

February 2, 2021

The Honorable Charles Schumer
Majority Leader
United States Senate
S-230, The Capitol
Washington, DC 20515

The Honorable Mitch McConnell
Minority Leader
United States Senate
S-221, The Capitol
Washington, DC 20515

The Honorable Nancy Pelosi
Majority Leader
U.S. House of Representatives
H-222, The Capitol
Washington, D.C. 20510

The Honorable Kevin McCarthy
Minority Leader
U.S. House of Representatives
H-204, The Capitol
Washington, D.C. 20510

Dear Leaders Schumer and McConnell, Pelosi and McCarthy:

Congratulations on the success of last month's COVID-19 Economic Relief package, providing urgent resources to millions of Americans. Our organizations especially wanted to thank you for vital investment in Long-term COVID-19 research at the National Institutes of Health. The \$1.15 billion provided in that package will form the backbone of the American scientific response to the next phase of the pandemic, addressing the "25 to 35% or more have lingering symptoms," according to Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases.ⁱ

These "lingering symptoms," also known as "post-acute COVID-19 syndrome" or "Long COVID," can become permanently disabling. These patients represent a secondary Long COVID pandemic of chronic illness and disability already impacting an estimated 3.2 million Americans. A recent study found that at 7 months after the onset of COVID-19, 67.5% of patients were unable to work or required a reduced work schedule.ⁱⁱ Experts in the field of post-viral illness are estimating that approximately "10% will be left with an illness that meets the NASEM case definition for myalgic encephalomyelitis (ME/CFS)... **Over the course of one year, that would at least double the number of Americans suffering from ME/CFS.**"ⁱⁱⁱ Currently, ME/CFS is estimated to cost the U.S. economy up to \$51 billion each year in lost productivity and medical costs.^{iv} *This predicted increase in the ME/CFS patient population could, therefore, potentially cost the US economy up to \$102 billion next year.* As you continue your life-saving work on a 2021 COVID relief package, I urge you to prioritize investments that will address and even prevent this impending Long COVID wave.

On December 4th, many in the ME/CFS community joined 20 other research, patient, and health organizations to provide recommendations regarding the 2020 COVID relief package. In addition to the \$1.15 billion investment your leadership has provided to NIH, this letter also recommended additional support for other government agencies and interagency collaboration. Long COVID epidemiology, medical education and patient care are key areas where the Centers for Disease Control and Prevention (CDC), Agency for Healthcare Research and Quality (AHRQ) and the Patient-Centered Outcomes Research Institute (PCORI) can play crucial roles. Below are Long COVID and post-viral disease recommendations from the ME/CFS community.

1. **CDC: Study Long COVID epidemiology, natural history and prevalence.** By rapidly providing funding and guidance to existing researchers in related disease fields (such as ME/CFS), the CDC can leverage existing infrastructure to find answers quickly about post-acute COVID-19 syndrome and related illnesses.
2. **CDC: Generate and Disseminate medical guidance about Long COVID to medical providers and front-line health professionals.** The CDC could improve health outcomes for millions of Americans by quickly disseminating medical guidance about diagnostics and appropriate care for Long COVID to medical providers

and front-line health professionals. We also encourage collaboration with ME/CFS disease experts and stakeholders as resources on potential complications from similar post-viral diseases and syndromes.

3. **PCORI: Facilitate Data Harmonization and Consolidate Patient Registry Resources.** Acting as a bridge for public-private partnerships, PCORI is uniquely placed to fund vital research infrastructure like data management centers, patient registries and biobanks and research key questions of health equity. These collaborative hubs should prioritize data regarding 1) symptoms and treatments for both acute COVID-19 patients and Long COVID patients, 2) longitudinal tracking of patient outcomes over time, 3) patient data related to healthcare and treatment access disaggregated by age, gender, race, ethnicity, and geography, and 4) matching control groups from related diseases.
4. **AHRQ: Conduct Long COVID Diagnostic and Treatment Efficacy Studies.** AHRQ has a key role to play in studying Long COVID healthcare delivery. Collaborating with stakeholders and utilizing data sets from PCORI (recommended above), AHRQ will play a key role in analyzing Long COVID health care delivery, potential disparities, and the efficacy of diagnostics and treatments from partner agencies.
5. **Long COVID Commission: Interagency Collaboration and Stakeholder Engagement.** In order for any of these initiatives, including those already funded at the NIH, to be successful, interagency collaboration is essential. Our community strongly recommends the creation of a Long COVID Commission or Advisory Committee to facilitate improved transparency, expert and stakeholder engagement, and streamline federal response to the Long COVID health crisis.

We appreciate your leadership as Congress continues to respond to this public health emergency. We fervently hope that you will implement and fully resource these recommendations in the upcoming 2021 COVID-19 relief package.

Thank you for your attention to our request.

Sincerely,



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President and Chief Executive Officer
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Founder & CEO/President
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Annette Whittemore
President and Chief Executive Officer
Whittemore Peterson Institute



Lori Kroger, RN
President and Founder
PandoraOrg



Minnesota ME/CFS Alliance



Florida ME/CFS Patient United



Massachusetts ME/CFS & FM Association

CC: Chairman Richard Shelby, Senate Appropriations Committee
Vice Chair Patrick Leahy, Senate Appropriations Committee
Chairwoman Rosa DeLauro, House Committee on Appropriations
Ranking Member Kay Granger, House Committee on Appropriations

ⁱ Strazewski, Len. *Dr. Fauci Offers 2021 Forecast on COVID-19 Vaccines, Treatments*, American Medical Association, 9 Nov. 2020, www.ama-assn.org/delivering-care/public-health/dr-fauci-offers-2021-forecast-covid-19-vaccines-treatments.

ⁱⁱ Komaroff, Anthony L., and Lucinda Bateman. "Will COVID-19 Lead to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?" *Frontiers*, Frontiers, 23 Dec. 2020, www.frontiersin.org/articles/10.3389/fmed.2020.606824/full

ⁱⁱⁱ [ibid](#)

^{iv} Jason, L.A., and Mirin A.A. "Updating the National Academy of Medicine ME/CFS prevalence and economic impact figures to account for population growth and inflation." *Fatigue: Biomedicine, Health & Behavior*, 28 Jan 2021, <https://doi.org/10.1080/21641846.2021.1878716>