Senate Hearing Highlights Long COVID Crisis

Hearing focuses on long COVID—but not COVID-19 prevention—as advocacy groups bring their demands to DC.

January 24, 2024 By Betsy Ladyzhets and The Sick Times

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On January 18, the Senate Committee on Health, Education, Labor, & Pensions (HELP) convened a hearing about long COVID, discussing research priorities and healthcare challenges for the disease. Senators heard from people with long COVID and scientists studying it in front of a packed room full of long COVID advocates and allies, along with thousands watching online.

"We hear what you're experiencing," Senator Bernie Sanders, the committee's chair, said to people with long COVID during his opening remarks. "We take it seriously. We think we have not, as a Congress, done anywhere near enough, and we hope to turn that around."

While advocates and scientists agreed the hearing was a milestone in the government's response to this crisis, they also called out ways in which the event emulated challenges that people with long COVIDd face: navigating spaces without precautions against SARS-CoV-2 infection, a lack of accessibility for people with severe symptoms, and insufficient support for accessing healthcare or other facets of daily life.

For some people with long COVID who attended or watched the hearing, a lack of universal masking among Senators and their staff undercut their remarks about the disease's debilitating outcomes.

The Senators in attendance "got the urgency around finding treatments" and accelerating research for long COVID and associated diseases, said Angela Vázquez, former president of Body Politic, who testified at the hearing. Legislators specifically called out the National Institutes of Health's RECOVER initiative, which has failed to support clinical trials for promising new treatments according to prior reporting from MuckRock and STAT News.

But the hearing didn't spend much time on immediate support for people with long COVID, disability benefits, or on the severe outcomes of llong COVID including cardiovascular outcomes, immune dysregulation, and death, advocates said.

People with long COVID — including the hearing's speakers and advocates who attended — gave the Senators plenty of suggestions for new policies. Some advocates called for a "long COVID moonshot" similar to the Biden administration's Cancer Moonshot, demanding at least $1 billion in funding annually to support research. One advocacy group, called Long COVID Moonshot after this demand, produced T-shirts worn by many audience members and handouts sharing key statistics about the disease. In addition, during the days leading up to the hearing, Long COVID Moonshot coordinated calls to Senate offices to ensure the politicians attended.

"If you look back at previous HELP Committee meetings, there's like four people there, usually," out of 21 committee members, said Sawyer Blatz, a member of the Moonshot group. The group counted 14 Senators in attendance at the hearing, including 12 of the 15 legislators whose offices the advocates had called. For some Senators, staff told the advocates, "They were going to shuffle around their schedule to make sure they could be there," Blatz said. "Without our calls, maybe they wouldn't have gone." Another Senator whom the group had called, Sen. Ben Ray Luján, attended part of the hearing but had to leave early, a representative of his office told The Sick Times.

Advocates with Long COVID Action Project are escorted out of the hearing after disrupting the proceedings with banners and chants, demanding the federal government declare long COVID a national emergency.Public Herald

A separate advocacy group, the Long COVID Action Project (LCAP), announced its demands with an

unsanctioned action: early in the hearing, two advocates advanced to the front of the Senate chamber with banners reading, “Declare Long COVID a national emergency.” The advocates voiced this demand through chants, also calling for $28 billion in research funds and comparing long COVID to HIV/AIDS. Security guards removed them from the hearing and, later, the building, the two advocates told The Sick Times.

> Long covid hearing quickly interrupted by two protesters, unfurling banners and demanding that long covid be declared a national emergency.
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> pic.twitter.com/F9rqd8K05q
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> — Dan Diamond (@ddiamond) January 18, 2024

LCAP’s action aimed to draw attention to the resources it considers “needed to address this crisis,” said Linda Roberts, one of the advocates, who is using an alias. Its $28 billion ask is based on research by health economist David Cutler, who has studied the disease’s implications for the U.S. economy. The group sent letters to Senate offices, requesting that an LCAP speaker testify at the hearing, but was not given a spot; some staffers dismissed the group, as demonstrated by a call between Sen. Tammy Baldwin’s chief of staff and advocate Joshua Pribanic. “We did try the normal channels, and went to direct action when those normal channels did not work,” Roberts said. “Long COVID requires a unique urgency.”

