

Congress of the United States
Washington, DC 20515

March 17, 2020

The Honorable Pete Visclosky
Chair
Appropriations Subcommittee on Defense
H-405 The Capitol
Washington, DC 20515

The Honorable Ken Calvert
Ranking Member
Appropriations Subcommittee on Defense
H-405 The Capitol
Washington, DC 20515

Dear Chair Visclosky and Ranking Member Calvert:

As you begin work on the Fiscal Year 2021 Defense Appropriations bill, we respectfully request that you include language adding Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, commonly referred to as ME/CFS, to the list of Congressionally Directed Topic Areas in the Peer Reviewed Medical Research Program (PRMRP).

ME/CFS is a chronic, complex, multi-system disease characterized by profound fatigue, cognitive impairment, sleep disorders, autonomic dysfunction, chronic pain, and other symptoms often exacerbated by exertion of any sort. 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 but a vast majority, about 90 percent, of people with the illness remain undiagnosed.¹ There is currently no reliable clinical diagnostic criteria or Federal Drug Administration approved drug or treatment for ME/CFS.

Although the causes of ME/CFS remain unknown, evidence suggests symptoms can be triggered by extreme systemic stress and exposure to viruses or environmental factors such as neurotoxins – situations and circumstances active duty service members are commonly and more likely to be subject to.

The PRMRP listed ME/CFS as a Congressionally Directed Topic Area last year and we are awaiting the results of the award review process. A recent study **found that 89 percent of veterans with Gulf War Illness also suffer from ME/CFS.**² In fact, the clinical presentations of ME/CFS and GWI are nearly identical,³ leading some researchers to hypothesize that GWI is a subset of ME/CFS. A study published in the Annals of Internal Medicine on the health of Gulf War Veterans found that Gulf War deployment is associated with an increased risk for ME/CFS,⁴ with another study

¹ “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>.

² Cayla M Fappiano, James N Baraniuk, Gulf War Illness Symptom Severity and Onset: A Cross-Sectional Survey, Military Medicine, , usz471, <https://doi.org/10.1093/milmed/usz471>

³ Myalgic encephalomyelitis/chronic fatigue syndrome and gulf war illness patients exhibit increased humoral responses to the herpesviruses-encoded dUTPase: Implications in disease pathophysiology, Journal of Medical Virology, March 17, 2017, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5513753/>.

⁴ “Gulf War veterans’ health: medical evaluation of a U.S. cohort,” Annals of Internal Medicine, June 7, 2005, <https://annals.org/aim/fullarticle/718427/gulf-war-veterans-health-medical-evaluation-u-s-cohort>.

showing that 15.7 percent of Gulf War veterans qualified under the 1994 definition of CFS.⁵ While not exclusive to military service members or veterans, there is a clear relationship between military service and incidents of ME/CFS.

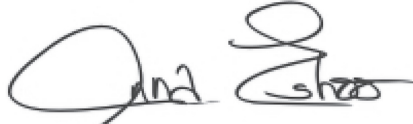
The inclusion of ME/CFS as a PRMRP Congressionally Directed Topic Area – thereby supporting research efforts related to the illness – will help improve our understanding of the prevalence and impact of ME/CFS among military service members, veterans, and beneficiaries, as well as define the underlying pathology to develop strategies for effective treatment and prevention.

Again, we appreciate your leadership on this issue and thank you for your consideration of this request.

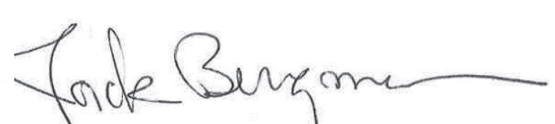
Sincerely,



ZOE LOFGREN
Member of Congress



ANNA G. ESHOO
Member of Congress



JACK BERGMAN
Member of Congress

Member of Congress

⁵ “Prevalence of Chronic Fatigue and Chemical Sensitivities in Gulf Registry Veterans,” Archives of Environmental Health: An International Journal, August 11, 1998, <https://www.tandfonline.com/doi/abs/10.1080/00039899909602493>.

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Congress of the United States
Washington, DC 20515

March 13, 2020

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 2021 Labor, Health and Human Services, and Education Appropriations bill, we respectfully request that you provide increased funding at \$8.4 million for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Programs at the Centers for Disease Control and Prevention (CDC), and to include the attached report language to complement this work.

ME/CFS is a chronic, complex, multi-system disease characterized by profound fatigue, cognitive impairment, sleep disorders, autonomic dysfunction, chronic pain, and other symptoms often exacerbated by exertion of any sort. 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.¹ The CDC has labeled ME/CFS as “America’s hidden health crisis,” as a vast majority, about 90 percent, of people with ME/CFS remain undiagnosed.²

It costs individuals, the U.S. health care system, and our economy an estimated \$17-\$24 billion annually, as 25 percent of patients are bedbound or housebound at some time in their lives and an estimated 69 percent are unable to work.

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. An additional \$3 million is requested to conduct a nationwide epidemiological study to update data on disease demographics and prevalence.

Nationwide ME/CFS Epidemiological Study

Current data on the demographic groups and number of people affected by ME/CFS is limited, localized, and outdated. There is a lack of accurate information about ME/CFS prevalence, risk, and natural history, making it difficult to mount an appropriate government response to the ME/CFS health crisis. However, a seven-year pediatric study recently found that 95 percent of youth who tested positive for ME/CFS were undiagnosed and that African American and Latinx youth were twice as likely to be living with undiagnosed ME/CFS. It was also found that the

¹ “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>.

² Ibid.

prevalence of pediatric ME/CFS was 0.75 percent,³ with a higher prevalence among African American and Latinx youth compared to their Caucasian peers. The CDC has not assessed the prevalence of ME/CFS in either adults or children since 2006, despite the Institute of Medicine providing new clinical criteria in 2015. Given that ME/CFS epidemics have historically followed viral outbreaks such as the current COVID-19 epidemic,⁴ it is vital that the CDC is armed with timely and relevant data about this complex and costly disease. As such, \$3 million of the increased funds should be used to conduct a nationwide ME/CFS epidemiological study, the results of which would be reported to Congress within four years.

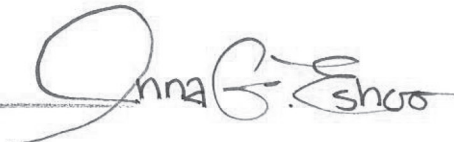
Much needed funding, focused research, and improved medical education will strengthen support for and improve the lives of ME/CFS patients across the country.

Again, we urge you to support \$8.4 million in ME/CFS funding in the FY21 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



JACK BERGMAN
Member of Congress

Member of Congress

³ Leonard A. Jason, Ben Z. Katz, Madison Sunnquist, Chelsea Torres, Joseph Cotler, Shaun Bhatia. The Prevalence of Pediatric Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in a Community-Based Sample. *Child & Youth Care Forum*, 2020; DOI: 10.1007/s10566-019-09543-3

⁴ Hyde, Byron M., et al. *The Nightingale Research Foundation Review of the Clinical and Scientific Basis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome*. Nightingale Research Foundation, 1993.

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