

April XX, 2019

Chairman Richard Shelby
Defense Appropriations Subcommittee
122 Dirksen Senate Office Building
Washington, DC 20510

Ranking Member Richard Durbin
Defense Appropriations Subcommittee
115 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Shelby and Ranking Member Durbin,

As you begin work on the Fiscal Year 2020 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 U.S. Food and 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 commonly experienced by active duty service members.

The PRMRP listed ME/CFS as a Congressionally Directed Topic Area in 2011, but the disease was later removed despite its prevalence among service men and women² and despite clinical presentations similar to those of Gulf War Illness (GWI).³ Chronic, multi-system illnesses have been reported among military personnel returning from combat since the Civil War. However, it was only following Operations Desert Shield and Desert Storm in the Persian Gulf that the scope and impact of such illnesses began receiving widespread attention.

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 “Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS),” War Related Illness and Injury Study Center, U.S. Department of Veterans Affairs, <https://www.warrelatedillness.va.gov/education/healthconditions/chronic-fatigue-syndrome.asp>.

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/>.

Additionally, ME/CFS and GWI are often compared and studied together due to overlapping symptomology and because experts believe the two are related.⁴ 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,⁵ with another study showing that 15.7 percent of Gulf War veterans qualified under the 1994 definition of CFS.⁶ 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,

⁴ “Exercise – induced changes in cerebrospinal fluids miRNAs in Gulf War Illness, Chronic Fatigue Syndrome and sedentary control subjects,” Nature Research, November 10, 2017, <https://www.nature.com/articles/s41598-017-15383-9>.

⁵ “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>.

⁶ “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>.