

# Congress of the United States

Washington, DC 20510

December 17, 2018

The Honorable Alex Azar  
Secretary  
U.S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, DC 20201

Dear Secretary Azar,

We write regarding efforts throughout the U.S. Department of Health and Human Services (HHS) to better understand and improve health outcomes for Americans living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). We have heard concerns from our constituents regarding the end of the Chronic Fatigue Syndrome Advisory Committee (CFSAC) in September, the pace and scale of HHS' work on ME/CFS, and the apparent lack of a comprehensive ME/CFS strategy.

While we are encouraged to see the initiatives underway at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) to help improve the quality of life for individuals living with ME/CFS, we believe more must be done to reflect the unique research and treatment challenges compounding the burden of this disease. We ask that you work with stakeholders in the ME/CFS community to fill the gap left by CFSAC's dissolution, ensure that information about ongoing and future initiatives regarding ME/CFS are easily accessible to the public, and build upon existing efforts to improve the quality of life for the ME/CFS community.

It is estimated that ME/CFS impacts up to 2.5 million Americans.<sup>1</sup> ME/CFS is a chronic, multisystem condition for which there is no known cause, treatment, or cure. Individuals living with this debilitating disease are often unable to attend school or work. As a result, ME/CFS costs the economy an estimated \$17 to \$24 billion per year.<sup>1</sup>

For decades, Americans living with ME/CFS have struggled to access effective, comprehensive care to help treat their disease. This is not only due to the "relative paucity of research conducted on ME/CFS,"<sup>1</sup> but also to a dearth of clinical expertise available to treat individuals with ME/CFS. This lack of ME/CFS expertise is getting worse as many experts and clinicians near retirement. Additionally, inappropriate clinical guidance has led to improper clinical care that harms patients. Taken together, these issues perpetuate challenges to access effective care and hinder our collective ability to improve health outcomes and quality of life for individuals living with ME/CFS and their loved ones.

We appreciate that agencies within HHS are taking steps to address some of these issues. For example, earlier this year, the National Institute of Neurological Disorders and Stroke Advisory

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<sup>1</sup> *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*, National Academies Press. (Feb. 2015), <https://www.ncbi.nlm.nih.gov/pubmed/25695122>.

Committee within NIH established the Chronic Fatigue Syndrome Working Group (distinct from the inter-agency CFSAC) to convene a variety of stakeholders to help inform the science around the agency's ME/CFS efforts. The NIH is also conducting an intramural study on individuals who contracted the disease after an infection, funding three Collaborative Research Centers and a Data Management Coordinating Center, and hosting research investigators, including Young Investigators, at its campus next year. The CDC has made substantial revisions to its website and is working to update treatment information for health care providers.

However, by disbanding the CFSAC, HHS created a void in both intra-departmental and inter-agency collaboration and removed a platform for streamlined stakeholder engagement. Vital ongoing projects were halted mid-stream. This is particularly unfortunate considering outside stakeholders, including Members of Congress, no longer have access to a one-stop-shop, both for learning about all federal initiatives to address ME/CFS and for providing input on federal plans and recommendations.

To help us better understand how HHS will fill the CFSAC vacuum and build upon its ME/CFS efforts, please answer the following questions by January 12, 2018:

1. In the absence of CFSAC, what are HHS' plans for engaging stakeholders in its activities and fostering communication and collaboration between stakeholders and the agencies that participated in CFSAC? How will the projects that were underway at the time of CFSAC's dissolution be completed?
2. Please describe HHS' strategic plan to expedite the delivery of diagnostics, treatments, and approved drugs. How is the department working with outside stakeholders, including engaging with medical associations, to address the lack of clinical expertise in ME/CFS?
3. Please describe how the NIH will enhance extramural research on ME/CFS? How will NIH help incentivize researchers to enter the field?
4. Does the CDC have a strategy and timeline for conducting national epidemiological research to better understand ME/CFS prevalence, risk factors, natural history, and prognosis? What is the CDC's strategy for educating medical providers and the public on ME/CFS? Please describe any additional resources or authorities the CDC may require to actualize these strategies.

