

# Long COVID advocates ask Congress to improve federal response

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Long COVID patients and experts have called on lawmakers to expand clinical trials and better educate doctors on what researchers currently know about the potentially debilitating chronic condition.

Protesters were carted out of the Senate Health, Education, Labor and Pensions Committee room after interrupting the hearing with calls to declare another federal "moonshot" initiative—referencing President Joe Biden's Cancer Moonshot program. The committee heard testimony from two panels, one of researchers and the second of patients and their families.

"We are living through the largest mass disabling event in [modern history](#)," Angela Meriquez Vázquez, a long COVID patient from Los Angeles, testified to the committee.

The prevalence of long COVID is hard to quantify thanks to its varying symptoms, but the Centers for Disease Control and Prevention estimated the condition affected 7% of Americans in 2022. Women are more likely than men to report having the condition, as were people aged 35 through 49.

Barriers to treatment are also apparent. Evidence suggests people of color are prescribed the COVID-19 therapeutic Paxlovid at lower rates. People in rural areas struggle to reach long COVID treatment centers, especially when they're sick. Coordinating care among a team of specialists is hard, and insurance barriers can be high if specialists are out of network or out of state. Plus the exhaustion means it's tough to work to keep the insurance needed to pay for the treatment.

The worst long COVID cases include ME/CFS, also known as [chronic fatigue syndrome](#); dysautonomia, which affects [heart rate](#) and [blood pressure](#); and mast cell activation syndrome, in which patients suffer repeat anaphylactic attacks.

Witnesses outlined ways in which Congress and the administration could improve the national response. Tiffany Walker, an internist and long COVID researcher with Emory University, testified that [clinical trials](#)

run by the National Institutes of Health's \$1.15 billion RECOVER initiative were valuable, but were too slow and siloed to address long COVID in real time.

"Trial funding needs to occur at a much greater scale and should not be limited to one consortium," she said, adding that NIH should include input from more doctors on the ground and real-world data. Real-time data could help move patients more quickly to new treatments showing promise.

Kansas Republican Roger Marshall, who said one of his closest loved ones has been "incapacitated" by long COVID for around two years, asked HELP Chairman Bernie Sanders, I-Vt., to have NIH testify on its approach to long COVID research. The CDC should also be focusing more on therapeutics, he said.

"I share your frustration," Marshall said. "I'm frustrated that our CDC seems to be more focused on, I guess, vaccines than they are treatment for long COVID."

The debilitating nature of some long COVID cases has driven some patients to suicide, including a man in Sanders' state of Vermont. Witnesses testified that they have had to fight with doctors to even recognize they're sick, especially early on.

Paperwork is also a major obstacle. Rachel Beale, a patient from Southampton County in Virginia, testified that she has been denied Social Security Disability Insurance without explanation.

"There's a set of problems that make this, within the SSDI insurance framework, really tough," said Virginia Democrat Tim Kaine, who said his own long COVID makes him feel like "every nerve ending in my body is in an alka seltzer 24/7."

Patient advocates called for better aggregation and real-time dissemination of new trends in treatments.

Nicole Heim, the parent of a teenage daughter with long COVID, said she often has to educate doctors on what she has learned through different treatment results. Her daughter was vomiting daily until probiotics and a colonoscopy helped clear lingering COVID from her gastrointestinal tract—a fact that shocked a gastroenterologist she recently visited.

"I think that's part of the problem, is that the doctors need the information," she said.

Heim also asked Congress to loosen restrictions on seeing doctors via telehealth in other states. Licensing laws have made her drive to a West Virginia gas station from her home in Virginia to video conference with a physician.

Insurance approvals for care can also delay treatment. Sanders promised to bring insurance CEOs before the committee following hearings he held with pharmaceutical and pharmacy benefit manager CEOs in recent months.

"These companies make tens of billions of dollars in profit every single year," he said. "And there are very few Americans who don't have to struggle to get the care that they deserve. So that's an issue we will deal with in this committee."

Congress is mired in a tense fight over spending levels, so increasing funding for long COVID research will be difficult. But the call for more action was apparent.

"I'm assuming that all of you believe that the [federal government](#) has got

to play a much more active role with substantial sums of money for research, development, clinical trials, etc. etc.," Sanders said to the panel of researchers.

They were unequivocal in their response.

"Absolutely."

"Yes."

"No doubt."

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