United States Senate

May 14, 2024

Chair Tammy Baldwin Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education Washington, DC 20515 Ranking Member Shelley Moore Capito Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education Washington, DC 20515

Dear Chair Baldwin and Ranking Member

Capito:

As the Committee considers the Fiscal Year (FY) 2025 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill, it is imperative Congress take into account the urgent needs of patients experiencing Post-Acute Sequelae of SARS CoV-2 infection (PASC), commonly referred to as Long COVID. We write to request a total of \$1.22 billion to support national Long COVID research, consisting of the following:

- \$1 billion in FY25 funding to the National Institutes of Health Office of the Director to support Long COVID research initiatives outside of the RECOVER Initiative, focusing on accelerating drug trials, discovery of biomarkers and therapeutics, and research that includes Long COVID associated conditions, such as dysautonomia, postural orthostatic tachycardia syndrome (POTS), and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS);
- \$200 million in FY25 funding to ARPA-H for Long COVID research to ensure high-risk, high-reward research specifically focused on drug trials, development of biomarkers, and research that includes Long COVID associated conditions, such as dysautonomia, postural orthostatic tachycardia syndrome (POTS), and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS);
- **\$20 million** in FY25 funding to the Office of Long COVID Research and Practice (OLCRP), located within OASH, to ensure effective coordination across agencies, conduct public-private sector convenings, issue reports, foster clinician education, hold workshops, and accelerate the U.S. Government response across 14 federal agencies.
- \$13.5 million in FY25 to the Agency for Healthcare Research and Quality to continue its work on dissemination of best practices in caring for those living with Long COVID.

Long COVID desperately needs federal attention, resources, and funding. Medical experts continue to document the extensive damage and long-term impacts of Long COVID,¹ with the CDC confirming COVID- 19 and Long COVID can impair numerous organs, including the

¹ Davis, H.E., McCorkell, L., Vogel, J.M. *et al.* Long COVID: major findings, mechanisms and recommendations. *Nat Rev Microbiol* 21, 133–146 (2023), https://doi.org/10.1038/s41579-022-00846-2.

heart, lungs, skin, kidneys, and brain.² Research also suggests symptoms of Long COVID are similar to other chronic conditions associated with viral triggers, like dysautonomia, postural orthostatic tachycardia syndrome (POTS), and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), among others.³

For millions of Americans, the long-term impact of COVID-19 has been debilitating, disabling, or caused irreversible damage to their mental and physical health, months or even years after their initial infection. According to the U.S. Census Bureau Household Pulse Survey, as of March 2024, roughly 17 million people-or 7% of all American adults-report currently having Long COVID.⁴ This is comparable to the number of Americans with cancer, and fast approaching the 20 million U.S. adults facing coronary artery disease. Congress must take into consideration this growing disease burden, and its tremendous potential for economic strain due to a decrease in labor force participation in nearly every employment sector including our health care systems.

We urge the committee to provide these critical funds to support Long COVID research to help this nation recover from the COVID-19 pandemic and prepare for future pandemics. Thank you for taking these recommendations into consideration and we look forward to working closely in coordination with the committee to support those experiencing the effects of Long COVID.

Sincerely,

Edward J. Markey United States Senator

Tim Kaine

United States Senator

Tamm Duckworth United States Senator

Cory A. Booker United States Senator

Sheldon Whitehouse United States Senator

² Centers for Disease Control and Prevention, Long COVID or Post-COVID Conditions, Multiorgan Effects of COVID-19 (March. 14, 2024), https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html.

³ Solve M.E., Long Covid, https://solvecfs.org/me-cfs-long-covid/covid/long-term-covid-19/ (last accessed May 10, 2022).

⁴ National Center for Health Statistics. U.S. Census Bureau, Household Pulse Survey, 2022–2024. Long COVID. Generated interactively: from https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm.

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