Thank you for your attention to our request. We look forward to working with the department to build upon your existing efforts to improve the quality of life for the ME/CFS community.

Sincerely,

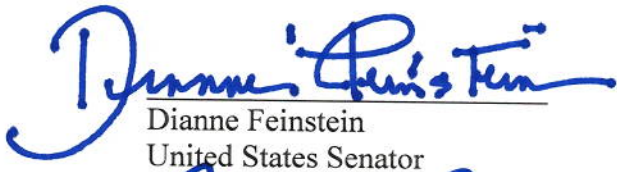


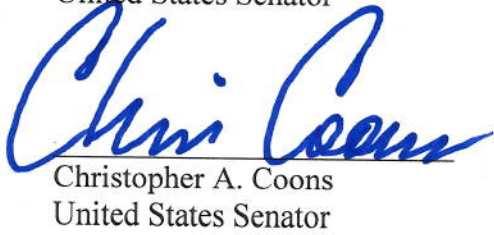
Edward J. Markey  
United States Senator

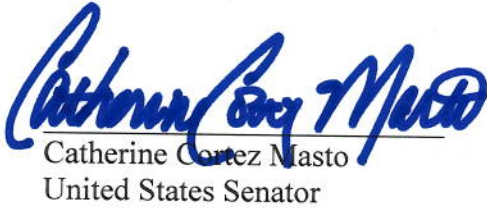


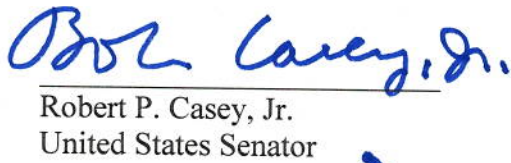
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United States Senator

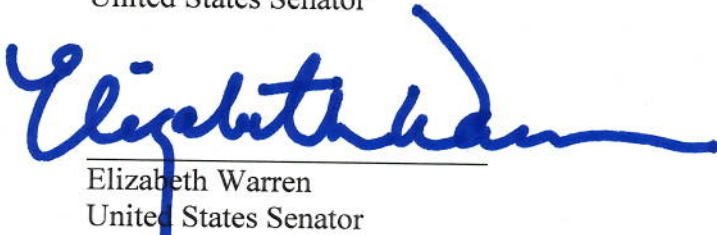


  
Dianne Feinstein  
United States Senator

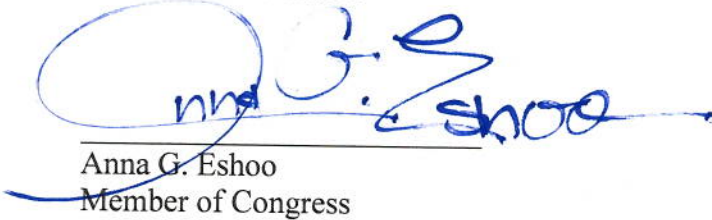
  
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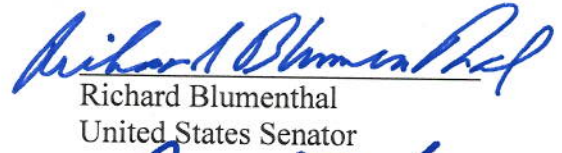
  
Catherine Cortez Masto  
United States Senator

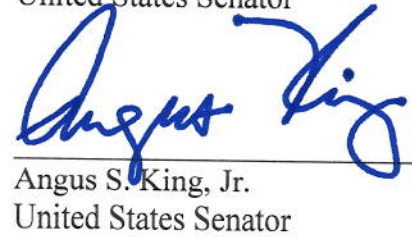
  
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United States Senator

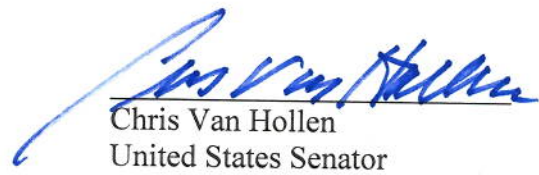
  
Elizabeth Warren  
United States Senator

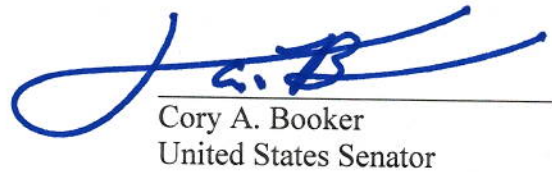
  
Kamala D. Harris  
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Anna G. Eshoo  
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Richard Blumenthal  
United States Senator