Despite their different demands, long COVID advocates agree that Thursday’s hearing was only a starting point for federal actions addressing the disease. “We have to keep pressure on the elected officials, keep this front and center,” said Gabriel San Emeterio, an advocate with the groups Strategies For High Impact and Long COVID Justice.

Senators address the need for clinical trials, healthcare

The Senate hearing shed light on some of advocates’ and scientists’ top concerns, most notably a need for clinical trials. “We developed vaccines at warp speed, we’re doing trials at snail speed,” said Ziyad Al-Aly, MD, a speaker at the hearing and clinical epidemiologist at Washington University and the St. Louis Veterans Affairs health system. Large trials examining many potential treatments at once are needed to find answers for a disease that is diverse and complex, Al-Aly said.

Sen. Sanders asked Al-Aly and three other scientific experts speaking at the hearing whether they thought “that the federal government has got to play a much more active role with substantial

sums of money for research, development, clinical trials, etc." The panel emphatically agreed with that statement. The researchers, two of whom work at long COVID clinics, also called for more support for these centers, explaining that many people with the disease require coordinated care from multiple specialists.

Long COVID clinics "remain rare and numbers continue to dwindle as clinics are shuttering," said Dr. Tiffany Walker, a professor of internal medicine at Emory University who leads the Atlanta Long COVID Collaborative, in her testimony. Walker and her colleagues were one of nine groups that received a grant from the Agency for Healthcare Research and Quality (AHRQ) last fall. This program is a good starting point for improving long COVID care, she said, but more support is needed for other centers and beyond the program's current five-year scope.

Speakers with long COVID discussed the challenges they'd faced in accessing healthcare, including denial from doctors. In response, several Senators emphasized that they believed people with long COVID were truly facing potentially disabling symptoms. Sen. Tim Kaine, who himself has long COVID, used his own experience to highlight differences in healthcare access. "U.S. Senators get believed," he said, while many other people with long COVID — especially women, minorities, and younger people — may face more challenges finding doctors who take their symptoms seriously.

Sen. Kaine referenced an editorial that he co-authored with Sen. Todd Young and former Sen. Jim Inhofe, both of whom also live with long COVID, calling for additional action from Congress. Similarly, Sen. Roger Marshall, MD, expressed that one of his family members has been "incapacitated" by the disease for two years. "This is personal for me," he said at the hearing, adding that he wants to see federal health agencies focus on long COVID treatments rather than vaccines.

Marshall, along with several other Republican Senators who asked questions at the hearing, demonstrated a recognition of long COVID that suggested there may be an opportunity for bipartisan legislation on this issue, said Olenka Sayko, an advocate with long COVID Moonshot. "Senators Cassidy, Marshall, Murkowski, and Braun showed that they understand what a big problem this is," she said. "I think it creates an opening for patient advocates to work with staffers on the Hill to help be part of the solution here."

Some Senators also called for better oversight of the NIH, pointing to criticism of the agency's RECOVER initiative — the largest recipient of federal long COVID funding so far. As MuckRock and STAT News reported last year, after receiving $1.15 billion in December 2020, the RECOVER initiative has moved slowly and devoted the majority of its funding to observational research. When RECOVER finally announced its first clinical trials in the summer, scientists and advocates expressed concern that it was not testing promising treatments.

RECOVER has focused on "risk factors and praying about it" rather than diagnosis and treatment, Sen. Marshall said. He suggested that future funding might be better directed to other agencies, such as the Biomedical Advanced Research and Development Authority (BARDA), which works closely with private companies. Sen. Bill Cassidy and Sen. Tammy Baldwin both referenced issues

with RECOVER as well, citing concerns about the slow pace of clinical trials. The NIH announced new funding for RECOVER trials at the end of 2023 but has yet to share details about how this additional $200 million will be used.

Responding to the Senators' comments, Al-Aly suggested that, rather than directing future long COVID funding away from the NIH, Congress should support a more coordinated and collaborative approach to research. This research currently has no "quarterback," leading to disorganized and redundant work, he said. Al-Aly recommends that the NIH set up a new institute focused on infection-associated diseases, with funding on the level of "a billion dollars a year in perpetuity."

