



**PATIENT-LED  
RESEARCH  
COLLABORATIVE**



**LONG COVID  
CAMPAIGN**  
CARE TREAT NOW

**FOR IMMEDIATE RELEASE**

## **Patient Groups Launch New Campaign to Secure Long Covid Funding in FY 2025**

[Washington DC, May 3, 2024] – Responding to Americans’ urgent need for comprehensive Long Covid research, treatment, and support, patient groups Patient-Led Research Collaborative (PLRC), Long Covid Moonshot (LCM), and Long COVID Campaign (LCC) today launched a new campaign calling on U.S. leaders to ensure over \$1.2 billion in Fiscal Year 2025 funding.

With the appropriations process underway, the organizations will mobilize patients, caregivers, healthcare workers, and concerned Americans to directly engage with legislators.

“Long Covid has derailed my life. I, and the twenty million other Americans affected by Long Covid, need help – yet there are still no FDA-approved treatments for us. It is beyond time for our government to invest in the clinical trials and research infrastructure that will bring us treatments and cures,” said Ezra Spier, a member of Long Covid Moonshot.

Long Covid Moonshot will support severely disabled patients to take action from their beds - with over 5,000 people from all 50 states using their call guides in the last few months alone. Long COVID Campaign, with the support of PLRC and LCM, will again mobilize patients from across the country to attend the upcoming Senate NIH Appropriations hearing, building on the January HELP Committee Long Covid hearing when patients in teal t-shirts packed even the overflow room.

“Over three years have passed since Congress provided the NIH RECOVER initiative \$1.15 billion, yet Americans still have no FDA-approved treatments, most funding supports observational studies, and there’s an alarming lack of urgency relative to the scale of the crisis,” said Meighan Stone, Executive Director of the Long COVID Campaign. “If Congress doesn’t take action, patients stand to lose more than half of this critical research funding, at a time when more investment is desperately needed.”

Entering the fifth year of the pandemic, Long Covid's debilitating toll surpasses that of heart disease and cancer, with 18% of affected workers unable to return to work for over a year. Brookings estimated in January 2022 that the disease could account for upwards of 15% of unfilled jobs, and Harvard economist David Cutler estimated a total economic cost of \$3.7 trillion in the first five years alone.

The campaign calls for the level of US government investment needed to respond to the growing public health crisis, urging that the FY25 Labor-HHS and Defense Appropriations bills include:

- At least \$1b in Long Covid research funding to the NIH Office of the Director

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- \$200m to ARPA-H for “high risk, high reward” Long Covid research
- \$20m to fund the Office of Long Covid Research & Practice
- \$13.5m to AHRQ to continue dissemination of best practices in Long Covid care
- The addition of 'Long Covid' as a Congressionally Directed Research Medical Program Topic Area

For more information about the campaign and our advocacy efforts, please visit [Long Covid Moonshot](#) and check out our [Call Guide](#). For tools on Long Covid research and patient engagement, please visit [Patient Led Research Collaborative](#). [Patient advocates can sign up at the Long COVID Campaign](#) for virtual or in-person Hill and Biden Administration meetings and Congressional hearing attendance opportunities.

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#### **About Patient-Led Research Collaborative:**

The Patient-Led Research Collaborative is a team of Long COVID patient-researchers. Our mission is to facilitate patient-led and patient-involved research into Long COVID and associated conditions while following rigorous research methodology, and to advocate for policies that enable patients, particularly the most marginalized, to access care and live with dignity. We ground our work in the principles of disability justice and participatory research methods, and in the knowledge that those who experience an illness are best able to identify research questions and solutions. [patientresearchcovid19.com](https://patientresearchcovid19.com)

#### **About Long Covid Moonshot:**

Long Covid Moonshot is a group of patients organizing around the urgent need for Long Covid research funding and other issues important to the community. Our mission is to enable the community to harness its collective voice for advocacy, and to work with partners across the Long Covid and chronic illness communities to advocate for change at the federal level. Follow us on [X](#) and [Instagram](#).

[longcovidmoonshot.com](https://longcovidmoonshot.com)

#### **About Long COVID Campaign:**

The Long COVID Campaign fights for equitable, accessible and affordable treatment for all. We educate and advocate for accelerated research, policies and programs to support people living with Long COVID globally. We work in partnership with patients, caregivers, health workers, civil society, the private sector and world leaders to develop, fund and scale solutions—and end Long COVID together.

[longcovidcampaign.org](https://longcovidcampaign.org)

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