TuSalud

It’s Been a Month. We Still Don’t Know Much About Kennedy’s Long COVID Consortium.

Preliminary meetings are occurring amid the ongoing government shutdown, while some advocates call for Health Secretary Kennedy’s removal.

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Key points you should know:

- On September 18, Health Secretary Kennedy convened a long COVID roundtable event with leading researchers and government officials. The event included commitments to further federal government action to tackle this disease.
- One month later, we don’t know much about Kennedy’s promised long COVID consortium, such as who is involved, what its goals might be, and further funding that may be available.
- Researchers who attended the roundtable event and Senator Todd Young said some meetings are happening behind the scenes to determine next steps for the consortium and other initiatives, but the government shutdown has caused delays.
- Meanwhile, some long COVID advocates are rejecting Kennedy and calling for his resignation, in a letter to Senators.

A month after Health Secretary Robert F. Kennedy Jr. convened top long COVID experts and government officials for a roundtable event, progress toward new government initiatives to tackle the disease appears to be moving slowly. Some preliminary discussions are happening behind the scenes, but federal health agencies have yet to announce specific next steps.

While the government shutdown is a likely damper on progress, that alone cannot account for many unanswered questions about Kennedy’s promised actions at the September 18 event. Meanwhile, some long COVID advocates are organizing to call for the health secretary’s removal, arguing that the community as a whole should reject him as an ally.

The Sick Times interviewed four researchers who spoke at the September roundtable event and reached out to health agencies requesting updates. All of those scientists characterized it as a promising step toward new clinical trials and other crucial research developments, noting that they found the government officials present — including directors of multiple health agencies — to be sincerely interested in advancing long COVID treatments.

“I think there was a shared sense of the scope and scale of the problem and a shared desire to figure out solutions. In both the public meeting and in private discussions, I found the officials to be knowledgeable and interested in what I had to say,” wrote Michael Peluso, infectious disease clinician at the University of California, San Francisco, in an email.

He added, “I came away from the meeting encouraged that this group of officials can make a difference in driving forward progress in long COVID.”

Ziyad Al-Aly, clinical epidemiologist at Washington University in St. Louis, similarly found the discussions productive. “The interest is sincere, participation was active,” he said. “I’m really eager to hear from them about what they see as the next steps and how can we [the scientific community] help.”

In his opening remarks at the event, Kennedy said that it marked the start of a new long COVID consortium, an initiative he’d also shared at a Senate hearing earlier in September. However, neither Kennedy nor his colleagues at the Department of Health and Human Services (HHS) have announced any further details about the consortium, such as how participants might be chosen, what the initiative’s goals might be, how it may operate, and what new funding may be available to support its operations.

The researchers who spoke to The Sick Times said they looked forward to contributing more to federal efforts, but weren’t yet certain of exact next steps. Bruce Patterson, a clinician who also spoke at the roundtable event, is one member of the upcoming consortium, according to reporting today by local news outlet the Traverse City Ticker.

Senator Todd Young (R-IN) similarly said that federal officials are “still working out” details of the consortium, in a statement responding to questions from The Sick Times. Sen. Young has repeatedly advocated for further government action on long COVID, at the September 18 event and in prior Senate hearings with Kennedy.

“Long COVID will remain a top health priority for me, and I look forward to my continued collaboration with this Administration to further understand and address this chronic condition,” Sen. Young said.

Kennedy’s recent statements about supporting people with long COVID contradict prior actions from the Trump administration, including closing the federal Office of Long COVID Research and Practice, canceling an HHS advisory committee, threatening research funding, and restricting access to COVID-19 vaccines. The September 18 event itself coincided with one day of the Centers for Disease Control and Prevention (CDC)’s vaccine advisory committee meeting, in which

members handpicked by Kennedy challenged established science on vaccines.