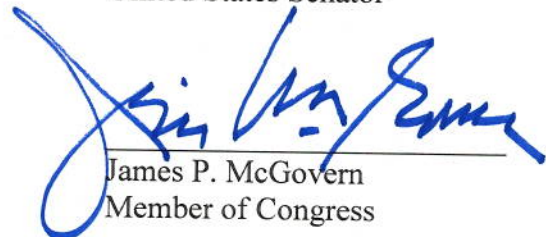
  
Angus S. King, Jr.  
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Chris Van Hollen  
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Cory A. Booker  
United States Senator

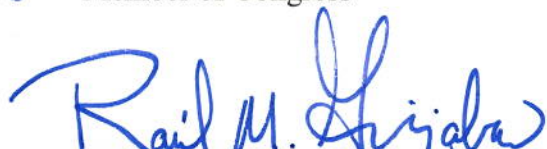
  
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Debbie Stabenow  
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James P. McGovern  
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Jamie Raskin  
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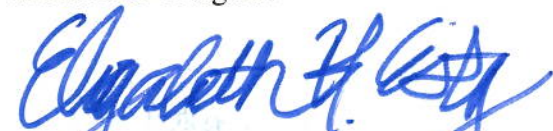
  
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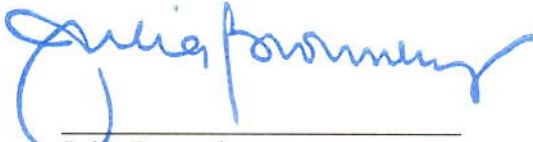
  
Mark DeSaulnier  
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Chellie Pingree  
Member of Congress

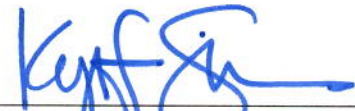
  
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Alan Lowenthal  
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Ann McLane Kuster  
Member of Congress



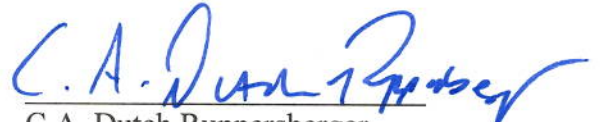
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Kyrsten Sinema  
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Katherine Clark  
Member of Congress



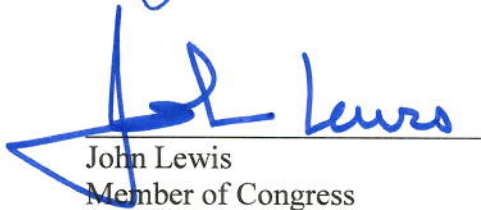
C.A. Dutch Ruppberger  
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Jackie Speier  
Member of Congress



Barbara Lee  
Member of Congress



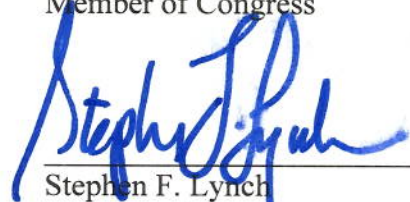
John Lewis  
Member of Congress



Bonnie Watson Coleman  
Member of Congress



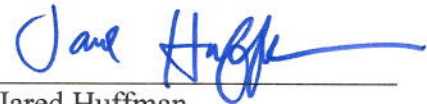
Ed Permuter  
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Stephen F. Lynch  
Member of Congress



David P. Joyce  
Member of Congress



Jared Huffman  
Member of Congress

CC: Dr. Francis Collins, Director, National Institutes of Health  
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