

United States Senate

May 25, 2022

The Honorable Patty Murray
Chair
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
Washington, DC 20510

The Honorable Roy Blunt
Ranking Member
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
Washington, DC 20510

Dear Chair Murray and Ranking Member Blunt:

As the Committee considers the Fiscal Year (FY) 2023 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 \$125 million to support national long COVID research and patient support, consisting of the following:

- **\$25 million** in FY23 funding to support the Centers for Disease Control and Prevention (CDC) to monitor and track incidence of long COVID among children and adults, including developing a patient registry for long COVID;
- **\$25 million** in FY23 funding to support long COVID research initiatives by the National Institutes of Health;
- **\$5 million** in FY23 funding to support the National Institute on Minority Health and Health Disparities efforts to study the prevalence of racial and ethnic disparities in the diagnosis, treatment, recovery, and quality of life of long COVID patients;
- **\$30 million** in FY23 funding to support the Department of Health and Human Services (HHS) to conduct community and provider outreach initiatives related to long COVID, which includes not less than **\$10 million** in FY23 funding to the Agency for Healthcare Research and Quality (AHRQ) to support translational research related to long COVID;
- **\$20 million** in F23 funding at the Department of HHS to support increasing the availability of legal assistance and social supports to individuals with long COVID who seek assistance in obtaining disability benefits, health care coverage, and other forms of government aid; and
- **\$20 million** in FY23 funding to support multidisciplinary long COVID clinics, also known as centers of excellence, to create or enhance capacity to treat patients with long COVID.

Long COVID desperately needs federal attention, resources, and funding. While medical experts are still learning more about the long-term impacts of COVID, the CDC has confirmed COVID-19 and long COVID can impair numerous organs, including the heart, lungs, skin, kidneys, and brain.¹ Research also suggests symptoms of long COVID are similar to other chronic conditions

¹ Centers for Disease Control and Prevention, *Post-COVID Conditions, Multiorgan Effects of COVID-19* (Sept. 16, 2021), <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>.

associated with viral triggers, like dysautonomia, postural orthostatic tachycardia syndrome (POTS), and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), among others.²

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. Researchers estimate that as many as 30 percent of people who get COVID-19 experience long COVID symptoms, leaving millions of Americans at risk.³ Congress must take into consideration the tremendous potential for economic strain due to a decrease in labor force participation in nearly every employment sector, but particularly our health care system.

We urge the committee appropriate \$25 million in FY23 to fund a CDC health surveillance initiative to help capture a comprehensive picture of long COVID's impact across the country. Congress has an obligation to support the CDC in their efforts to monitor the prevalence of lingering health issues post-COVID infection and implement real-time mitigation efforts to address public health crises.

The proposed \$25 million in FY23 NIH appropriations would help bolster ongoing long COVID research studies, including the RECOVER Initiative, to identify the causes, means of prevention, and treatment of individuals who have been sickened by COVID-19. Millions of long COVID patients have been grappling with new, long-term health issues at least two years following an infection. The research gathered would enable lawmakers and health officials to better understand the full scope and scale of this new chronic disease. Data-driven policies must be developed in relation to the new scientific discoveries related to long COVID.

A \$5 million appropriation for NIMH would focus specifically on studying racial and gender equity in long COVID treatment and recovery. Research shows that patients of color are less likely to receive effective care than whites,⁴ leaving patients of color particularly vulnerable to medical discrimination and neglect. Structural barriers to medical care further prevent patients of color from accessing life-saving diagnoses and treatment. Efforts to address long COVID should proactively seek to account for these inequities at the formation of these national medical research projects.

An appropriations of \$30 million in funding for HHS to implement long COVID community and provider outreach initiatives would significantly increase public awareness of this disease and help connect patients, providers, and advocates in the fight against long COVID. This funding would include support for translational research at the AHRQ that works to ensure that providers are equipped with the most information on long COVID.

²Solve M.E., *Long Covid*, <https://solvecfs.org/me-cfs-long-covid/covid/long-term-covid-19/> (last accessed May 10, 2022).

³Jennifer K. Logue et al., *Sequelae in Adults at 6 Months After COVID-19 Infection*, JAMA Network Open (Feb. 19, 2021), <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2776560>.

⁴Aaron E. Carroll, *Doctors and Racial Bias: Still a Long Way to Go*, N.Y. Times (Feb. 25, 2019), <https://www.nytimes.com/2019/02/25/upshot/doctors-and-racial-bias-still-a-long-way-to-go.html>.

The proposed \$20 million in FY23 funding for HHS to increase support for legal and social services would ensure that individuals living with long COVID have access to local, state, and federal assistance to help navigate a complex web of supports.

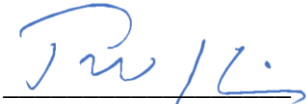
Finally, the \$20 million in FY23 funding for centers of excellence will ensure that those with long COVID have access to wrap-around care that minimizes the barriers to accessing quality treatment.

We urge the committee to provide these critical funds to support long COVID research to help this nation recover from the COVID-19 pandemic. 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



Tammy Duckworth
United States Senator



Tina Smith
United States Senator

/s/

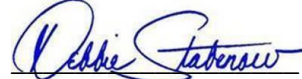
Angus King Jr.
United States Senator



Sheldon Whitehouse
United States Senator



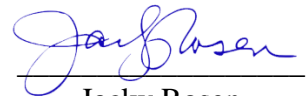
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