

Long COVID study will dig into treatment options. 'I think a lot of people are really desperate'

September 13 2023, by Ilana Arougheti, Chicago Tribune



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At first, Debbie Tumbarello's wedding was the height of romance—a Valentine's Day whirlwind straight out of "Sleepless in Seattle," she said.

Tumbarello, who lives in Inverness, Illinois, married her husband in Las Vegas on Feb. 14. She left Vegas with memories of a Beatles tribute show and a rooftop ceremony. However, she also left with COVID-19—and hasn't come back to full health since.

"The symptoms of the cold went away, but as the weeks progressed, I just started sleeping," Tumbarello said. "On the weekends, I'd be sleeping 14 to 16 hours a day ... My husband was freaking out. He's like, this is just not you."

After hearing about her brain fog, [extreme fatigue](#) and [joint pain](#), an infectious disease specialist at NorthShore University Health System diagnosed Tumbarello with long COVID.

Now, Tumbarello has prequalified for a nationwide study aiming to learn more about long COVID and design treatment and prevention programs. Sponsored by the National Institutes of Health, the study will test up to 11 combinations of treatments for long COVID. Organizers are not looking for a cure for COVID. They aim to learn why long COVID happens, both to stop future cases and to help those already experiencing debilitating symptoms.

"NIH is committed to a highly coordinated and scientifically rigorous approach to find treatments that will provide relief for the millions of people living with long COVID," said acting NIH director Lawrence Tabak.

NorthShore-Edward-Elmhurst Health has become one of the study's four primary sites—and NorthShore doctors are actively recruiting participants.

NIH researchers picked primary sites based on proximity to communities heavily affected by long COVID. Access to relevant

medical equipment, the expertise of nearby doctors and strong track records of diversity in local clinical trials also played a role.

The first phase of the study, which included 24,000 patients, involved observing people with long COVID to see when and why symptoms develop. Phase two, now starting at NorthShore, includes three [clinical trials](#) targeting cognitive dysfunction, sleep issues and viral particles.

Up to 40,000 people could participate in the study overall, some for up to four years. The entire initiative will receive \$1.15 billion in congressional funding over four years, \$811 million of which has already been allocated.

Some patients will receive either extended doses of Paxlovid or a placebo in the Recover-Vital clinical trial, meant to eliminate the lingering presence of SARS-CoV-2 viral matter in the body. Paxlovid is already used to treat some short-term COVID cases, but this trial will test whether the drug could also keep the virus from causing long-term damage to organs and the [immune system](#).

The Recover-Neuro section of the trials will address brain fog, memory problems and other neurological symptoms of long COVID. Some participants will use online programs meant to boost cognitive and executive functioning. Others will undergo transcranial stimulation, where small electric currents are sent through the brain to improve blood flow.

The third section of the trials, Recover-Sleep, will compare two different medications that could be used to stop excessive daytime sleepiness. Other proven interventions for problems falling or staying asleep will be tested in groups.

A fourth section, Recover-Autonomic, will take place at other sites. The

trial will test different combinations of medications to help symptoms related to the autonomic nervous system, controlling automatic processes in the body.

The study's first patient, Evanston resident Jobi Cates, started in the Recover-Vital clinical trial last week.

Cates, 52, contracted COVID for the first time in March 2023. What felt like a bad cold developed into a "heavy feeling" that reminded Cates of pneumonia. Within a month, her heart was racing constantly, an early sign of long COVID.

Cates took an extended leave from her job as executive director at a criminal justice nonprofit. However, "radical rest" was only so effective against what was eventually diagnosed as long COVID. Cates was also diagnosed with POTS, an autonomic nervous system disease causing heart, hormone and blood flow issues.

In the early months of long COVID, Cates didn't leave her apartment. She couldn't drive, prepare meals, sit upright at her computer or talk on the phone for more than 20 minutes. While heart medication has helped, her walks are limited to a block or two and her social contact is severely restricted.

"My life as I knew it before is over," Cates said. "Hopefully I get some of it back someday."

Long COVID can be difficult to identify, as symptoms vary widely, said Dr. Nirav Shah, the study's primary investigator at the Edward-Elmhurst sites. Many patients are "essentially disabled" by the time they are diagnosed, and remedies are sparse.

Shah, an infectious disease specialist at NorthShore, hopes the Recover

trials at Edward-Elmhurst will bring some long-awaited relief for Chicagoland patients.

"Our system is really excited," Shah said, "especially the clinicians who have been taking care of long COVID patients."

More recent strains of COVID seem to lead to long COVID less frequently, Shah said. Hispanic adults, as well as bisexual and transgender adults, tend to develop long COVID more frequently.

Both Cates and Tumbarello were fully vaccinated before contracting COVID this year.

Edward-Elmhurst Health includes eight hospitals across six counties. Shah leads a team of nine health care professionals from NorthShore who are organizing the study. Other NorthShore doctors are actively recruiting their own patients.

Being recruited directly "made a huge difference," Cates said.

"Trying to get into (a long COVID clinic or study) is a task that I don't necessarily have the energy for at this point," Cates said. "I don't have the energy to do even 1/100th of what I used to do in a day."

The team initially reached out to 2,000 potential long COVID patients in the Chicago area, Shah said. Between 50 and 75 people responded.

"I think a lot of people are really desperate for treatment options in a space where there hasn't been many," Shah said.

Prequalifying for the study mostly involved speaking with the study team about her symptoms. Tumbarello said. For her, brain fog has been a particular issue.

"Some days, I just have trouble putting the words together," Tumbarello said. "If you haven't had COVID, there's no way to describe it."

Tumbarello has been on medical leave from her job as an executive assistant since June. Her brain fog makes it difficult to get out of bed in the morning, she said, much less manage multimillion-dollar contracts.

Cates, too, experiences debilitating [brain fog](#). Her worst days, she said, remind her of when one of her parents was in the early stages of Alzheimer's disease.

"When I do get fatigued and sometimes even when I'm not, my brain gets very foggy and cloudy so I can't always think or talk the way I used to," Cates said.

Residents who think they may have long COVID and are interested in participating in the study can reach out to Edward-Elmhurst Health after consulting with their doctor, Shah said.

Cates and Tumbarello both encourage others to apply and to continue raising awareness for the trial.

"As much as I've lost from this, I'm still hopeful," Cates said. "All around Chicago, there are good people who, once they find out about long COVID, do whatever they can to try to help."

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Citation: Long COVID study will dig into treatment options. 'I think a lot of people are really desperate' (2023, September 13) retrieved 9 May 2024 from <https://medicalxpress.com/news/2023-09-covid-treatment-options-lot-people.html>

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