



Solve M.E.

July 21, 2022

The Honorable James E. Clyburn
Chairman
Select Subcommittee on the Coronavirus Crisis
2157 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Steve Scalise
Ranking Member
Select Subcommittee on the Coronavirus Crisis
2157 Rayburn House Office Building
Washington, D.C. 20515

Dear Chairman Clyburn and Ranking Member Scalise:

With deepest gratitude and on behalf of Solve M.E., I write to thank the Select Subcommittee and offer important additional resources, relevant to the exceptional and timely hearing on June 19, "Understanding and Addressing Long COVID And Its Health and Economic Consequences." As the most recent BA.5 variant of SARS-CoV-2 infects and reinfects millions of Americans, our leadership must be ready to face increasing numbers of Long COVID, post-acute sequela of COVID-19 (PASC) and associated conditions like Myalgic Encephalomyelitis/chronic fatigue syndrome (ME/CFS), postural orthostatic tachycardia syndrome (POTS) and other forms of dysautonomia.

To provide further insight into the economic impact of Long COVID, PASC, and associated conditions, we invite the Select Subcommittee and its staff to review the findings of our Solve Long COVID Initiative recent whitepaper, "[Long Covid Impact on Adult Americans: Early Indicators Estimating Prevalence and Cost](#)" published on April 5, 2022. In addition to confirming the figures of cost and prevalence presented by other witnesses in their testimony at the hearing, this paper further provides state-by-state cost and prevalence estimates and, most importantly, applies this data as a function of Labor Force Participation Rates (LFPR). These mathematical models provide a critical map of states and regions where Long COVID disability is causing the most economic challenges. We further calculate the share of economic cost per labor force participant, with notable findings highlighted in the section below:

"For the tightest metric, Disabling Long Covid figures taken from the Reported Case Model, the national average is \$2,417, but within that Maine's share per participant, \$1,388, is just 57% of the national average, and Oregon's 62%. The shares in five states running above \$3,000.00, Alaska, Arkansas, Mississippi, Rhode Island and South Carolina, run from 124% to 132% of the national average. These calculations illustrate the disproportionate economic burdens different states will carry in the coming years."

Since 1987, Solve M.E. has served as a catalyst for critical research into diagnostics, treatments, and cures for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), Long Covid and other post-infection diseases. Our work with the scientific, medical, and pharmaceutical communities, advocacy with government agencies, and alliances with patient groups around the world are laying the foundation for breakthroughs that can improve the lives of millions who suffer from various "long haul" diseases. Ms. Cynthia Adinig serves as a member of the board of directors of Solve M.E. and her testimony called for the passage of the bipartisan COVID-19 Longhaulers Act, a position we proudly share. We are also proud to collaborate with the Patient-Led Research Collaborative,

the AAPM&R, and over 1,000 other members of the Long COVID Alliance, which we co-founded in 2021. We echo and support the eight immediate actions presented in the testimony of Hannah Davis.

Additionally, we'd like to urge the Subcommittee to prioritize legislative solutions that catalyze public-private partnerships, especially those including decision-making shared with patient community and research infrastructure, such as patient registries. Patient involvement is critical, as was demonstrated by the pivotal research initiated and conducted by patients themselves, which was cited during witness testimony. Replicating the immense success of public-private partnerships in vaccine development, such as Operation Warp Speed, is key to a successful policy addressing Long COVID. To facilitate these collaborations, interagency coordination with stakeholders and industry will be critical; we further encourage the Subcommittee to explore a post-viral illness federal advisory committee.

Please consider our research efforts as a resource to your offices and committee staff as you continue to legislative urgent and innovative policy solutions. Long COVID, PASC, and associated conditions must be considered at every level of the pandemic response in order to mitigate the economic loss and human suffering of this mass disabling event.

Sincerely,

A handwritten signature in black ink that reads "Oved Amitay". The signature is written in a cursive, flowing style.

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