Sen. Bernie Sanders Introduces $10 Billion Long COVID Moonshot Legislation to Support Research, Healthcare, Education

The legislation includes support to track the disease, identify best practices for long COVID healthcare and provide guidance for pharmaceutical companies working on treatments.

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[On August 2], Sen. Bernie Sanders introduced the Long COVID Research Moonshot Act of 2024. The bill allocates $1 billion in federal funding per year for the next 10 years for long COVID research, treatments, public health education, and expanded healthcare.

A draft version of the Act received thousands of comments from the long COVID community in April. The official legislation, which would establish a new program at the National Institutes of Health (NIH), is co-sponsored by Democratic Sens. Tammy Duckworth, Ed Markey, Tina Smith, Peter Welch, and Tim Kaine, who has long COVID.

“For far too long, millions of Americans suffering from long COVID have had their symptoms dismissed or ignored – by the medical community, by the media, and by Congress,” Sanders said in a press release. “The legislation that we have introduced finally recognizes that long COVID is a public health emergency and provides an historic investment into research, development, and education needed to counter the effects of this terrible disease.”

Many long COVID advocates and researchers praised the bill as a major milestone for U.S. government action on long COVID. Along with funding for the NIH, the legislation includes support for other federal health agencies to track the disease, identify best practices for long COVID healthcare, provide guidance for pharmaceutical companies working on treatments, and more.

“The bill has a lot of transparency and accountability,” Lisa McCorkell, co-founder of the Patient Led Research Collaborative, said.* “I’m blown away by how comprehensive it is.” McCorkell called for a “Long COVID Moonshot” last fall in an opinion article in Nature, coauthored with researcher Michael Peluso.

She explained that the legislation requires the NIH to set up a long COVID research advisory board

and consult with patient-led organizations and advocacy groups representing people with long COVID and related diseases.

In response to comments from the long COVID community, the senator's office has made significant updates to the legislation. The bill names long COVID as an infection-associated chronic condition (IACC) and requires the NIH to support research in this category of diseases, specifically listing myalgic encephalomyelitis (ME), postural orthostatic tachycardia syndrome (POTS), and chronic Lyme disease as priorities.

"It's a vast improvement from the legislation that was teased in April," said Emily Taylor, president of Solve ME/CFS, which organized a petition calling for Sanders to include ME and other chronic diseases commonly diagnosed alongside long COVID in the bill. Taylor is "cautiously optimistic" that the bill has learned from the mistakes the NIH made in setting up its RECOVER initiative, which failed to build on prior research into IACCs, she said.

Other advocates, however, questioned the exclusion of key issues for the long COVID community, such as COVID-19 prevention measures, the hypothesis that viral persistence causes the disease, and prioritizing Black, Latino, and other marginalized communities that are disproportionately impacted by long COVID.

"Black and Latiné patients show a greater number of long COVID cases that are underreported to doctors," according to NIH-supported research, said advocate and filmmaker Chimére Sweeney in a statement. Sweeney called on Sanders' office to include specific language supporting Black Americans with long COVID in the Moonshot legislation; she received no response, she said.

To become law, the legislation will need to receive a majority of votes in both the Senate and House. If it passes these obstacles, it is then sent to the president, where it is either signed into law or vetoed. Advocacy groups are organizing to garner more Congressional support for the bill as well as other opportunities for long COVID-related funding, such as the federal budget for fiscal year 2025.

From draft proposal to new legislation

The Sick Times has identified several notable expansions and updates to the Long COVID Moonshot Act since Sanders proposed the legislation in April:

- The legislation includes more details about a proposed long COVID research program at the NIH, which would be set up within the Office of the Director. It requires this program to be led by a director with "demonstrated commitment to addressing long COVID and other IACCs," and requires long COVID advocates to be part of the process for selecting that director.

- The act explicitly includes other IACCs as a research priority for the NIH. It specifically names

ME, POTS, and chronic Lyme disease as examples of these diseases that must be included in research.

