



Solve M.E.

U.S. Senate Committee on Health, Education, Labor & Pensions
428 Dirksen Senate Office Building
Washington, DC 20510

November 3, 2021

Re: Please fully consider the scope and ramifications of Long COVID in extended pandemic response

Dear Senators:

On behalf of the Solve ME/CFS Initiative (Solve M.E.), I am writing to urgently call upon you to consider the full scope and ramifications of Long COVID as part of the upcoming hearing on Thursday, November 4, 2021, when the U.S. Senate Committee on Health, Education, Labor & Pensions discusses “The Road Ahead for the COVID-19 Response.”

Long COVID (also called Post Acute Sequelae of COVID-19- PASC) presents a potentially mass-disabling event and must be a central feature of any continued pandemic response. The WHO estimates that 10–20% of COVID-19 patients experience lingering symptomsⁱ. The UK Office for National Statisticsⁱⁱ is tracking the 1.7% of the population who are experiencing self-reported Long Covid, adversely affecting the day-to-day activities in two-thirds of them. This percentage would imply that there are currently 5-10 million Americans who are struggling with various degrees of disability, months after the initial infection. Experts say the condition is a major public health concern, given the substantial impact it has on society, ranging from increased health care costs to economic and productivity losses. A recent studyⁱⁱⁱ, tracking the health insurance records of nearly two million people in the United States who contracted the coronavirus in 2020, found that one month or more after their infection, almost one-quarter — 23 percent — of them sought medical treatment for new conditions.

Cases of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), one of these chronic post-viral conditions, are expected to double as a result of the pandemic^{iv}. Currently, ME/CFS is estimated to cost the U.S. economy up to \$51 billion each year in lost productivity and medical costs^v. This predicted increase in the ME/CFS patient population could, therefore, potentially cost the US economy up to \$102 billion next year. These growing patient populations represent a secondary wave of chronic illness, slow healing COVID-19 survivors, and long-term disability, which will disproportionately impact communities of color^{vi}.

With this knowledge driving us, we summarize below key recommendations from Long COVID and related disease patients, doctors, and leading scientists:

1. Fund research on treatments

Translating research into real improvements for patients takes time and significant investments. Accelerating “bench to bedside” results requires a simultaneous and multi-pronged approach. This process can be expedited by including existing disease experts, clinical care providers, and stakeholders from similar diseases in all Federal activities related to Long COVID. By leveraging existing infrastructure, research initiatives will prevent redundant work and will be better able to focus resources on innovative research. Neuroimmune clinical experts, chronic illness scientific knowledge, and related research infrastructure can be leveraged in a multitude of

ways, including diagnostics, treatments, comparison group data, patient engagement, and organizational structure. With the right investments, these existing tools will fast-track real outcomes and improvements for patients.

For example, H.R. 2754, the COVID-19 Longhaulers Act, would authorize funding for research and development of patient registries and biobanks to centralize and synthesize robust datasets regarding longitudinal outcomes of diverse symptoms and patient experiences. The bill would also expand the Chronic Conditions Data Warehouse research database to collect data on Long COVID treatment and service delivery. These datasets will prove key to identifying potential disparities, tracking and comparing patient outcomes over time, identifying risk/resiliency in diverse populations, and accelerating treatments to patients.

2. Expand medical care quality and capacity through medical education

The Federal response should continue to update and disseminate accurate medical guidance 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. By working with disease experts and stakeholders from Long COVID, ME/CFS, dysautonomia and other post-viral disease communities, information can be rapidly shared with medical providers and the public about common symptoms, treatment, and other post-viral illnesses related to PASC. Health outcomes for millions of Americans can be improved by providing medical guidance about diagnostics and care for Long COVID, including information about potential complications from post-viral diseases and syndromes.

3. Expand patient engagement and oversight through interagency coordination

For any of these initiatives to be successful, interagency collaboration and oversight are essential. We strongly recommend the creation of a Long COVID Commission or Advisory Committee to improve transparency, facilitate expert and stakeholder engagement, and streamline the federal response to the Long COVID health crisis. We encourage this body to create and maintain an inclusive dialogue with Long COVID patients, related disease patients, researchers, clinicians, and interagency partners.

Patient engagement and inclusion is increasingly seen as critical to public health program efficacy. However, early Long COVID projects have been stymied by limited transparency and little patient input in key decisions. It is essential to include patients voices at all stages of the research process, across all federal agencies working on Long COVID. Interagency coordination is needed to facilitate and promote inclusion, equity, transparency, and patient identified priorities.

I have attached additional Long COVID policy solutions compiled by Solve M.E. and other Long COVID disease experts, built upon the initial foundations of H.R. 2754, the COVID-19 Longhaulers Act. We urge the Committee to prioritize Long COVID in the upcoming hearing as a reflection of the historic threat to American health and productivity it represents. We appreciate your leadership as Congress continues to respond to this public health emergency.

Thank you for your attention to our request.

Sincerely,

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Encl (2)

ⁱ A clinical case definition of post COVID-19 condition by a Delphi consensus, 6 October 2021. (2021, October 6). World Health Organization. https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1

ⁱⁱ Office for National Statistics. (2021, October 7). *Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 7 October 2021*. Office for National Statistics. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/7october2021>

ⁱⁱⁱ FAIR Health, Inc. (2021, June 15). *A Detailed Study of Patients with Long-Haul COVID: An Analysis of Private Healthcare Claims*. <https://s3.amazonaws.com/media2.fairhealth.org/whitepaper/asset/A%20Detailed%20Study%20of%20Patients%20with%20Long-Haul%20COVID--An%20Analysis%20of%20Private%20Healthcare%20Claims--A%20FAIR%20Health%20White%20Paper.pdf>

^{iv} Komaroff Anthony L., Bateman Lucinda. Will COVID-19 Lead to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?. *Frontiers in Medicine*. 2021 Jan 7;1132. doi: [10.3389/fmed.2020.606824](https://doi.org/10.3389/fmed.2020.606824) ISSN=2296-858X

^v v 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>

^{vi} Artiga, S., Corallo, B., & Pham, O. (2020, August 17). *Racial Disparities in COVID-19: Key Findings from Available Data and Analysis*. *Kaiser Family Foundation*. <https://www.kff.org/racial-equity-and-health-policy/issue-brief/racial-disparities-covid-19-key-findings-available-data-analysis/>