



Solve M.E.

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

December 2, 2021

Re: Long COVID in extended pandemic response

Dear Senators:

On behalf of the Solve ME/CFS Initiative (Solve M.E.) and the undersigned partners, I am writing to urgently call upon you to consider the full scope and ramifications of Long COVID as part of the national COVID-19 pandemic response. This critical public health crisis was noticeably absent from the discussion on Thursday, November 4, 2021, when the U.S. Senate Committee on Health, Education, Labor & Pensions discussed “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. More recent estimates range from **31% to 67% of patients experience PASC at 6 or more months** after contracting SARS-CoV-2ⁱⁱ. The UK Office for National Statisticsⁱⁱⁱ is tracking the 1.9% of the population who are experiencing self-reported Long Covid, adversely affecting the day-to-day activities in two-thirds of them.

Collectively, these reports imply there are **currently between 5 – 14.6 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 and devastating loss to quality of life. A recent study^{iv}, 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 of them sought medical treatment for new conditions.

Additionally, **COVID-19 can trigger myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), in 46% of Long COVID patients^v and 13% of hospitalized patients^{vi}**. Cases of ME/CFS are expected to double as a result of the pandemic^{vii}. Currently, ME/CFS is estimated to cost the U.S. economy up to \$51 billion each year in lost productivity and medical costs^{viii}. This predicted increase in the ME/CFS patient population could, therefore, **potentially cost the US economy up to \$102 billion next year**. This is just one example of these growing patient populations who represent a secondary wave of chronic illness, slow healing COVID-19 survivors, and long-term disability, which will disproportionately impact communities of color^{ix}.

Driven by this sobering realization, we summarize below key recommendations from Long COVID and related disease patients, doctors, and leading experts:

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 and autonomic clinical experts, chronic illness scientific knowledge, and related research infrastructure can be leveraged in a multitude of ways to accelerate 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. Significant public-private investments, like “Operation Warp Speed” which successfully delivered rapid vaccine development, are critical mechanisms to address a critical public health crisis like Long COVID.

In the House of Representatives, key policy solutions such as the 21st Century Cures Act 2.0 would authorize funding for research and education programs to improve outcomes for patients with diverse symptoms and experiences. Additionally, ARPA-H could prove a critical agency in addressing these complex post-acute infection challenges.

2. Expand medical care quality and capacity through medical education

Federal agencies 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.

H.R. 2754, the COVID-19 Long Haulers Act addresses these knowledge gaps and would 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.

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 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.

We urge the Committee to prioritize Long COVID in future hearings and policy discussions 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,



Oved Amitay
President and CEO
Solve M.E.
OAmitay@solvecfs.org

In partnership with:

COVID-19 Longhauler Advocacy Project

American Academy of Physical Medicine & Rehabilitation

Megan Carmilani, Founder, Long Covid Families

John Wylam, President, Pandemic Patients

Courtney Miller, Board President, Simmaron Research Foundation

Ben HsuBorger, U.S. Advocacy Director, #MEAction

Miranda Erlanson, Founder, COVID Survivors From Texas

Lisa O'Brien, Founder, Utah Covid-19 Long haulers

Susan Buckley, Board Member, Massachusetts ME/CFS & FM Association

John Kelty, State chairperson, #MEAction Colorado

Jonah McGarva, Co-Founder & Director, Long Covid Canada

Ms. Coral Bohne, AK

Ms. Sallie Rediske, AK

Mr. Scott Johnson, AZ

Ms. Lisa Geiszler, CA

Dr. Arthur Mirin, CA

Cathleen Ballesteros, CA

Karman Kregloe, CA

Ms. Julie L. Ziegler, CA

Sharon Park, CA

Mr. Pavaman, CA
Keiko Ito, CA
Ms. Tommie Kestrel, CA
Christine Jamieson, Washington DC
Lisa Bryan, FL
Charlene Cintron, FL
Leon Pogorelis, FL
Victoria Beltz, FL
Catherine Milon, GA
Renee, GA
Michelle Winer, PT, GA
Ms. Kristin Krathwohl, IL
Dr. Sarah Raskin, IN
Ms. Tonia Stapleton, IN
Ms. Janis Ford, MA
Ms. Carrie L. Richards, MA
Mrs. Diane Reimer Bean, MD
Melinda Lipscomb, MD
William Hanlon, MN
Virginia Alexander, ND
Rinji Lizardo, NJ
Mr. Mike Heidenberg, NY
Dr. Meredith Cricco, NY
Mr. Joseph Noody, NY
Ms. Georgia Christenson, NY
Mr. Jeff Diver, NY
Sylvia Grummitt, NY
Adrienne Murphy, OH
Diane Goodman, RN, OH
Dr. Alexis N. Misko, OH
Mrs. Laurie Bedell, PA
Mama. Erica Hayes, PA
Mrs. Suzanne Foster Tobleman, TX
Liza Fisher, TX
Dr. Danielle Keifert, TX
Lori England, VA
Ms. Catherine Romatowski, VA
Mrs. Lesley Shackett, VA
Ms. Suzanne Romatowski, VA
Mr. Peter Romatowski, VA
Miss Sarah Jean Orgeles, WA
Ms. Kate Holden, WA
Ruth Prohaska, WA

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