

**FY25 Written Public Testimony for the Record**

**House Appropriations Committee**

**Subcommittee on Agriculture, Rural Development, Food and Drug Administration, and**

**Related Agencies**

Lisa McCorkell, MPP

Co-Founder, Patient-Led Research Collaborative

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 to encourage the Committee to provide guidance to the Food and Drug Administration that will elevate and strengthen efforts to identify treatments for Long COVID.

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<sup>1</sup> were experiencing Long COVID, with about one-quarter of people with Long COVID experiencing significant activity limitations.<sup>2</sup> Long COVID impacts all demographics, with transgender people, women, and Hispanic/Latino populations being disproportionately impacted.<sup>3</sup> Vaccination does not meaningfully protect against Long COVID,<sup>4</sup> and reinfection increases one's risk of developing it.<sup>5</sup> 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.<sup>6</sup> People with Long COVID are significantly more likely to experience housing<sup>7</sup> and food insecurity,<sup>8</sup> and economic costs to the US economy are in the trillions of dollars over just the next few years.<sup>9</sup> 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.<sup>10</sup> There are no FDA-approved treatments for Long COVID, and patients who have access to high-quality healthcare are generally trying dozens of repurposed drugs and supplements and often face difficulty getting insurance to cover these.

We first encourage the Committee to support efforts at the FDA that focus on the potential efficacy of repurposed pharmaceuticals as treatments for Long COVID. In particular, we believe the FDA should be directed to continue supporting the CURE ID platform. The platform provides a robust and highly effective mechanism for gathering information from patients and healthcare providers on their real-world experiences treating Long COVID with repurposed drugs.

Our second recommendation focuses on the development of guidance for Long COVID clinical trials. There are significant challenges in constructing clinical trials for conditions like Long COVID that are multisystemic, have several phenotypes, and do not have biomarkers. Drug trials use different endpoints and inclusion/exclusion criteria. We hope the Committee can urge the FDA to issue guidance on Long COVID trials that bring cohesion to the field. Such guidance should be informed by meaningful engagement of relevant stakeholders including Long COVID and infection-associated chronic conditions patient organizations, researchers, and treating physicians. Additionally, we hope the Committee will support Long COVID being designated as a priority area of recruitment for the FDA Patient Representative Program.

It is clear that dozens of pharmaceuticals already on the market that can be repurposed are worthy of trialing, either because of their relation to potential mechanisms of Long COVID or because of already having seen some success in improving outcomes by patients with Long COVID or other infection-associated chronic conditions. Greater attention from

the FDA will only help people who currently have Long COVID or other infection-associated chronic conditions, and it will also help prepare for future pandemics.

In December 2023, Patient-Led Research Collaborative led a letter to President Biden that was signed by over 1000 clinicians, researchers, patients, and allies.<sup>11</sup> 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. The above simple report language could go a long way in ensuring better outcomes for people with Long COVID. Our lives and livelihoods are at stake. Please respond accordingly.

## References

---

- <sup>1</sup> Vahratian A, Adjaye-Gbewonyo D, Lin JS, Saydah S. Long COVID in children: United States, 2022. NCHS Data Brief, no 479. Hyattsville, MD: National Center for Health Statistics. 2023. DOI: <https://dx.doi.org/10.15620/cdc:132416>
- <sup>2</sup> 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>
- <sup>3</sup> 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>
- <sup>4</sup> Al-Aly, Z., Bowe, B. & Xie, Y. Long COVID after breakthrough SARS-CoV-2 infection. *Nat Med* 28, 1461–1467 (2022). <https://doi.org/10.1038/s41591-022-01840-0>
- <sup>5</sup> Bowe, B., Xie, Y. & Al-Aly, Z. Acute and postacute sequelae associated with SARS-CoV-2 reinfection. *Nat Med* 28, 2398–2405 (2022). <https://doi.org/10.1038/s41591-022-02051-3>
- <sup>6</sup> Tran, VT., Porcher, R., Pane, I. *et al.* Course of post COVID-19 disease symptoms over time in the ComPaRe long COVID prospective e-cohort. *Nat Commun* 13, 1812 (2022). <https://doi.org/10.1038/s41467-022-29513-z>
- <sup>7</sup> Packard SE, Susser E. Association of long COVID with housing insecurity in the United States, 2022–2023. *SSM Popul Health*. 2023 Dec 14;25:101586. doi: 10.1016/j.ssmph.2023.101586. PMID: 38222672; PMCID: PMC10787291.
- <sup>8</sup> Karpman M, Fiol O, Popkin SJ, McCorkell L, Waxman E, & Morriss S. Employment and Material Hardship among Adults with Long COVID in December 2022. Urban Institute. <https://www.urban.org/research/publication/employment-and-material-hardship-among-adults-long-covid-december-2022>
- <sup>9</sup> Cutler, D. The Economic Cost of Long COVID: An Update. [https://scholar.harvard.edu/sites/scholar.harvard.edu/files/cutler/files/long\\_covid\\_update\\_7-22.pdf](https://scholar.harvard.edu/sites/scholar.harvard.edu/files/cutler/files/long_covid_update_7-22.pdf)
- <sup>10</sup> De Beaumont. Poll: Physicians agree Long COVID is a problem but are unprepared to treat it. 2023. <https://debeaumont.org/wp-content/uploads/2023/03/Long-COVID-Brief.pdf>
- <sup>11</sup> 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/>