TuSalud

Millions of Americans Have Long COVID. Will Kamala Harris Acknowledge Them?

Many advocates believe the Biden administration has turned its back on COVID-19, but some see more hope in a Harris presidency.

September 30, 2024 By Betsy Ladyzhets and The Sick Times

In early August, the newly minted Kamala Harris campaign posted a job opportunity: disability engagement director. The director would meet with disability communities across the United States, build relationships with disability advocates, and help people participate in campaign events.

Some long COVID advocates expressed excitement for the role on social media, and hoped that it would be filled by someone familiar with their disease. For these advocates, the disability engagement director is part of a broader opportunity presented by Harris' move to the top of the ticket: to make their case for national recognition. For others disillusioned by the Biden administration's response to the ongoing COVID-19 pandemic, however, the campaign has a higher bar to clear before they will support Harris.

Advocates say that people with long COVID, a potentially debilitating chronic disease that can impact all parts of the body, represent a growing voting bloc in this year's presidential election. Leaders from long COVID advocacy groups and the broader disability community are considering how to make their case to Harris' staff, with a particular interest in Anastasia Somoza — a disability advocate who was hired for the engagement director role — and Tim Walz, Harris' running mate who has championed long COVID research as governor of Minnesota.

"VP Harris is part of an administration that has turned its back on public health," said Karyn Bishof, founder and president of the COVID-19 Longhauler Advocacy Project, in an email. However, Bishof added, Harris' "track record suggests that she could prioritize the well-being of those most affected [by long COVID], particularly women and marginalized communities, and perhaps push for more honest and accessible education and care." Bishof pointed to Harris' experience supporting health care and women's rights and her selection of Walz as reasons for optimism about long COVID organizing under a potential Harris administration.

One recent review paper found over 400 million people have developed long COVID worldwide,

costing an estimated $1 trillion to the global economy. About 18% of U.S. adults have experienced the disease, with higher rates among women and LGBTQ+ people, and 1 in 4 people currently living with it experience “significant activity limitations,” according to surveys from the Centers for Disease Control and Prevention (CDC). Many can no longer work, attend school, or engage with their communities. And the numbers grow with every new COVID-19 wave.

Some people with long COVID have shared these experiences with politicians and in the media as they organize for scientific research, health care, and social support. At a Senate committee hearing in January, long COVID advocates packed the chamber and encouraged senators to attend with phone campaigns. The hearing contributed to new legislation introduced this summer that would provide over $10 billion in funding for research and health care.

Scott Hugo, a housing justice attorney with long COVID, wrote an open letter to the Harris campaign asking it to recognize this growing population. In an interview, he explained the connection he sees between the campaign’s message of supporting vulnerable members of society and the struggles people with long COVID face to find medical care, access government services, and educate their loved ones about the disease. By publicly discussing long COVID, Harris could inspire people in this community to vote and organize when they were previously apathetic about the election, he suggested.

“None of us are disposable, and I think that’s what the Democratic Party understands,” Hugo said. His message to the Harris campaign: “You want us in your coalition, and you need us in that coalition to win.”

Somoza and the campaign’s press team did not provide comments for this story.

New openings for Long COVID advocates

President Joe Biden has been unpopular with many in the long COVID community. While claiming that the pandemic has ended, Biden has presided over 800,000 COVID-19 deaths and the rollback of public access to tools like tests and vaccines. He and Harris have rarely acknowledged the continued costs of ongoing disease spread, including the millions of Americans with long COVID.

In fact, the president has only publicly said the term “long COVID” during events commemorating the Americans with Disabilities Act — a move that has garnered criticism from advocates as an empty gesture. People with long COVID, scientists, and medical providers have called on Biden to highlight the disease in other public statements, such as his State of the Union address, and include it in federal budget requests.

Biden’s presidency has been “a big letdown,” said Dr. Marjorie Roberts, a longtime advocate who has had long COVID since spring 2020. When he was elected, “I thought the cavalry had arrived,” she said, recalling the memorial for Americans who died of COVID-19 that the Biden team set up on the eve of his inauguration. But after that: “I kept waiting, kept waiting, and here it is almost four years later — nothing.”

While Harris is part of that administration, her new position as a presidential candidate offers a chance for "a more compassionate and transparent approach" to public health that could garner more trust from the long COVID community, especially through a focus on the connections between long COVID and other intersecting health and social issues, Bishof said.

Research has shown that long COVID disproportionately impacts women and gender minorities, as well as other marginalized groups. It can also complicate pregnancy, fertility, and other aspects of reproductive health. For women and LGBTQ+ people, "Long COVID adds to existing health care challenges, where individuals often face barriers to access and higher rates of chronic condition," Bishof said. Issues that are already part of Harris' platform could easily be connected to calls for more equitable long COVID health care and support systems, she added.

