PATIENT-LED RESEARCH COLLABORATIVE

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FY 2024 HHS Budget Request
Research on Long COVID and Associated Conditions (LCAC)

U.S. House of Representatives
Committee on Appropriations
Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies

Mr. Chairman, Ranking Member DeLauro, members of the subcommittee, I appreciate this opportunity to provide this testimony on behalf of the Patient-Led Research Collaborative and to share a number of observations regarding FY 2024 funding requests related to Long COVID and Associated Conditions (LCAC).

I imagine all of you are already aware of the scale of the challenge posed by Long COVID. The most recent CDC findings indicate that nearly 30% of people with a COVID-19 infection experience Long COVID and that nearly one in five people with it are forced to severely limit their daily activities because their symptoms are so debilitating.[1] Recent studies place the economic cost of Long COVID at $3.7 trillion, with up to four million people being kept out of the workforce because of it.[2]

The Patient-Led Research Collaborative is a group of Long COVID patients who are also researchers. In addition to having intimate, first-hand knowledge of COVID-19,

[1] Centers for Disease Control and Prevention, National Center for Health Statistics, Household Pulse Survey: Long COVID, https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm.
[2]National Institute for Health Care Management, “Long COVID: New Research and the Economic Toll,” December 15, 2022, Presentation by Dr. David Cutler (Harvard) and Katie Bach (Brookings), https://nihcm.org/publications/long-covid-new-research-and-the-economic-toll?utm_source=NIHCM+Foundation&utm_campaign=11bb1854d4-121522_long_COVID_archivemailing&utm_medium=email&utm_term=0_6f88de9846-11bb1854d4-360270612.

PLRC members bring expertise from a range of fields, including biomedical research, cognitive and neuroscience, public policy, machine learning, human-centered design, health activism, and public and stakeholder engagement.

Over the past three years, our work on Long COVID has led to 11 articles in major journals, including the recent comprehensive review published in *Nature Reviews Microbiology* in January,[3] and our co-founders have testified on Long COVID before subcommittees of the House Committees on Energy and Commerce and Oversight, respectively.

Addressing Long COVID first and foremost requires understanding its many precedents as an infection-associated illness. Infection-associated illnesses are not a new phenomenon, but they have been neglected for decades in research and provider education. These conditions include ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome), MCAS (mast cell activation syndrome), and dysautonomia, which itself includes such conditions as POTS (postural orthostatic tachycardia syndrome) and orthostatic hypotension. A majority of people with Long COVID experience one or more of these associated conditions.[4,5]

These conditions are often chronic and disabling. Consider ME/CFS, which affects an estimated 50% of Long COVID patients. [Include footnote for stat?] It is considered one of medicine's most neglected diseases, and it inflicts patients with profound and unrelenting fatigue, cognitive dysfunction, sleep abnormalities, dysautonomia, pain, and

[3]Davis et al, *Long COVID: major findings, mechanisms, and recommendations*, Nature Reviews Microbiology, January 13, 2023, https://www.nature.com/articles/s41579-022-00846-2
[4] Twomey, R. et al. Chronic fatigue and postexertional malaise in people living with Long COVID: an observational study. Phys. Ther. 102, pzac005 (2022).
[5] Larsen, N. W. et al. Characterization of autonomic symptom burden in long COVID: a global survey of 2,314 adults. Front. Neurol. 13, 1012668 (2022).

other symptoms that are made worse by exertion of any sort. Up to 75% of people with ME/CFS cannot work full-time, and 25% have severe ME/CFS, which often means they are bed-bound, have extreme sensitivity to sensory input, and are dependent on others for care.[6]

A number of HHS agencies are rightly supporting research and services related to LCAC in their requests for FY 2024:

- The Health Research and Services Administration is proposing a new $130 million initiative to provide integrated specialty care to Long COVID patients and to provide training and capacity building for providers.
- The Centers for Disease Control and Prevention is requesting an additional $25 million for the study of Long COVID conditions.
- The Agency for Healthcare Research and Quality is requesting $19 million, an increase of $9 million, to expand accessibility to multidisciplinary Long COVID clinics and to support the primary care community in caring for Long COVID patients.

These requests are all vitally needed, and we encourage the committee to support them and expand them beyond the requested levels if possible.

For the LCAC community, however, a paramount concern is that the National Institutes of Health has requested no new funding for FY 2024 for research related to LCAC. You may know that until now, NIH's research on LCAC, notably the RECOVER Initiative[7], has been supported with funds provided by Congress in December 2020 through the

[6]See Davis et al., above.
[7] RECOVER: Researching COVID to Enhance Recovery, https://recovercovid.org/.

Coronavirus Response and Relief Supplemental Appropriations Act (P.L. 116-260). The $1.15 billion provided then has covered RECOVER's efforts to date.

Starting last summer, NIH officials signaled in public statements that RECOVER needed additional funding, and in November, the Administration sought an additional $750 million in the emergency supplemental package it submitted.[8] Those funds unfortunately were not provided, leaving the funding situation unresolved.

It is therefore surprising, perplexing, and frustrating to everyone dealing with LCAC that NIH's FY 2024 budget request does *not* request any additional funding for RECOVER or for any Long COVID research throughout the Institutes. Again, after requesting $750 million *as an emergency supplemental* in November, the agency is now requesting *no new funding*. NIH has not shared what happened between November and March to spur such a dramatic change in the agency's thinking. Long Covid patients, however, are painfully aware that no treatments for the condition have been developed to date.

We hope that this subcommittee can engage NIH and have them explain their actions and shed light on this confounding and concerning situation.

In addition, other aspects of NIH's stewardship of this research have displayed a similar lack of transparency. Patients have engaged with NIH and its awardees over the course of the Initiative, and we have a number of concerns that we believe warrant the subcommittee's attention.

- **Lack of centralized leadership and coordination.** We find it puzzling that an effort of this scale – in both dollars and participants – and of such national importance has

[8] Meredith Wadman, Science, *Long Covid is a 'national crisis.' So why are grants taking so long to get?,* Science**,** June 10, 2022,

no single point of accountability and has no defined presence in the NIH Office of the Director. Leadership of RECOVER is spread across three institutes, with oversight provided by an Executive Committee that also includes the heads of two additional NIH centers plus over a dozen other officials. Patient representatives have become frustrated by the lack of clear lines of authority and accountability. An office within the NIH Office of the Director that coordinates research into all of NIH's research into Long COVID and associated conditions would push the field forward faster and be more accountable to the public.

- **Disregard of Patient Input.** Patient representatives have been included in planning and oversight activities at multiple levels of the initiative, but in many cases input from patient representatives has been dismissed or ignored. NIH is pursuing studies and interventions that we expect will prove harmful to patients and will not yield useful results for addressing fundamental aspects of Long COVID.

In closing, let me once again thank the Committee for this opportunity to share a few observations on how best to advance research on LCAC. We hope you can help NIH develop a more sustainable and productive path forward for RECOVER and also expand its efforts to address infection-associated illnesses more broadly. We know that the number of people experiencing the debilitating symptoms of Long COVID and these associated conditions runs well into the millions, and the impact on our economy is growing as we speak.

I hope you, as you review the budget requests for FY 2024, will support HHS's efforts to address LCAC and that you will ensure that the patient voice is heard in these efforts.