

Long COVID Sidelined in Congress

With limited data and funding, advocates are pleading with lawmakers to support research and surveillance of long COVID in the new Congress. From Erin Durkin at the National Journal and featuring LCA partner Andrew Wylam of Pandemic Patients:

Patients suffering from long-term impacts of a COVID-19 infection are still searching for answers in the new year.

Post-COVID conditions, also known as long COVID, can encompass a wide range of symptoms such as brain fog, fatigue, and shortness of breath. A late 2022 report from the Centers for Disease Control and Prevention found that long COVID was a factor in the deaths of [3,544 people](#) from January 2020 through June 2022. Possibly up to 4 million Americans could be out of work due to the condition, totaling \$230 billion in lost earnings, estimated the [Brookings Institution](#).

Advocates want the new Congress to support long-COVID research and access to treatment for patients suffering from these long-term complications.

“A lot of folks are really suffering, and they’re wondering whether people are paying attention to them,” Sen. Tim Kaine said.

Kaine told *National Journal* Wednesday that he is still living with his own long-COVID symptom, a constant nerve-tingling. “It still feels very unusual, and three years later it hadn’t gotten worse and it hadn’t gotten better,” he said. In the last Congress, the Virginia Democrat championed a bill that would have financed research into long-term COVID-19 symptoms, required a study looking at the health care system’s response to long COVID, and called for the development of a public education campaign. Kaine plans this year to reintroduce this bill, known as the CARE for Long COVID Act.

Getting additional resources for long COVID through the new Congress will require cooperation from a Republican-run House, which was in disarray this week after failing to select a speaker. “Exactly how that all will shake out and what does it mean for whether the House ... is able to be productive or not—I’d be lying if I told you I wasn’t nervous about it,” Kaine said. In the meantime, he

said, the long-COVID problem is only going to get bigger and “Congress is going to have to react to it.”

The Biden administration in November asked for \$750 million to support long-COVID research and treatment. It was part of a \$10 billion emergency supplemental request to support the pandemic response, but in a setback to advocates, Congress did not grant this funding.

The Health and Human Services Department said the money would have provided support to the department’s work on long COVID, to doctors who treat patients suffering from the condition, and to community organizations that provide case management and other services.

“I wish that Congress were taking this a little more seriously,” said Andrew Wylam, president and cofounder of the advocacy group Pandemic Patients. Wylam said lawmakers have not provided the same level of a response to long COVID as they did for acute infections early in the pandemic.

“It’s hard seeing the administration say, ‘We need a whole-of-government approach, we need a coordinated approach to long COVID, and we are going to do all these great things,’ but then when it comes time for Congress to actually participate in that—as the holders of the purse strings, they have to follow through for the administration to really make some progress here in a lot of ways,” Wylam said.

The White House earlier this year [outlined](#) actions to address challenges associated with long COVID. This included assessing where access to care could be enhanced through Medicare, Medicaid, and the insurance marketplace. The government has a responsibility in ensuring that long-COVID care is accessible through federal programs like Medicare and Medicaid, said associate epidemiology professor Francesca Beaudoin, director of the Long Covid Initiative at Brown University.

“This plan also emphasizes Centers of Excellence and Long COVID clinics, but the more we learn about Long COVID, the more it seems like it will be a challenge to house all things Long COVID in one clinic,” Beaudoin wrote in an email to *National Journal*, noting that some clinics have shuttered altogether.

Congress would also have to put up the dollars to help implement the administration's Centers of Excellence initiative, said Eric Gascho, vice president of policy and government affairs at the National Health Council.

Generally, Gascho said, providers need more education concerning long COVID. "There is a congressional role there," he said. "Maybe it's developing Centers of Excellence—at the very least, greater attention placed on primary-care physicians and making sure that they have a better understanding of long COVID."

But the conversation around long COVID is currently hampered by limitations in data collection and analysis, Wylam said. He would like to see the CDC improve surveillance efforts.

"It's so hard to have conversations about long COVID with policymakers, but also just the public in general," he said. "The numbers that we're relying on—the range is so broad."

A lack of data could also mean that kids with long-term symptoms are being neglected. "I think children have been completely left out of the conversation ... and one of the impediments is that we don't have data," said disability advocate Megan Carmilani, founder and president of Long COVID Families.

"The lack of data is not proof of lack of harm," Carmilani added.

Carmilani, who has infection-triggered conditions from childhood illnesses, said she suggested to Kaine's office that a surveillance program for long COVID be established in schools. The proposal is based on the CDC's School-Based Active Surveillance Project for myalgic encephalomyelitis/chronic fatigue syndrome, or ME/CFS.

The [current project](#) includes educating school nurses to identify ME/CFS and potentially long COVID because people have reported similar symptoms between the two conditions. Carmilani suggested a similar project could be implemented for long COVID broadly.

She said that training staff to identify long COVID could help with early intervention for children, "but it's going to take a huge investment in training of public-school staff and teachers."

Long COVID did receive some attention in the spending bill Congress passed shortly before Christmas, as Rep. Ayanna Pressley noted in a statement to *National Journal*.

“Folks with long COVID are struggling,” said Pressley, who also sponsored a bill in the House focused on long COVID. “They have suffered in silence and continue to face physical and mental anguish without adequate treatment. I was proud to secure several provisions in the recent government spending package that would support COVID long haulers by: prioritizing research of post-COVID respiratory conditions and racial and ethnic health disparities; addressing data gaps of chronic effects of COVID; and expanding access to digital and telehealth—but more must be done.”

Lawmakers approved \$10 million to the Agency for Healthcare Research and Quality for long-COVID research, similar to an idea proposed in Kaine’s bill. “This still is not a high enough priority for Congress,” Kaine said. “The Biden administration has done a good job, I think, of laying out why we need to do more, but we’ve got to see policy and budget support that matches the need.”