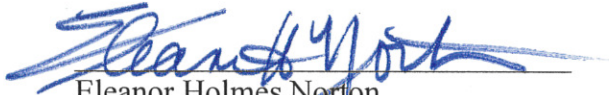
Daniel Lipinski
Member of Congress



Scott Peters
Member of Congress



John Lewis
Member of Congress



Eleanor Holmes Norton
Member of Congress