Bernie Sanders Seeks Feedback on $10 Billion “Moonshot” for Long COVID

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Last week, Senator Bernie Sanders proposed a “moonshot” for Long COVID, which would allocate $1 billion a year for the next 10 years to mandatory research into the disease. The Senator and the United Senate Committee on Health, Education, Labor, and Pensions (HELP) are currently seeking email feedback on a draft of this legislation, not yet formally introduced to the Senate, until April 23, 2024.

The announcement follows the senator’s recent Long COVID Awareness Day resolution and the Senate HELP Committee hearing on long COVID in January. “It is my strong belief that the crisis of long COVID is a public health emergency that we can no longer ignore,” Sanders said in a statement.

Beyond the $10 billion mandatory funding over 10 years to the National Institutes of Health (NIH), Sanders’ draft proposes that people with long COVID be included in a “centralized coordinating entity” as well as an accelerated grant process that would prioritize biological research and biomedical interventions and therapeutics, which the NIH has failed to do since launching its RECOVER program in 2021.

The draft also calls for the NIH to form an advisory board composed of healthcare providers, researchers, and people with long COVID and other “COVID-induced chronic conditions.” In addition, it requires federal agencies to educate the public and providers on long COVID and its ongoing risks.

For the bill to become law, it will need to be formalized and pass through the HELP Committee, before receiving a majority of votes in both the Senate and House. If it makes it past these obstacles, it is then sent to the president where it is either signed into law or vetoed.

“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 co-founder of Long COVID Moonshot, in

a press release.

The group began calling for increased funding after Lisa McCorkell, co-founder of the Patient-Led Research Collaborative, and researcher Michael Peluso, MD, wrote an op-ed calling for $10 billion in funding over 10 years in Nature in October 2023.

Sherman wrote to The Sick Times that she was excited to see an emphasis on education of long COVID for healthcare providers in the draft, as she said such education has been ignored, especially in rural communities. While Sherman believes research is important for long COVID, she'd also like to see additional legislation focusing on social services for people with the disease, as well as indoor air quality to help mitigate COVID-19 and future pandemics.

Epidemiologist and researcher Ziyad Al-Aly, who testified at the Senate HELP Committee meeting on long COVID in January, said he supports the draft and that it might be the "best shot" for research into this disease. However, he says he would like to see funding beyond 10 years, giving a billion dollars per year in perpetuity.

"Diseases don't just disappear," Al-Aly said. "I worry that in 10 years we'll run out of money and still have more research to do — what do we do then?" Many other diseases, like HIV/AIDS and cancer, Al-Aly explained, are still with us today despite significant funding and major advancements in science.

Other long COVID advocacy groups like the Long COVID Foundation and Long COVID Action Project (LCAP) have said that the one billion dollar amount per year isn't enough to address the crisis. LCAP has demanded $28 billion per year, citing the assessment of Harvard economist David Cutler, who found the disease may have an impact of $3.7 trillion on the American economy.
Meanwhile, some myalgic encephalomyelitis (ME) advocacy groups are concerned about the "narrow scope" of the moonshot draft proposal. Emily Taylor, the president of Solve ME/CFS, wrote in a petition: "A solution that addresses one group of patients while abandoning the others is hurtful and harmful to a community already ignored for decades." Her organization is calling for Sen. Sanders to add the term "and associated conditions" to the act, to include ME, dysautonomia, and other diagnoses common after SARS-CoV-2 infection.

Similar to Sen. Sanders' proposal, Solve ME/CFS also calls for a center at the NIH that studies infection-associated chronic conditions and illnesses (IACCIs), which they say affect up to 73 million Americans based on analysis shared in a new white paper.

Some people with ME and researchers who study it would like to see ME explicitly mentioned in the act. Many advocates have noted the NIH's bias against ME, which has been largely underfunded by the institute. Todd Davenport, a clinician and researcher, wrote in an open letter published in Virology Blog: "Investment in research for ME and other IACCs not only will help us unlock the mysteries of Long Covid because of their overlap, but it will provide equity to people in need."

Sen. Sanders' proposed act isn't the first piece of legislation on long COVID. Sen. Tim Kaine's CARE

for Long COVID Act was introduced in March 2023, but still has not passed through the HELP Committee. Rep. Ayana Pressley's TREAT Long COVID Act, introduced in April 2022, has been similarly stalled.

"To be frank, most legislation that gets introduced in Congress never makes it out of committee," said Olenka Sayko, a long COVID patient-advocate. For the bill to become law, it will need to pass through the HELP Committee before passing through both the Senate and House with majority votes.

"The process is arduous and complex," Sayko wrote to The Sick Times, "But no matter what, people with long COVID and their allies need to get ready to push for this legislation with their elected officials, especially if their legislators are Republicans."

Sayko noted the large turnout of senators at the Senate HELP Committee hearing on long COVID in January, which isn't typical for committee meetings. The significant media coverage of the hearing and the unanimous agreement among those who testified on increased funding for long COVID may give the bill a better chance of making it through the legislative process than past legislation on long COVID, she wrote.

For the bill to receive broad bipartisan support, Sayko said it will take more work from the patient community, particularly to convince Republicans who have legislative oversight.

But until then, Sayko recommends that the community provide feedback to the HELP Committee. "It's the system's way of making sure that the proposal reflects stakeholders' priorities."

Sen. Sanders and the HELP Committee are seeking feedback on the proposed Long COVID "moonshot" draft until April 23, 2024. Email them at: LongCOVIDComments@help.senate.gov.

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