

FOR IMMEDIATE RELEASE

Patient Groups Praise Senator Sanders' Legislative Proposal for a Long Covid Moonshot

Washington DC, April 9th 2024

On Tuesday, Senator Bernie Sanders (I-VT) <u>announced his legislative proposal</u> for a Long Covid Moonshot, which calls for \$10 billion in research funding for Long Covid over the next 10 years – an initiative explicitly called for by Long Covid patient <u>advocacy organizations</u>, starting with an <u>October 2023 comment in Nature</u> by Patient-Led Research Collaborative's cofounder Lisa McCorkell and UCSF's Dr. Michael Peluso.

Long Covid patient groups <u>Patient-Led Research Collaborative</u> and <u>Long Covid</u> <u>Moonshot</u> praised the landmark proposal, saying it marks a pivotal moment in the collective advocacy efforts of the Long Covid community.

Long Covid, a debilitating condition affecting tens of millions of Americans, currently has no FDA-approved treatment. It presents a complex array of symptoms and new-onset conditions like ME/CFS, MCAS and POTS that demand urgent attention and innovative research solutions. Recognizing this critical need, Senator Sanders' proposal includes provisions to quickly launch clinical trials aimed at accelerating the discovery of effective treatments for patients with the various conditions and complications of Long Covid.

Highlights from the proposal include:

- A mandatory \$1b in funding per year to the NIH, sustained over the next decade, a commitment that is essential to providing researchers with the stability and resources needed to pursue ambitious research, run clinical trials, and make meaningful breakthroughs
- An expedited grant process that prioritizes non-behavioral therapeutic and preventative interventions, including repurposed drugs
- Medical provider education as well as education to inform the general public about Long Covid
- A research advisory board that includes a diverse group of patients with lived experience

 A centralized coordinating structure at the NIH with leadership that has experience directing a research program on Long Covid or other infection-associated chronic conditions

Long Covid Moonshot and Patient-Led Research Collaborative applaud Sanders' inclusion of ME/CFS, POTS, MCAS, and other new-onset conditions in the proposal, and continue to encourage Sanders to ensure that the consideration of Covid-induced conditions includes the millions of people who have been sick with similar infection-associated chronic conditions for decades that need help now. This investment in Long Covid research holds promise in uncovering solutions for infection-associated chronic conditions, further amplifying its impact on public health.

"The scale and urgency of the Long Covid crisis demands action from Washington. We hope this proposal results in bipartisan legislation that delivers meaningful change for the millions suffering, and we look forward to helping patients connect with their legislators to express support for Long Covid research," said Claudia Sherman, a founding member of Long Covid Moonshot.

Lisa McCorkell, co-founder at the Patient-Led Research Collaborative, adds: "Long Covid is a crisis currently affecting 1 in 15 adults and millions of children, most of whom will not recover without investment in trialing treatments. It's extremely urgent that significant ongoing resources are budgeted to match the scale of this problem - for Long Covid and all infection-associated chronic conditions."

Both groups join the broader patient community in celebrating the culmination of years of advocacy, including the efforts of many sick patients organizing from their beds. We urge patients, healthcare professionals, lawmakers, and allies from all political backgrounds to unite behind Senator Sanders' proposal and build bipartisan support for a Long Covid Moonshot.

We applaud Senator Sanders for listening to patients and championing this crucial legislative proposal. His responsiveness to patient voices underscores a commitment to prioritizing the needs of those suffering with this life-changing condition and ensuring that translates into tangible results.

For more information from Sanders' team on how to provide feedback on this proposal, please visit <u>NEWS: Chairman Bernie Sanders Releases Long COVID Moonshot</u>
Legislative Proposal

For more information on how to advocate for increased funding for Long Covid research, please visit <u>Long Covid Moonshot</u>, and for tools on Long Covid research and patient engagement, please visit <u>Patient Led Research Collaborative</u>.

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.

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.

For media inquiries, please contact:

Lindsay Humphreys info@longcovidmoonshot.com (202) 854-8745

Hannah Davis team@patientledresearch.com