Accessibility concerns, following up with action

While viewing the Senate hearing as an opening for greater research support, some experts and advocates expressed disappointment with a lack of focus on preventing new SARS-CoV-2 infections, as the best way to prevent new cases of long COVID is to curb the virus' spread.

Most Senators and their staff members were not wearing masks during the hearing, people watching the live stream were quick to point out on social media. Sen. Sanders and Sen. Ed Markey wore masks at times, but removed them to speak, according to people who attended the hearing. The event also required all speakers to attend in person, meaning people with long COVID traveled to D.C. during a major COVID-19 surge.

To some people with long COVID, these parameters came across as dismissing the disease's risks and excluding people with the most severe cases. "There's a hearing where we're showing how devastating long COVID can be, and yet can't model the most basic preventative measure that we can take to prevent new long COVID cases," Sayko said. Roberts, from LCAP, echoed this criticism: "It was a very scary room to be in as someone who is extremely concerned about getting COVID again," she said.

An option to testify virtually may have helped the hearing better highlight more debilitating long COVID symptoms, such as organ damage, cardiovascular events, and fatalities, that are often not represented in public discussion of the disease, some advocates said. Advocacy groups also had limited time to prepare for the hearing, as it was announced with only one week's notice. People with long COVID who attended noted that the travel to and from the event caused them to have debilitating crashes.

Kate Larose, pandemic equity coordinator at the Vermont Center for Independent Living, brought these accessibility concerns to HELP Committee staffers ahead of the hearing, she told The Sick Times. An "accessible, inclusive testimony" would include both virtual opportunities for testimony and universal masking with high-quality respirators, she said: "If you do anything less…what you are creating is the equivalent of a U.S. Senate hearing for wheelchair users without a ramp to the room."

The Sick Times reached out to Sen. Sanders' office for a comment about these accessibility

concerns and has not heard back, as of publication.

One audience member, Congressional candidate Joaquín Beltrán, called out the hearing's disconnect on prevention by holding up a sign reading, "MASKS SAVE LIVES." Al-Aly also emphasized this topic in his remarks, calling for more durable vaccines and improvements to indoor air quality. "If we are serious about preventing long COVID, then we have to prevent repeated infections with COVID," he told The Sick Times.

In addition to the minimal focus on prevention, some long COVID advocates were disappointed by a limited discussion of direct support for people with the disease. Clinical trials don't immediately help the people who are currently losing the ability to work, their housing, and other aspects of day-to-day life, Larose said. People need "access to income, access to life, access to education, access to employment that's not discriminating, childcare, healthy food," and other supports that "people with disabilities are always told are there for us," she said.

Vázquez, from Body Politic, agreed that the hearing didn't spend enough time exploring how the federal government could directly support people who have become disabled by long COVID. People "could benefit from immediate government assistance," such as cash aid, housing assistance, and public health insurance, she said.

Scientists and advocates who watched the Senate hearing considered it a major step for the federal government's long COVID policy but emphasized that the conversation will need to be followed up with actions: increased research funding, support to long COVID clinics, prevention efforts, and new NIH office, to name a few. The hearing was "a good start," Al-Aly said; now it needs to translate into a "concrete action plan" from the federal government that moves research forward.

San Emeterio from Long COVID Justice, who has also been involved with HIV/AIDS advocacy, suggested that a program similar to the Ryan White Care Act may be one option for improving care and support for people with long COVID. "It would be a good first step," they said, though they cautioned that federal programs tend to be set up for short time periods, meaning continued pressure will likely be needed for years in the future.

Some advocates who traveled to D.C. for the hearing met with other legislators and their staff, while others are planning for a Long COVID Awareness Day march at the capitol, on March 15. Vázquez expressed optimism in continued connections between advocates and political staff: "I don't see this hearing as performative," she said. "I think there are folks working behind the scenes working in policy to make a shift for the better for Long Covid patients."

Editor's note, January 23, 3:30 pm EST: This story has been updated with information from Sen. Ben Ray Luján's office about his attendance at the hearing.

This article was published by The Sick Times, a new website chronicling the long COVID crisis, on January 23, 2024. It is republished with permission.

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