These contradictions were a major theme of a virtual rally on Saturday [October 18] organized as part of the national "No Kings" day of action against the Trump administration. The roundtable event was "more empty promises" from Kennedy and other health officials, said Meredith Moffett-Hurst, one of the event's speakers, in an interview.

Urgency recognized, but next steps unclear

The roundtable event consisted of two panel discussions, the first with patient advocates and clinicians and the second with researchers. Both featured top health officials, including Kennedy himself (who moderated the panels), National Institutes of Health (NIH) director Jay Bhattacharya, Food and Drug Administration (FDA) commissioner Marty Makary, and Advanced Research Projects Agency for Health (ARPA-H) interim director Jason Roos, along with Republican legislators.

Such high-level representation from across the federal government is unusual at long COVID meetings, contributing to optimism from some researchers and advocates about the event's potential impact. "Over the last five years, meetings like this have really not been typical," Peluso said. "It brought together stakeholders from a variety of backgrounds and perspectives and could be an important step on the path toward more resources for long COVID care and research."

Discussion at the meeting ranged from the challenges people with long COVID have faced finding healthcare, to the urgent need for biomarkers, to potential treatments that may be studied in trials. "What I took away was the genuine interest by the HHS to advance therapy and care for patients with long COVID at a much faster pace than what has been done to date," wrote Akiko Iwasaki, an immunologist at Yale University and panelist in the research session.

At the event and in a press release later that day, the HHS announced that the agency will launch an "online hub" for long COVID treatment information and a national public awareness and education campaign. Further details about these two actions are not yet available, according to brief statements that The Sick Times received from both the HHS and CDC press offices.

ARPA-H interim director Roos also committed to tackling Long COVID, stating that the agency would have a plan to share in the coming weeks. A month has now passed. Scientists and advocates have specifically called on ARPA-H — a newer agency established in 2022 — to get involved in long COVID work; it focuses on high-risk, high-reward research, and is known for moving more quickly than other federal health agencies. For instance, the agency has funded innovative projects in cancer treatments and hospital air quality.

"ARPA-H could be a great mechanism for developing newly discovered agents that target the root causes of long COVID and other post-acute infection syndromes," Iwasaki said. Peluso noted that ARPA-H might be well-positioned to tackle "really hard problems that might be less 'flashy,'" such as new diagnostic tests.

Sen. Young similarly highlighted ARPA-H's potential role: "The NIH has overseen a lot of

foundational research. And while I'm sure there's more that can be done, the emphasis needs to be translating this research into trials that actually have a shot at getting patients more access to therapeutics. ARPA-H can deploy resources with that objective."

While the roundtable event included different research and healthcare perspectives, notably missing were representatives from pharmaceutical companies. Sen. Young proposed convening a follow-up event that would focus on those companies' needs and challenges for developing long COVID treatments.

When asked about updates on that event, Sen. Young said, "My team is working with HHS and other stakeholders to get this event scheduled, but we don't have any specific updates to share at this time."

ARPA-H and the FDA have not responded to questions from The Sick Times about progress on long COVID efforts since September 18.

The government shutdown, now in its third week, is likely impeding these initiatives. Hundreds of workers across the HHS have been laid off during the shutdown, while thousands more are furloughed. The CDC has not updated surveillance data on COVID-19 or other infectious diseases. And the NIH's RECOVER-Treating Long COVID initiative postponed a webinar scheduled for this week, according to an email sent to registrants.

"We have had some preliminary discussions with individual agencies and stakeholders since the meeting," Peluso said. "We are all looking forward to hearing the next steps, but I suspect this has been delayed by the current government shutdown."

Hossein Estiri, a data scientist at Harvard Medical School and Massachusetts General Hospital, also noted that the government shutdown was causing delays. He "personally followed up" with ARPA-H and the NIH, he said, to initiate further conversation about using large healthcare datasets and AI tools to identify potential long COVID treatments.