Meighan Stone, executive director of the advocacy organization Long COVID Campaign, also sees this opportunity. She noted that Harris' sister, Maya Harris, has spoken openly about her experience with lupus. "[Harris] knows intimately the experience, particularly of women of color, of not being able to access health care," Stone said. "I think that really is promising for our community."
"With a new administration comes new opportunities to organize, to advocate," said Dom Kelly, co-founder and president of New Disabled South. Kelly served as an advisor for Stacey Abrams' 2022 gubernatorial campaign, where his role included talking to disability community members and developing a policy platform. He sees potential for long COVID advocates to engage with Somoza.

Stone pointed out that Somoza's role is not novel to Harris' campaign: Biden's 2020 campaign included a similar position starting after that year's Democratic National Convention. Molly Doris-Pierce, the advocate in that role, hosted roundtables on disability issues and worked on other disability-focused events. But Stone agreed that Harris offers opportunities for long COVID advocates.

"We should absolutely meet with the disability engagement director, but also with the most senior campaign staff who are developing the campaign platform," said Stone, who has previously worked on presidential campaigns and with the federal government. She's particularly interested in who Harris may pick to lead federal health agencies, as these roles were likely "thrown back up in the air" when the ticket changed, she said.

As another example of openings for long COVID advocacy, Ezra Spier, member of the organization Long COVID Moonshot, pointed to a mention of the disease in the 2024 Democratic Party Platform. "It is exactly one sentence," Spier said, which includes long COVID clinical trials and a new research office formed under Biden. "It is one more sentence than I expected."

Walz's leadership in Minnesota

When Harris announced Walz as her pick for vice president, long COVID advocates quickly pointed out that, along with leading progressive health care and social policies, Walz has supported a unique long COVID program in Minnesota.

Minnesota's state health department was the first in the United States to set up a state-funded research and education program dedicated to long COVID. The program includes surveys to study how the disease impacts Minnesota residents, educational materials and support for health care providers, and grants to community organizations.

"Others have done little pieces of things, but our program is by far the most comprehensive of what's out there," said Kate Murray, the program's manager.

The health department's work started in 2021 using a CDC grant for agencies to study relationships between COVID-19 and health disparities, Murray said. In 2022, she and her colleagues worked on a budget proposal for the state legislature to continue the program, as the CDC funding was ending. The proposal didn't pass in 2022 but made it into the 2023 budget along with other proposals supported by a budget surplus and Democratic leadership in the state legislature.

Walz put the long COVID proposal "on his shortlist," Murray said. In addition to Walz's support, she attributed the budget win to local advocacy groups and state Sen. Lindsey Port, who has long COVID. This state funding has sustained and expanded the long COVID program, including new grants to health and community organizations working to raise awareness about and support people with the disease.

To advocates, Walz's leadership in funding Minnesota's long COVID program suggests he could champion legislation like the Long COVID Moonshot Act recently introduced by Sen. Bernie Sanders or raise the disease's national profile in other ways. He might increase awareness within the federal government, convene meetings of different federal agencies, or start a long COVID task force, Stone suggested.

"His accomplishments align with the goals and needs of the long-hauler community," said Greg Ceponis, a long COVID patient advocate based in Nevada. "When a lot of the community has really lost trust in the government, Walz has proven he's willing to go to the plate."

A desire to share stories

Some long COVID advocates who spoke to The Sick Times and The 19th hope to take Harris' position as an opportunity to share their stories and ideas with people on the campaign. "We have to do our part by organizing, by making our voices heard, and by underscoring to her and the rest of the country that we are a political force," said Hugo, the open letter author. Similar organizing has already helped to raise long COVID's profile in Congress, said Spier from Long COVID Moonshot.

"Folks in the community should be sharing their stories with the campaign directly, talking about the impacts of long COVID, how it has changed their lives," said Kelly at New Disabled South. In addition, long COVID advocates should be part of coalition calls with other members of the disability community, he said.

The Harris campaign could also help support public education about long COVID, a common goal across advocacy groups. While research indicates millions of Americans have the disease, many may not recognize or identify with it — and this is especially true for people in communities underserved by the health system. Better public awareness could foster additional political organizing, advocates say.

Others in the long COVID community remain skeptical of Harris, however, as they feel abandoned by the Biden administration's minimal response to this growing crisis. Harris and her team have yet to publicly acknowledge long COVID, and she describes the pandemic "in the past tense," said Roberts, who has been waiting for meaningful government action on this disease since 2020.

"We are an untapped market," Roberts said, of the millions of Americans with long COVID. "We're just sitting here waiting. All I need is for them to acknowledge us.… That's a start."

This article was produced in partnership with The 19th.

This article was published by The Sick Times, a website chronicling the long COVID crisis, on September 24, 2024. It is republished with permission.

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