- It also includes long-term effects from COVID-19 vaccinations as a research priority, requiring that the NIH conduct comparative studies on these patients and people with long COVID.

- The Act requires regular public reports about the NIH's long COVID research, including public budget information. (Lack of transparency has been a concern for the RECOVER initiative.)

- It adds more detail to a new process for the NIH to fast-track funding to Long Covid researchers. Priorities for this grant program include identifying treatments, studying Long Covid in children, including other IACCs along with Long Covid, and supporting institutions with a track record of providing care to "historically underserved communities."

- The act requires that any federal funding supporting research into new drugs for long COVID — or existing drugs that are repurposed for this disease — must come with contract terms for companies to sell treatments at a "fair and reasonable" price.

In addition to $10 billion in funding for the NIH, the act also provides funding for the FDA, the Centers for Disease Control and Prevention (CDC), state and local health departments, and other federal agencies.

The budget includes, over 10 years:

- $320 million for long COVID and IACC surveillance at the CDC;
- $450 million for the CDC to offer in grants to state, local, and tribal health agencies;
- $107.5 million for a national public education campaign at the CDC;
- $166 million for FDA data collection to identify treatment options;
- $90 million for the FDA to develop guidance for drug companies on clinical trial outcomes;
- $30 million for the Department of Health and Human Services (HHS) to educate doctors about long COVID;

- $50 million for applied research at the National Institute on Disability, Independent Living, and Rehabilitation Research;
- $200 million for the Agency for Healthcare Research and Quality to continue supporting long COVID clinics and develop best practices.

Discussing the Act on social media, some people in the long COVID community expressed disappointment that the legislation does not include support for COVID-19 precautions, such as requiring masks in medical settings, providing free tests, or funding improvements to indoor air quality. Many people with long COVID consider these precautions crucial for reducing the risks of reinfections, which can lead to new and worse symptoms.

The group Long COVID Action Project, which focuses on science and advocacy around SARS-CoV-2 viral persistence, criticized the act for failing to prioritize this area of research and for supporting the IACC category, which it argues takes attention away from the long COVID crisis. "LCAP withholds support for Moonshot in favor of more comprehensive HEAL legislation drafted by long COVID grassroots activists," the group said in a statement.

Next steps for the Moonshot Act

While Congress is on vacation for its August recess, some long COVID groups are starting to prepare advocacy campaigns around the Moonshot Act. The legislation's next steps will be review by the Senate Committee on Health, Education, Labor, & Pensions (HELP), which held a hearing on long COVID in January, followed by potential further changes to the text, a vote in the Senate, then referral to the House of Representatives.

Both the Senate and House must approve the Act with majority votes, and the president will need to sign it into law. This process could be time-consuming given the political polarization in Congress and upcoming elections, said Taylor at Solve ME/CFS.

"This bill was introduced without a Republican, in a contentious Congress," Taylor said. "The way we are going to most effectively overcome those challenges is by building a broad base, which includes Republicans [and] other disease spaces." Republicans typically do not support legislation that focuses on one specific disease, she explained, so advocates will need to either argue that long COVID merits an exception to this policy or that the act is relevant to a broader category of health issues.

The advocacy group Long COVID Moonshot, which has focused on this legislation as a central goal, is similarly considering a broad base of support. For the bill to be considered when Congress returns from its recess, "we'll need many more signatories, including across-the-aisle bipartisan support," said Claudia Sherman, a member of the group, in a statement to The Sick Times.

"We will be mobilizing patients while the Senate is in recess with both broad advocacy, and working hand-in-hand with other patient groups to set up patient meetings with their reps

(virtually and in-person) to help communicate the urgent need for this bill to pass," Sherman said.

People interested in meeting with their representatives can fill out this form. Long COVID Moonshot also has phone call scripts available on its website.

Miles W. Griffis contributed reporting.

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