

Congress of the United States
Washington, DC 20515

April 28, 2021

The Honorable Rosa DeLauro
Chair
Appropriations Subcommittee on Labor,
Health and Human Services, and Education
2358-B Rayburn House Office Building
Washington, DC 20515

The Honorable Tom Cole
Ranking Member
Appropriations Subcommittee on Labor,
Health and Human Services, and Education
2358-B Rayburn House Office Building
Washington, DC 20515

Dear Chairwoman DeLauro and Ranking Member Cole:

As you begin work on the Fiscal Year 2022 Labor, Health and Human Services, and Education Appropriations bill, we respectfully request that you provide increased funding at \$15.4 million to study the intersection of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Post-Acute COVID-19 Syndrome (PACS) at the Chronic Fatigue Syndrome Programs at the Centers for Disease Control and Prevention (CDC), and to include the attached report language to complement this work.

While the cause of ME/CFS is unknown, multiple studies have found it has a viral trigger, often following acute infections from the Spanish flu of 1918 to Epstein-Barr to Ebola. Some patients experiencing PACS – so called long haulers – meet the U.S. National Academies of Sciences, Engineering and Medicine (NAEM) diagnostic criteria for ME/CFS and may become permanently disabled.¹ Dr. Anthony Fauci during a July 2020 news conference stated that many COVID-19 patients develop symptoms strikingly similar to ME/CFS and that “this is something we really need to seriously look at because it very well might be there is a post-viral syndrome associated with COVID-19.”²

The Institute of Medicine estimated in a 2015 report that between 836,000 and 2.5 million people in the United States suffer from ME/CFS.³ The direct and indirect costs on individuals, the U.S. health care system, and our economy is an estimated \$36-\$51 billion annually.⁴ Experts in the field of post-viral illness assume, based on the course of symptoms following different acute infections, that approximately 10 percent of COVID-19 patients will meet the NAEM case definition for ME/CFS in the long run, meaning the number of Americans suffering from ME/CFS would at least double.⁵

¹ Komaroff A. “The tragedy of long COVID,” Harvard Health Blog, 15 October 2020, <https://www.health.harvard.edu/blog/the-tragedy-of-the-post-covid-long-haulers-2020101521173>.

² Fauci A. “COVID-19 Conference,” AIDS 2020: Virtual, 11 July 2020, <https://covid19.aids2020.org/2020/04/23/announcing-a-special-one-day-covid-19-conference/>.

³ “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness,” Institute of Medicine of the National Academies, May 2015, <http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>.

⁴ Jason, L.A., and Mirin A.A. “Updating the National Academy of Medicine ME/CFS prevalence and economic impact figures to account for population growth and inflation.” *Fatigue: Biomedicine, Health & Behavior*, 28 Jan 2021, <https://doi.org/10.1080/21641846.2021.1878716>.

⁵ Komaroff A, Bateman L. “Will COVID-19 Lead to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?” *frontiers in Medicine*. 18 January 2021, <https://doi.org/10.3389/fmed.2020.606824>.

Requested funds include level funding for existing CDC programs addressing ME/CFS, such as the Multisite Clinical Assessment of ME/CFS (MCAM) study, the Common Data Elements project, and medical education efforts. The additional \$10 million is requested to conduct a nationwide epidemiological study to understand and identify:

- The natural history of ME/CFS, PACS, and related post-viral illnesses;
- The prevalence of PACS, ME/CFS, and related post-viral illnesses in COVID-19 patients;
- Potential risk, resiliency, and disparity through socioeconomic data on PACS; and
- The accessibility of quality care for increased ME/CFS cases as a result of the COVID-19 pandemic.

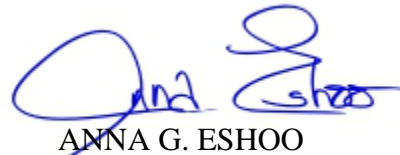
It is critical that our response to the pandemic include, not only efforts to stem the spread of COVID-19, but also steps to prevent and control its lasting repercussions. Much needed funding, focused research, and improved medical education will strengthen support for and improve the lives of ME/CFS patients and COVID-19 long haulers across the country.

Again, we urge you to support \$15.4 million in ME/CFS and PACS funding in the FY22 appropriations bill to fund the appropriate research and to develop strategies for effective treatment and prevention. We appreciate your leadership on this issue and thank you for your consideration of this request.

Sincerely,



ZOE LOFGREN
Member of Congress



ANNA G. ESHOO
Member of Congress

/s/
CINDY AXNE
Member of Congress

/s/
KAREN BASS
Member of Congress

/s/
SUZANNE BONAMICI
Member of Congress

/s/
JULIA BROWNLEY
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CAROLYN BOURDEAUX
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SHARICE L. DAVIDS
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DANNY K. DAVIS
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