September 8, 2017

Francis Collins, Director
National Institutes of Health
1 Center Drive, Room B1-126
Bethesda, Maryland 20892-0001

Dear Dr. Collins:

We are writing to encourage you to strengthen and accelerate the National Institutes of Health’s (NIH’s) work on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS).

As you know, ME/CFS is a complex, debilitating, and chronic disease afflicting up to 2.5 million Americans of all ages and races. It costs individuals, the U.S. health care system, and our economy $17-$24 billion annually.

We are encouraged to see that the NIH has reinvigorated the Trans-NIH ME/CFS Working Group, launched an intramural clinical study of ME/CFS patients, and published two Requests for Applications. The profound disease burden of ME/CFS, the paucity of knowledge about even its cause, and the absence of diagnostic tools and treatments calls for this kind of investment and action. We continue to be concerned by the lack of Food and Drug Administration approved treatments for the disease.

We believe that the recent $2 billion increase in NIH funding in the Fiscal Year 2017 Appropriations Act provides the NIH a unique opportunity to achieve groundbreaking advancements in ME/CFS research and treatment without affecting research on other diseases. Accordingly, we urge the NIH to seize this opportunity to quickly advance diagnosis, treatment, and a cure for ME/CFS by conducting and supporting research at a level commensurate with other similarly burdensome diseases.

We are pleased that the NIH has made many complicated diseases treatable through scientific excellence, and we encourage you to accelerate your efforts on ME/CFS. Thank you for your attention to this critical issue, and we look forward to your response.

Sincerely,

Mark E. Amodei
Member of Congress

Dean Heller
United States Senator
Dina Titus  
Member of Congress

Jacky Rosen  
Member of Congress

Catherine Cortez Masto  
United States Senator

Ruben J. Kihuen  
Member of Congress