Dear Colleague:

Please join us in sending the below bipartisan letters to support Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) research in the FY22 Appropriations bill.

The first is to Labor HHS in support of $15.4 million for ME/CFS programs at the Centers for Disease Control and Prevention (CDC) and to study the intersection of ME/CFS and Post-Acute COVID-19 Syndrome (PACS), as well as for accompanying report language. The second is to Defense requesting that ME/CFS be kept on the list of Congressionally Directed Topic Areas in the Department of Defense’s Peer Reviewed Medical Research Program (PRMRP).

As you may know, 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. Individuals experiencing PACS – also referred to as long haul COVID – exhibit strikingly similar symptoms to ME/CFS. While the cause of ME/CFS is unknown, multiple studies have shown it has a viral trigger and ME/CFS epidemics have historically followed viral outbreaks such as the current COVID-19 pandemic. Dr. Anthony Fauci, in remarks drawing comparisons between ME/CFS and PACS, said 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."

A nationwide ME/CFS epidemiological study is necessary now more than ever to understand the natural history, prevalence, and potential risks related to ME/CFS, PACS, and related post-viral illnesses.
Much needed funding, focused research, reliable data, and improved medical education will strengthen support for and improve the lives ME/CFS and PACS patients across the country. We hope you will join us in urging the Appropriations Committee to provide $15.4 million in funding for ME/CFS and to keep ME/CFS in PRMRP’s authorized topic areas.

To sign on, or for further information, please contact Priscilla Kim in Rep. Lofgren’s office at Priscilla.Kim@mail.house.gov. The deadline to sign on is COB MONDAY, APRIL 26th.

Sincerely,

ZOE LOFGREN ANNA G. ESHOO
Member of Congress Member of Congress

April XX, 2021

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 $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 (NASEM) 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 NASEM case definition for ME/CFS in the long run, meaning the number of Americans suffering from ME/CFS would at least double.[5]

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,


April XX, 2021

Dear Chair McCollum and Ranking Member Calvert:

As you begin work on the Fiscal Year 2022 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).

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 servicemembers are commonly and more likely to be subject to.

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 direct and indirect costs on individuals, the U.S. health care system, and our economy is an estimated $36-$51 billion annually. [2] Those numbers are expected to grow significantly with some of the over 30 million Americans infected with COVID-19 now experiencing Post-Acute COVID-19 Syndrome (PACS) – so called long haul COVID – that could lead to permanently debilitating symptoms strikingly similar to ME/CFS. 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 U.S. National Academies of Sciences, Engineering and Medicine case definition for ME/CFS in the long run, meaning the number of Americans suffering from ME/CFS would at least double. [3]

The PRMRP listed ME/CFS as a Congressionally Directed Topic Area and funded two projects last year. A recent study found that 89 percent of veterans with Gulf War Illness also suffer from ME/CFS. [4] In fact, the clinical presentations of
ME/CFS and GWI are nearly identical, leading some researchers to hypothesize that GWI is a subset of ME/CFS. A study published in the Annals of Internal Medicine on health of Gulf War Veterans found that Gulf War deployment is associated with an increased risk for ME/CFS, with another study showing that 15.7 percent of Gulf War veterans qualified under the 1994 definition of CFS. 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 and PACS – will help improve our understanding of the prevalence and impact of ME/CFS among military servicemembers, 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,


