

May XX, 2020

The Honorable Mitch McConnell
Majority Leader
United States Senate
Washington, DC 20515

The Honorable Charles Schumer
Minority Leader
United States Senate
Washington, DC 20515

Dear Leader McConnell and Leader Schumer:

As Congress continues to work on legislation to address the COVID-19 pandemic, we encourage you to support increased funding for post-viral-disease research into Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). Viral outbreaks have triggered an increase in ME/CFS patients in the past,¹ and the current coronavirus disease pandemic is likely to do so as well. We therefore must prepare for a potential increase in ME/CFS cases in COVID-19 survivors. We urge you to provide funding in future coronavirus response legislation that would bolster existing ME/CFS research initiatives at the National Institutes of Health (NIH).

ME/CFS is a complex, debilitating, predominantly post-viral² chronic disease afflicting up to 2.5 million Americans of all ages and walks of life.³ Studies show that many viruses can cause ME/CFS.⁴ Severe Epstein-Barr virus (mononucleosis) infections—which can affect a person’s spine, brain, and nerves—trigger ME/CFS in up to 10% of patients.⁵ SARS coronavirus, which is highly similar to the novel coronavirus causing the current pandemic (SARS-CoV-2), led to persistent impaired health in many survivors, with 17% failing to return to their original work

¹ American ME and CFS Society, *Outbreaks*, <https://ammes.org/outbreaks/> (last accessed May 6, 2020).

² Mayo Foundation for Medical Education and Research, *Chronic Fatigue Syndrome*, (Jan. 5, 2018), www.mayoclinic.org/diseases-conditions/chronic-fatigue-syndrome/symptoms-causes/syc-20360490.

³ Institute of Medicine, *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*, National Academies Press (Feb. 10, 2015), <https://www.ncbi.nlm.nih.gov/pubmed/25695122>.

⁴ Ian Hickie et al., *Post-Infective and Chronic Fatigue Syndromes Precipitated by Viral and Non-Viral Pathogens: Prospective Cohort Study*, British Medical Journal Publishing Group, (Sept. 14, 2006), <https://www.bmj.com/content/333/7568/575>.

⁵ Ben Z. Katz et al., *Chronic Fatigue Syndrome after Infectious Mononucleosis in Adolescents*, Pediatrics (July 2009), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2756827/>.

within a year;⁶ many of the survivors that failed to return to work experienced ME/CFS-like symptoms.⁷

The current pandemic may cause a drastic increase in the number of ME/CFS patients in the United States. There are more than one million confirmed cases of SARS-CoV-2 in America⁸, and the Centers for Disease Control and Prevention projects that 160 to 214 million Americans could be infected with SARS-CoV-2 before the pandemic is controlled.⁹ If COVID-19 follows the predicted pattern of the older SARS coronavirus, by this time next year as many as 408,000 to 3,570,000 Americans may become sick with ME/CFS-like symptoms.¹⁰ If COVID-19 behaves like Epstein-Barr, in two years the United States could see an additional 175,000 to 1,500,000 Americans chronically ill and possibly permanently disabled by ME/CFS.¹¹ **We have a well-founded fear that COVID-19 could increase the number of cases of ME/CFS in the United States by 250% within two years.** Congress must take the necessary steps to maximize the ability to properly diagnose and treat post-COVID-19 patients with ME/CFS-like symptoms.

Research shows that rapid diagnosis and appropriate treatment early in the course of ME/CFS (within one year of onset) can vastly improve outcomes for those affected by this debilitating disease.¹² To address this urgent crisis, we call for a supplemental NIH appropriation of \$15 million each year over the next four years to bolster and expand existing ME/CFS research initiatives, specifically, by funding the research opportunities outlined in the National Advisory Neurological Disorders and Stroke Council (NANDSC) Working Group report. We also call for report language accompanying the appropriation that encourages leaders to direct NIH to prioritize (1) new ME/CFS disease-specific funding announcements, including those with set-aside funds, to deliver needed diagnostics and treatments as quickly as possible, (2) an initiative to reach consensus on the ME/CFS case definition, and (3) mechanisms to incentivize

⁶ Herridge MS et al. *One-Year Outcomes In Survivors Of The Acute Respiratory Distress Syndrome*. N Engl J Med. (Feb. 20, 2003), <https://www.ncbi.nlm.nih.gov/pubmed/12594312>.

⁷ Harvey Moldofsky and John Patcai, *Chronic Widespread Musculoskeletal Pain, Fatigue, Depression and Disordered Sleep in Chronic Post-SARS Syndrome; A Case-Controlled Study*, BMC Neurology (Mar. 24, 2011), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3071317/>.

⁸ Ctrs. for Disease Control and Prevention, *Coronavirus Disease 2019 Cases in the US*, <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/cases-in-us.html> (last updated May 6, 2020).

⁹ Sheri Fink, *Worst-Case Estimates for U.S. Coronavirus Deaths*, N.Y. Times, (Mar. 13, 2020), <https://www.nytimes.com/2020/03/13/us/coronavirus-deaths-estimate.html>.

¹⁰ Steve Topple et al., *The Other Potential Coronavirus Catastrophe No One is Talking About, The Canary*, (Mar. 16, 2020), <https://www.thecanary.co/global/world-analysis/2020/03/15/the-other-potential-coronavirus-catastrophe-no-one-is-talking-about/>.

¹¹ *Id.*

¹² Taylor & Francis, *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome*, https://www.tandfonline.com/doi/abs/10.1300/J092v11n01_02

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researchers to enter the field.¹³ By taking these steps, the U.S. health care system will be better equipped to identify risk factors quickly, appropriately diagnose patients, and prevent the long-term disability of COVID-19 survivors.

NIH continues to play an essential role in our scientific understanding of ME/CFS, but there is still much work left to do. Strengthening the existing research infrastructure for ME/CFS will equip our nation with the resources necessary to improve the overall health of our nation moving forward.

We appreciate your leadership as Congress continues to respond to this public health emergency. Thank you for your attention to our request.

Sincerely,

¹³ Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriations Bill, 2020 Report of the Committee on Appropriations, H.R. 2740 Committee Report, <https://www.congress.gov/116/crpt/hrpt62/CRPT-116hrpt62.pdf>