



## FOR IMMEDIATE RELEASE

### Patient Groups Applaud Chairman Sanders' Introduction of the Long COVID Research Moonshot Act

Washington DC, August 2, 2024 – Patient groups [COVID-19 Longhailer Advocacy Project](#) (C19LAP), [Long Covid Campaign](#) (LCC), [Long Covid Moonshot](#) (LCM) and [Patient-Led Research Collaborative](#) (PLRC) today welcomed HELP Committee Chairman Sanders' (I-VT) Senate introduction of the **Long COVID Research Moonshot Act** with co-sponsors Senators Duckworth (D-IL), Kaine (D-VA), Markey (D-MA) Smith (D-MN) and Welch (D-VT). Already endorsed by over 45 patient, clinician, disability, and advocacy groups, the legislation **would establish and fund a new \$11.4 billion** comprehensive Long COVID research plan and program over the next decade.

"This legislation is a critical step forward by providing the meaningful, sustained investment needed to enhance our understanding of Long COVID, develop treatments, educate providers and the public, and grow the Long COVID and infection-associated chronic condition research ecosystem long-term" said **Lisa McCorkell, co-founder of PLRC**. "Every member of Congress has a large number of constituents with Long COVID – we need Congress to support this bill so we can find answers and improve care for the growing Long COVID community."

The **Long COVID Research Moonshot Act** would require the NIH to establish a new \$10 billion research program, led by a director with Long COVID research expertise and in consultation with an empowered advisory board of Long COVID and infection-associated chronic condition (IACC) researchers and patients. Responding to patient community organizing [ignited by a October 2023 Nature call to action](#) from PLRC's McCorkell and University of California-San Francisco clinician-researcher Dr. Michael Peluso, the bill includes not only substantive funding, but also a slate of new transparency, reporting, consultation, and grant expediting requirements.

"Today, Senator Sanders answered the call from over 17 million people in the United States suffering from Long COVID and demanding action," said **Meighan Stone, executive director of the Long COVID Campaign**. "With its comprehensive all-of-government plan and the scale of funding needed to deliver the clinical trials, diagnostic tests and FDA approved medications patients urgently need, the Long COVID Research Moonshot Act is a critical step in treating Long COVID like the public health emergency that it is."

Alongside prioritization of expedited clinical trials and development of new interventions, the **Long COVID Research Moonshot Act** provides an additional \$1.4 billion in mandatory funding for robust provider and public education, surveillance, and clinical trial support efforts across the Food and Drug Administration, Centers for Disease Control, Health and Human Services and other U.S. government agencies to collaboratively address the growing public health crisis.

"Today is a big step for the thousands of patients and allies who are demanding robust, coordinated, and sustained Long COVID research," said **Claudia Sherman, founding member of Long COVID Moonshot**. "Long COVID can happen to anyone, threatening people's lives

and livelihoods. That is why Moonshot activists took up this call, and that is what will fuel us forward in defeating this crisis.”

The proposed legislation will also ensure Long COVID research coordination and findings benefit people living with IACCs, such as but not limited to, postural orthostatic tachycardia syndrome (POTS) and other forms of dysautonomia and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), amongst other conditions that many people with Long COVID experience.

“Education must be prioritized to ensure all stakeholders can address the needs of people with Long COVID and its socio-economic impacts,” said **Karyn Bishof, founder and president of the COVID-19 Longhailer Advocacy Project**. “Long COVID remains misunderstood and neglected nearly five years into the pandemic. As of July 2024, the U.S. is still seeing nearly one million new COVID-19 cases per day, underscoring the urgent need for action in the interest of public health. This bill promises the much-needed resources we have advocated for years.”

Now in the fifth year of the pandemic, Long COVID continues to negatively impact the U.S. public and economy. A 2023 study found Long COVID patient functional limitations and quality of life to be lower than severe conditions like stroke and metastatic cancers, with only 40% being able to work full time at two years post-infection. In 2022, The Brookings Institution estimated Long COVID 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 of the growing public health crisis.

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### **About The Long COVID Research Moonshot Act**

The bill would ensure targeted, robust investments in Long COVID research, education and awareness across U.S. government agencies, over the next 10 years:

- **CDC:** \$32 million/year for the next 10 years for Long COVID and IACC surveillance; \$45 million/year for the next 10 years for grants to state, local, and tribal health departments; \$21.5 million/year for the next 5 years for a national public education campaign.
- **FDA:** \$16.6 million/year for the next 10 years to continue electronic reporting for patients to identify current treatments and treatments under development for Long COVID; \$9 million/year for the next 10 years to develop and validate clinical outcome assessments.
- **HHS:** \$3 million/year for the next 10 years for provider education.
- **AHRQ:** \$10 million/year for the next 10 years to continue the Long COVID Care Network; \$10 million/year for the next 10 years to develop and distribute best clinical care practices
- **National Institute on Disability, Independent Living, and Rehabilitation Research:** \$10 million/year for the next 5 years for applied research on Long COVID and other IACCs.
- **IACCs:** The Long COVID Research Program will ensure timely cross-agency coordination on IACC advances; conduct comparative research on Long COVID and other IACCs; grant awards will be prioritized for research that includes patients with IACCs with similar phenotypes to Long COVID; Organizations that represent IACCs with similar phenotypes to LC will be consulted on the Research Plan; CDC directed to collect data on the incidence, prevalence, and severity of IACCs.

### [COVID-19 Longhailer Advocacy Project](#) (C19LAP)

The COVID-19 Longhailer Advocacy Project is a grassroots, all-volunteer, patient led 501(c)(3) nonprofit organization with 60 state and community-based chapters across the U.S. whose mission is to advance the understanding of Long COVID and expedite solutions and assistance to Longhailers and their families. C19LAP has a focus on awareness and education, development of resources through bi-directional communication with relevant stakeholders and Long COVID community engagement, and advancement of patient-centered care coordination and research. Follow us on [X](#) or email us at [contact@longhailer-advocacy.org](mailto:contact@longhailer-advocacy.org)

[Long Covid Campaign](#) (LCC) 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. Follow us on [X](#) or reach out to [info@longcovidcampaign.org](mailto:info@longcovidcampaign.org)

[Long Covid Moonshot](#) (LCM) is a group of patients organizing around the urgent need to uplift opportunities for Long Covid research funding and other issues important to those impacted. Our mission is to empower 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. Follow us on [X](#) and [Instagram](#).

[Patient-Led Research Collaborative](#) (PLRC) strengthens and facilitates research into Long COVID and advocates for policies that improve the quality of life for Long COVID patients. We conduct our own patient-led research; partner with health and research organizations globally to improve study design, guidelines, and education for medical providers and the general public; and advocate for better treatment, care, and support for all patients. 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. Follow us on [X](#) and [Instagram](#) or reach out to [team@patientledresearch.com](mailto:team@patientledresearch.com).

NASEM Long COVID Definition and Report: [Front Matter | A Long COVID Definition: A Chronic, Systemic Disease State with Profound Consequences | The National Academies Press](#)