

**Congress of the United States**  
**Washington, DC 20515**

February 13, 2020

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) work on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS).

As you know, ME/CFS is a complex, debilitating, and chronic disease afflicting up to 165,000 Floridians of all ages and walks of life. It costs individuals, the U.S. healthcare system, and our economy \$17-\$24 billion annually.

We are encouraged to see that the NIH hosted a scientific conference for ME/CFS last year and established three coordinated research centers and a data management center for ME/CFS. We also applaud the unanimous adoption of the recent report of the National Advisory Neurological Disorders and Stroke Council (NANDSC) Working Group for ME/CFS. Yet, the profound disease burden of ME/CFS, the paucity of knowledge about its cause, and the absence of diagnostic tools and treatments calls for additional investment and action.

We encourage the NIH to urgently address the research opportunities outlined in the NANDSC working group report and prioritize the "(1) new ME/CFS disease specific funding announcements, including those with set-aside funds, to deliver needed diagnostics and treatments as quickly as possible, (2) an initiative to reach consensus on the ME/CFS case definition, and (3) mechanisms to incentivize researchers to enter the field;" as recommended by the Appropriations Committee.

Given the profound impact of ME/CFS on the people of Florida, we are especially concerned by the lack of Food and Drug Administration approved treatments for the disease and the absence of treatment trials or clinical trials for ME/CFS.

Building on these recent initiatives holds great promise for ME/CFS patients and, for many of them, time is of the essence. Given the recently approved increases in funding, NIH is now uniquely positioned to translate recent scientific advancements into evidence-based treatments for patients.

We commend and thank the NIH for the many positive contributions for the scientific understanding of ME/CFS to date and recognize there is still much work to do. We encourage you to accelerate your efforts on ME/CFS on behalf of the hundreds of thousands of Floridians with ME/CFS. Thank you for your attention to this critical issue, and we look forward to your response.

Sincerely,



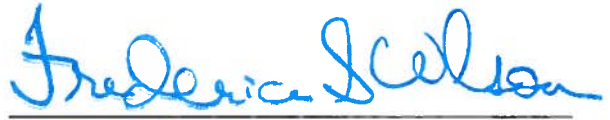
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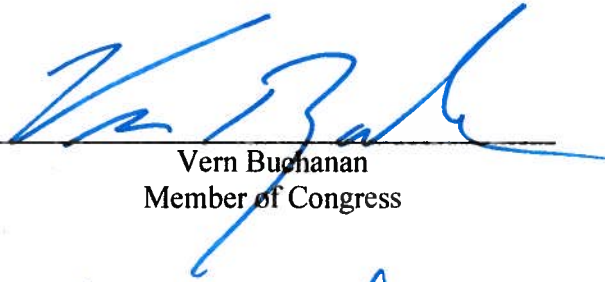
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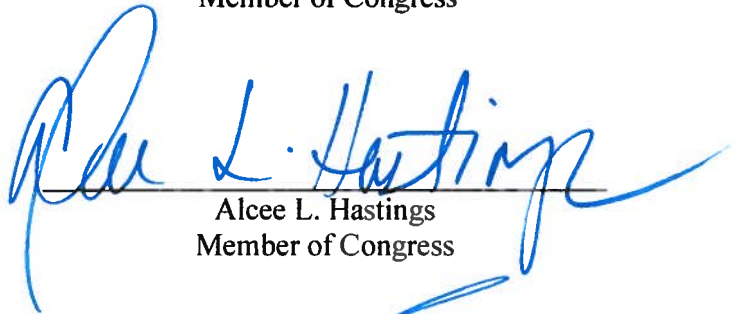
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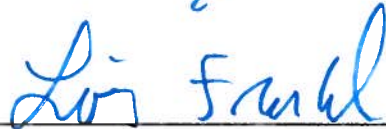
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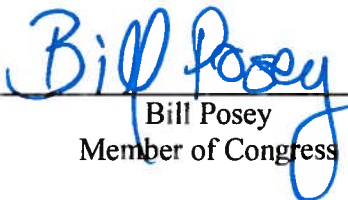
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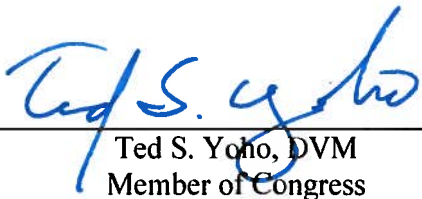
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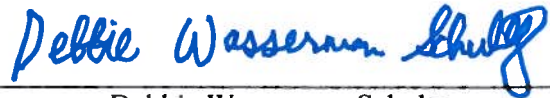
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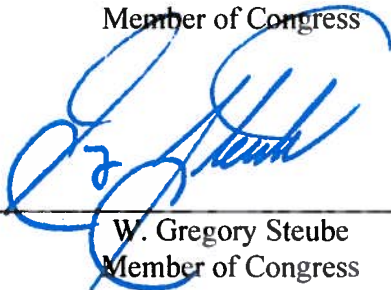
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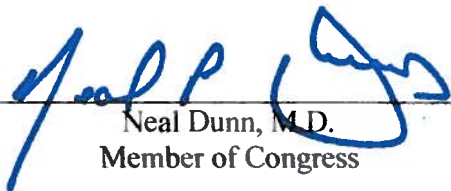
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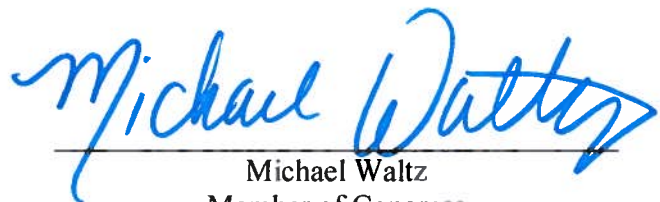
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