FY25 Written Public Testimony for the Record
House Appropriations Committee
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

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My name is Lisa McCorkell, and I am a resident of Oakland, California, a co-founder of the Patient-Led Research Collaborative, and a person living with Long COVID since March 2020. I write in support of the following appropriations for FY25:

- At least $1 billion to the National Institutes of Health (NIH) for Long COVID research
- $200 million to the Advanced Research Projects Agency for Health (ARPA-H) for Long COVID research
- $20 million to the Health and Human Services (HHS) Office of Long COVID Research and Practice for coordination across the US government
- $13.5 million to the Agency for Healthcare Research and Quality (AHRQ) for continuation of its network of Centers of Excellence
- $167.5 million to the Health Resources and Services Administration (HRSA) for Long COVID clinics

Long COVID is an infection-associated chronic condition that occurs after a COVID-19 infection. As of April 2024, at least 6.9% of American adults and millions more children[1] were experiencing Long COVID, with about one-quarter of people with Long COVID experiencing significant activity limitations.[2] Long COVID impacts all demographics, with transgender people, women, and Hispanic/Latino populations being disproportionately impacted.[3] Vaccination does not meaningfully protect against Long COVID,[4] and reinfection increases one's risk of developing it.[5] Of patients sick with Long COVID at 2 months, only 15% were in remission at one year, with one-third of those in remission relapsing later on.[6] People with Long COVID are significantly more likely to experience housing[7] and food insecurity,[8] and economic costs to the US economy are in the trillions of dollars over just the next few years.[9] Because overlapping conditions like myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), postural orthostatic tachycardia syndrome (POTS) and other forms of dysautonomia, and mast cell activation disorders have not received adequate research funding and are not often taught in medical schools, patients face a medical system where only 7% of physicians are very confident diagnosing Long COVID and only 4% are very confident treating it.[10]

Despite the scale of the crisis, there are no annual line items in the NIH budget to facilitate research on Long COVID. The Congressional appropriation provided in FY 2021 that led to the Researching COVID to Enhance Recovery (RECOVER) Initiative is nearly depleted. While an additional $515 million was provided by HHS for RECOVER in 2024, those funds are largely intended to continue the observational cohort for four additional years.

Furthermore, while the observational cohort that RECOVER has established could prove to be useful long-term, the highest priority currently is for significantly more investment into clinical trials and pathobiology studies in order to have a chance at meaningfully improving patient outcomes in the next several years.

In an October 2023 *Nature* comment, Dr. Michael Peluso and I called for a "moonshot for Long COVID" - an annual investment of at least $1 billion to the NIH for research on Long COVID.[11] This funding should be provided outside of the RECOVER Initiative, and focused on accelerating drug trials, biomarker discovery, pathobiology research, and research across infection-associated chronic conditions like POTS and ME/CFS. Currently there are only 12 interventional clinical trials listed on ClinicalTrials.gov that are known to be funded by NIH.[12] For a condition as complex as Long COVID with over 200 symptoms, several phenotypes, and dozens of comorbidities, we need to be seeing closer to 50-100 NIH-funded clinical trials per year. Dozens of pharmaceuticals already on the market can be repurposed that are worthy of trialing, whether due to their relation to potential mechanisms of Long COVID or having seen some success in improving outcomes by patients with Long COVID or other infection-associated chronic conditions. Industry is ready to participate - they just need the funding to do so and guidance from FDA. An investment of at least $1 billion per year would also help build the field of infection-associated chronic conditions because scientists would be able to count on this as a career; building the field now will now only help people who currently have Long COVID or other infection-associated chronic conditions, but will also help prepare us for future pandemics.

In addition to a moonshot based at NIH, the high-risk, high-reward research that ARPA-H leads is also essential to addressing this challenge. We recommend providing $200 million to ARPA-H, to fund approximately four portfolios that could lead to significant innovation on biomarkers and therapeutics.

Our community is very supportive of HHS's Office of Long COVID Research and Practice in its vital work coordinating the Long COVID response across US government agencies. The Office currently, however, has only minimal staff and resources. Providing $20 million per year would enable the office to add staff, ensure effective coordination across HHS, convene stakeholders, conduct public and clinician education, and elevate the nation's ability to respond to Long COVID and to future pandemics.

AHRQ has established the Long COVID Care Network which provides grants to Centers of Excellence to expand access to care for people with Long COVID and to implement new care delivery models and evaluate its effectiveness. The Centers are multidisciplinary Long COVID clinics across the US providing clinical care and Long COVID education. The Network's goal is to foster and replicate best practices for Long COVID care across Centers and for all healthcare workers. As an External Contributor to the Network, I have seen firsthand the

value of the Network and Centers, and how important it will be for improving patient outcomes.

Significant resources must be dedicated to expanding clinical care access, particularly for underserved, rural, and vulnerable populations who are disproportionately impacted by Long COVID. $167.5 million would enable HRSA to leverage other biomedical and care delivery research investments to ensure high-quality care is provided to all people with Long COVID. While treatment options are limited, having access to this care now can help with access to disability benefits, safety net programs, work accommodations, and potentially some symptom management, while also establishing healthcare relationships and infrastructure to ensure quick access to better treatments once they are available.

In December 2023, Patient-Led Research Collaborative led a letter to President Biden that was signed by over 1000 clinicians, researchers, patients, and allies.[13] This letter asked President Biden to include a response to Long COVID and other infection-associated chronic conditions in budgets across the federal government - for biomedical research and clinical trials, to improve access to social safety net programs, to address social determinants of health, for healthcare provider education, for healthcare delivery research, for equitable access to high-quality care, for public health education, for home- and community-based care, and for prevention efforts. President Biden did not answer this call. The House of Representatives now has the opportunity to correct his wrong and show that people with Long COVID are valued constituents. Failure to adequately address Long COVID will result in significant economic, health, quality of life, and societal costs in the trillions of dollars. Our lives and livelihoods are at stake. Please respond accordingly.

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[11] McCorkell L, Peluso MJ. Long COVID research risks losing momentum - we need a moonshot. Nature. 2023 Oct;622(7983):457-460. doi: 10.1038/d41586-023-03225-w. PMID: 37853144.

[12] See https://longcovidstudies.net/

[13] Patient-Led Research Collaborative. Address the Crisis of Long COVID and Other Infection-Associated Chronic Conditions in FY25 Budget. 2023. Available at https://patientresearchcovid19.com/advocacy/letter-to-president-biden-fy25-budget/