"I thought that the urgency from the HHS is really on point," Esteri said, reflecting on the roundtable conversations. Participating in the event "reenergized me and my research group" to continue their work on long COVID, he said, adding that the scientific community has a responsibility to keep generating evidence about the scale of the long COVID crisis.

"Snake oil salesman": Some advocates reject Kennedy

Some long COVID advocates hailed the roundtable event as a major step forward. "Partnership between Sec. Kennedy and Sen. Young on today's announcements — ARPA-H delivering a draft long COVID strategy in 'weeks, not months' and convening key pharmaceutical companies — are major victories for patients after five years of waiting," wrote advocate Meighan Stone, executive director of the Long COVID Campaign, in a statement shortly after the event.

The COVID-19 Longhauler Advocacy Project similarly thanked Kennedy for convening the

roundtable in a statement the following week. The group also noted they "hope to see additional stakeholders added to the conversation" going forward, referencing concerns about the panels' failure to represent the diverse long COVID research and patient communities.

But others have been skeptical that Kennedy and his colleagues are the right leaders to tackle long COVID. The roundtable event received criticism on several fronts: in addition to the lack of diversity on the panels, it was announced with under 24 hours of public notice, and most of the speakers did not wear masks, failing to protect themselves or fellow in-person attendees from COVID-19 during a surge.

Statements at the event in support of long COVID research, from Kennedy and other health officials, also contradicted prior Trump administration actions that have harmed people with Long COVID as well as other chronic diseases. Kennedy has spread misinformation about HIV/AIDS, falsely claimed that Tylenol causes autism, proposed an autism "registry," and failed to promote vaccines during this year's measles outbreak. A number of health and medical groups have called for his resignation.

Moffett-Hurst, one of the speakers at Saturday's "No Kings" virtual rally, noted that this administration had dismantled the prior HHS long COVID advisory committee, set up under the Biden administration, before it even had a chance to start meeting.

"[They] defunded the committee that was already funded and staffed," she said, and then "replaced it" with promises of a new consortium that may not have the same rigorous selection process that applied to the prior advisory committee.

In addition to attacks on long COVID research, the Trump administration has "made it impossible to protect ourselves" from acute COVID-19 and other infectious diseases, said Tania Powers, another long COVID advocate who spoke at Saturday's rally. The administration has politicized masks, escalating anti-mask rhetoric that started under Biden, she said, and has failed to share accurate public health information.

Powers was "cautiously optimistic" about Kennedy when he took office, she said. "I liked the moniker of 'Make America Healthy Again.' But all of his actions are coming across as a grifter … He really is coming across as a snake oil salesman, ableist, and pro-eugenics."

For Renee Semarge, another rally speaker who worked as a public health educator before she developed long COVID, Kennedy's efforts to restrict access to COVID-19 vaccines are particularly egregious. "We have some evidence that having more boosters lessens people's chances of getting Long COVID," she said — though she acknowledged that they do not prevent infection — and Kennedy's actions have made it more difficult for people to access those vaccines.

At the rally, organizer Megan (who did not disclose her last name) asked attendees with long COVID and other infection-associated chronic conditions to sign a letter that she authored calling on the Senate Committee on Health, Education, Labor, and Pensions to demand Kennedy's resignation. The letter has received about 180 signatures as of Monday afternoon, including some

from prominent advocates, researchers, and clinicians, she told The Sick Times. She plans to send it on November 3.

“It was really hard to take anything said at that roundtable in good faith,” she said during the rally, pointing to Kennedy’s track record of threatening research as well as his attacks on other disability communities.

Megan called on the long COVID community to stand in solidarity with other groups: “When you have groups of your fellow disabled people, like the Autistic Self-Advocacy Network, speaking out about how someone has harmed their community, and leading organizations of doctors across specialties suing that person over their unscientific policies, you have to look at the bigger picture.

“You can’t just focus on how the situation might benefit you and research into your disease alone.”

This article was published by The Sick Times, a website chronicling the long COVID crisis, on October 21, 2025. It is republished with permission.

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