## Congress of the United States Mashington, DC 20515

March 29, 2023

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

Dear Chair Calvert and Ranking Member McCollum:

As you begin work on the Fiscal Year 2023 Defense Appropriations bill, we respectfully request that you include language to keep Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, commonly referred to as ME/CFS, in the list of Congressionally Directed Topic Areas in the Peer Reviewed Medical Research Program (PRMRP), and to set aside \$5 million within PRMRP for research on Long COVID and ME/CFS with a focus on military populations.

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 experience.

Most Americans have had COVID-19 and a substantial number experience long-term symptoms called "Long COVID".<sup>i</sup> In July of 2022, the CDC published an analysis showing 1 in 5 American adult COVID survivors under the age of 65 are experiencing symptoms consistent with Long COVID<sup>ii</sup>, forcing an estimated 4 million people out of the labor force and many more to work with debility at any given time.<sup>iii</sup> The broader economic impact has been estimated at \$3.7 trillion, due to reduced quality of life, lost earnings, and medical costs.<sup>iv</sup>

Also, COVID-19 is associated with the development of other infection-associated chronic conditions, including ME/CFS. It has been estimated that the number of Americans with ME/CFS has increased sixfold since the pandemic began as a result of COVID.<sup>v</sup> People with ME/CFS report substantial impairment<sup>vi</sup> and an estimated 25% are confined to their homes or completely bed bound.<sup>vii</sup> For many, it is a lifelong illness. The cost to families and larger society is profound: current ME/CFS prevalence estimates translate to \$149 to \$362 billion in medical expenses and lost income, exclusive of other costs, such as disability benefits, social services, and lost wages of caretakers. The cost to our military readiness, veterans, and their families could be even more significant as viral infections trigger more and more cases.

We thank you for the consistent inclusion of ME/CFS as a PRMRP Congressionally Directed Topic Area and ask that you provide \$12 million in dedicated funding to match the urgency and need around understanding the prevalence and impact of ME/CFS and Long COVID. It is critical

that our response to the pandemic include steps to prevent and control lasting repercussions from COVID, along with efforts to stem the spread of the disease. Again, we appreciate your leadership on this issue and thank you for your consideration of this request.

Sincerely,

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<sup>ii</sup> Bull-Otterson, L. (2022). Post–COVID Conditions Among Adult COVID-19 Survivors Aged 18–64 and ≥65 Years — United States, March 2020–November 2021. *MMWR. Morbidity and Mortality Weekly Report*, 71. https://doi.org/10.15585/mmwr.mm7121e1

<sup>iii</sup> Bach, K. (2022, August 24). New data shows long Covid is keeping as many as 4 million people out of work. *Brookings*. https://www.brookings.edu/research/new-data-shows-long-covid-is-keeping-as-many-as-4-million-people-out-of-work/

<sup>iv</sup> The Economic Cost of Long COVID: An Update - David Cutler. (2023, March 16). https://www.hks.harvard.edu/centers/mrcbg/programs/growthpolicy/economic-cost-long-covid-update-david-cutler

<sup>v</sup> Mirin, A. A., Dimmock, M. E., & Jason, L. A. (2022). Updated ME/CFS prevalence estimates reflecting post-COVID increases and associated economic costs and funding implications. *Fatigue: Biomedicine, Health & Behavior*, *10*(2), 83–93. https://doi.org/10.1080/21641846.2022.2062169

<sup>vi</sup> Nacul, L. C., Lacerda, E. M., Campion, P., Pheby, D., Drachler, M. de L., Leite, J. C., Poland, F., Howe, A., Fayyaz, S., & Molokhia, M. (2011). The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers. *BMC Public Health*, *11*(1), 402. https://doi.org/10.1186/1471-2458-11-402

<sup>vii</sup> Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. (2015). National Academies Press. https://doi.org/10.17226/19012

<sup>&</sup>lt;sup>i</sup> O'Mahoney, L. L., Routen, A., Gillies, C., Ekezie, W., Welford, A., Zhang, A., Karamchandani, U., Simms-Williams, N., Cassambai, S., Ardavani, A., Wilkinson, T. J., Hawthorne, G., Curtis, F., Kingsnorth, A. P., Almaqhawi, A., Ward, T., Ayoubkhani, D., Banerjee, A., Calvert, M., ... Khunti, K. (2023). The prevalence and long-term health effects of Long Covid among hospitalised and non-hospitalised populations: a systematic review and meta-analysis. EClinicalMedicine, 55, 101762. https://doi.org/10.1016/j.eclinm.2022.101762