

December 4, 2020

The Honorable Mitch McConnell
Majority Leader
United States Senate
S-230, The Capitol
Washington, DC 20515

The Honorable Charles Schumer
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 McConnell and Schumer, Pelosi, and McCarthy:

More than 13.9 million Americans have been infected with novel coronavirus. Some “25 to 35% or more have lingering symptoms,” according to Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases.ⁱ Doctors and researchers are already reporting large numbers of patients experiencing chronic post viral symptoms, presently called Long COVID. This is consistent with the experience of other viral outbreaks in the past that cause long-term morbidity beyond the initial acute disease, especially in women. A study of 38 US hospitals published earlier this year found that 66% of patients with acute respiratory distress syndrome experienced severe, disabling fatigue after 12 months.ⁱⁱ ***If this data trend continues, an estimated 3.2 million Americans will be temporarily or permanently disabled by post-COVID-19 symptoms over the next 12 months.***

We, the undersigned organizations, call upon you to urgently prioritize Long COVID and post-viral disease funding in future Congressional COVID-19 relief packages or appropriations agreements. It is imperative to immediately expand the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) programs to diagnose, study, track, and treat the lasting health impacts of COVID-19 and Long COVID. Given the similarities to known post viral chronic illnesses, we strongly encourage these Long COVID programs to coordinate with related disease experts, clinicians, and stakeholders; specifically Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), postural orthostatic tachycardia syndrome (POTS), other forms of dysautonomia, and mast cell activation syndrome (MCAS). These chronic illnesses, which are known to be associated with viral triggers, are more likely to occur in women and impact every race, age group, and socio-economic class.

Preliminary evidence suggests that a subset of COVID-19 survivors experience neurological and immunological complications as a result of their infection, even after the virus is no longer detectable. In fact, more than half of people who recover from and test negative for SARS-CoV-2 report ongoing symptoms, especially fatigue, more than 10 weeks later.ⁱⁱⁱ Severe Acute Respiratory Syndrome (SARS), which is highly similar to the novel coronavirus causing the current pandemic (SARS-CoV-2), led to persistent impaired health in many survivors, ***with 27% qualifying for a diagnosis of ME/CFS four years***

later.^{iv} Many of the survivors that failed to return to work experienced post-viral symptoms consistent with ME/CFS and Dysautonomia.^v Dr. Fauci has called the Long COVID symptoms, “highly suggestive” of ME/CFS.^{vi} Recently, the U.S. ME/CFS Clinicians Coalition issued an open letter to all medical providers stating:

Given the similarity in symptoms and the preceding infectious illness, we recommend that you consider a diagnosis of post-viral fatigue syndrome or ME/CFS (ICD-10 93.3) in the differential diagnosis of those patients who remain ill for an extended time following a COVID-19 infection and meet established ME/CFS criteria.^{vii}

In the coming months, leadership, coordination, and resources from the NIH and CDC will be absolutely critical to quickly accelerate post-viral research to meet the needs of a rapidly growing Long COVID patient population. There are four specific areas where NIH and CDC can act decisively now, if provided the appropriate resources from Congress:

- 1. Convene experts and stakeholders to establish data harmonization. (\$300,000 over 2 years)**
Lacking coordination and leadership, there is no standardized approach to this data collection. The private, academic, and citizen driven research utilize different criteria, resulting in divided and siloed research progress. Leadership, collaboration and standardized guidelines for Long COVID are urgently needed. It is essential that research data is disaggregated by sex and race to provide a more complete understanding of Long COVID and health disparities. NIH and CDC in collaboration with scientists, disease experts and clinicians can meet this need to accelerate research progress.
- 2. Expand existing post-viral disease research and case tracking. (\$60 million over 2 years)** By rapidly providing funding and guidance to existing researchers in related disease fields (such as ME/CFS, Dysautonomia, or MCAS), the NIH can leverage existing infrastructure to find answers quickly about COVID-19 and its lasting impacts. Specifically, the NIH can utilize supplemental grants to add COVID-19 and Long COVID patient cohorts to existing post-viral research initiatives, including clinical trials. The NIH can also expand its rapid response “shark tank” grant approval process to include Long COVID research. Additionally, the CDC can expand existing COVID-19 tracking efforts to include Long COVID and post viral disease symptoms.
- 3. Expand and Build Long COVID Collaborative Research Centers (CRCs) and Centers of Excellence (CoEs). (\$110 million over 2 years)** The NIH and CDC are uniquely positioned with resources and expertise to rapidly leverage the brightest and most experienced clinicians and researchers in related fields and bring them to bear on the Long COVID crisis. With the appropriate resources and leadership, NIH and CDC can jointly provide care, research, and critical testing grounds for future treatments in the form of CRCs and CoEs, especially in rural areas where expert care is not accessible.
- 4. Disseminate/Promote medical guidance about Long COVID to medical providers and front-line health professionals. (\$3.5 million over 2 years)** Working with disease experts and stakeholders

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from Long COVID, ME/CFS, dysautonomia and other post-viral disease communities, the CDC can disseminate medical guidance with updated and accurate information about Long COVID. Studies have found that many medical providers have not been accurately educated about post-viral chronic diseases, especially ME/CFS and dysautonomia, resulting in poor diagnostics and patient experiences. The CDC could improve health outcomes for millions of Americans by quickly disseminating medical guidance about diagnostics and care for Long COVID, including information about potential complications from post-viral diseases and syndromes.

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 upcoming appropriations legislation or a COVID-19 relief package before the end of the year.

Thank you for your attention to our request.

Sincerely,



Solve M.E.







The American Dysautonomia Institute (ADI)

CC: Chairman Richard Shelby, Senate Appropriations Committee
Vice Chair Patrick Leahy, Senate Appropriations Committee
Chairwoman Nita Lowey, House Committee on Appropriations
Vice Chair 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 Neufeld K.J, et al. *Fatigue Symptoms during the first year after ARDS*. *Chest*. (2020) S0012- 3692(20)30686-3. [https://journal.chestnet.org/article/S0012-3692\(20\)30686-3/pdf](https://journal.chestnet.org/article/S0012-3692(20)30686-3/pdf)

ⁱⁱⁱ Townsend L, Dyer AH, Jones K, Dunne J, Mooney A, Gaffney F, et al. (2020) *Persistent fatigue following SARS-CoV-2 infection is common and independent of severity of initial infection*. *PLoS ONE* 15(11): e0240784. <https://doi.org/10.1371/journal.pone.0240784>

^{iv} 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>.

^v 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/>.

^{vi} Tuller, David, and Steven Lubet. "Post-Covid Syndrome Prompts New Look at Chronic Fatigue Syndrome." *STAT*, 23 July 2020, www.statnews.com/2020/07/21/chronic-fatigue-syndrome-keys-understanding-post-covid-syndrome/

^{vii} US ME/CFS Clinician Coalition. (October 30, 2020). *US ME/CFS Clinician Coalition Letter: Post-COVID "Long Haulers" and ME/CFS [open letter to clinicians]*. *US ME/CFS Clinician Coalition*. Retrieved from https://drive.google.com/file/d/15Z1pPMsTvXKe_eJtNG3YxNXx9gB2xxU/view