

As the search for treatments continues, many Maine patients still struggle with long COVID

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By Joe Lawlor

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Celia Koski of Westbrook has had long COVID since 2020. She has many symptoms and is participating in the Maine Medical Center's research on the subject. *Ben McCanna/Staff Photographer*

Celia Koski is never sure until she wakes up in the morning if she can make it to work at her skin care business. Diagnosed with long COVID-19 in 2020, Koski has good and bad days.

"I never know day to day whether I'm going to be able to work or not," said Koski, who suffers from symptoms including fatigue, "brain fog," headaches, tremors, severe joint pain and double vision. "It's such a bizarre disease and it's so new. It's frustrating not having the answers. But on the other hand, I understand why they don't."

The 65-year-old Westbrook resident said she tells her clients up front that she may have to cancel appointments on short notice. She's also had to scale back the total number of people she sees. Despite the frustrations, Koski said, she's still "very hopeful."

Koski is Patient No. 22 in the Maine Health Institute for Research's study of long COVID-19 patients, which is part of the National Institutes of Health RECOVER study (Researching COVID to Enhance Recovery). The aim is to help scientists learn about long COVID-19 and why some patients experience symptoms months or even years after being infected with the coronavirus. A better understanding could lead to effective treatments for long COVID, and some treatments already are being tested in clinical trials.

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It's unclear how many people have symptoms of long COVID – and to what extent. Estimates range from a low of 10% to as many as 50% of people who have been infected with COVID-19 have had symptoms that persist for months or years. Many estimates settle somewhere in the middle at 20% to 25%.

Dr. Clifford Rosen, principal investigator for the Maine Health Institute for Research, said that the societal impacts of long COVID are staggering, with many people having to drop out of the workforce or greatly scale back how much they work.

Rosen and fellow researchers at MaineHealth, through the study, could be part of the solution.

So far, 109 Maine patients are participating in the RECOVER study of 12,500 patients nationwide, enrolled through the institute. Maine joined the RECOVER study in December 2021 – receiving a \$1.5 million federal grant – and the first Maine patients were enrolled this year.

Scientists still don't know the cause or causes of long COVID, but Rosen said they're making progress.



Dr. Clifford Rosen, of Maine Health Institute for Research, is leading the Long COVID research effort at Maine Health. *Carl D. Walsh/Staff Photographer*

“One theory is that the virus is still there in the tissues, hiding out in the fat cells,” he said. “So people’s immune systems are not quite up to snuff because the virus has never been cleared.”

Another possibility is that the immune system is tricked into thinking the virus is still present even when it’s gone, causing immune reactions that make people feel sick.

“One of the questions we are looking to answer is whether the immune system (in long COVID patients) is not doing its job well enough or (is) doing its job too well,” Rosen said.

He said researchers also are looking at whether a spike protein on the coronavirus that has been detected in the blood of long COVID patients up to a year after they are infected plays a role in how long they suffer from symptoms. Another theory is that tiny blood clots known as microclots could be causing the problems.

As a patient in the RECOVER study, Koski has undergone a series of tests and evaluations, including genetic tests, blood tests, CAT scans, glucose measurements, physical therapy assessments and neurological exams. They are meant to establish a baseline of what types of symptoms people are experiencing and aid efforts to discover why.



Celia Koski of Westbrook is still hopeful researchers will find a way to ease her long COVID symptoms.
Ben McCanna/Staff Photographer

“I try to stay patient, and I’m hopeful that something is going to work,” Koski said.

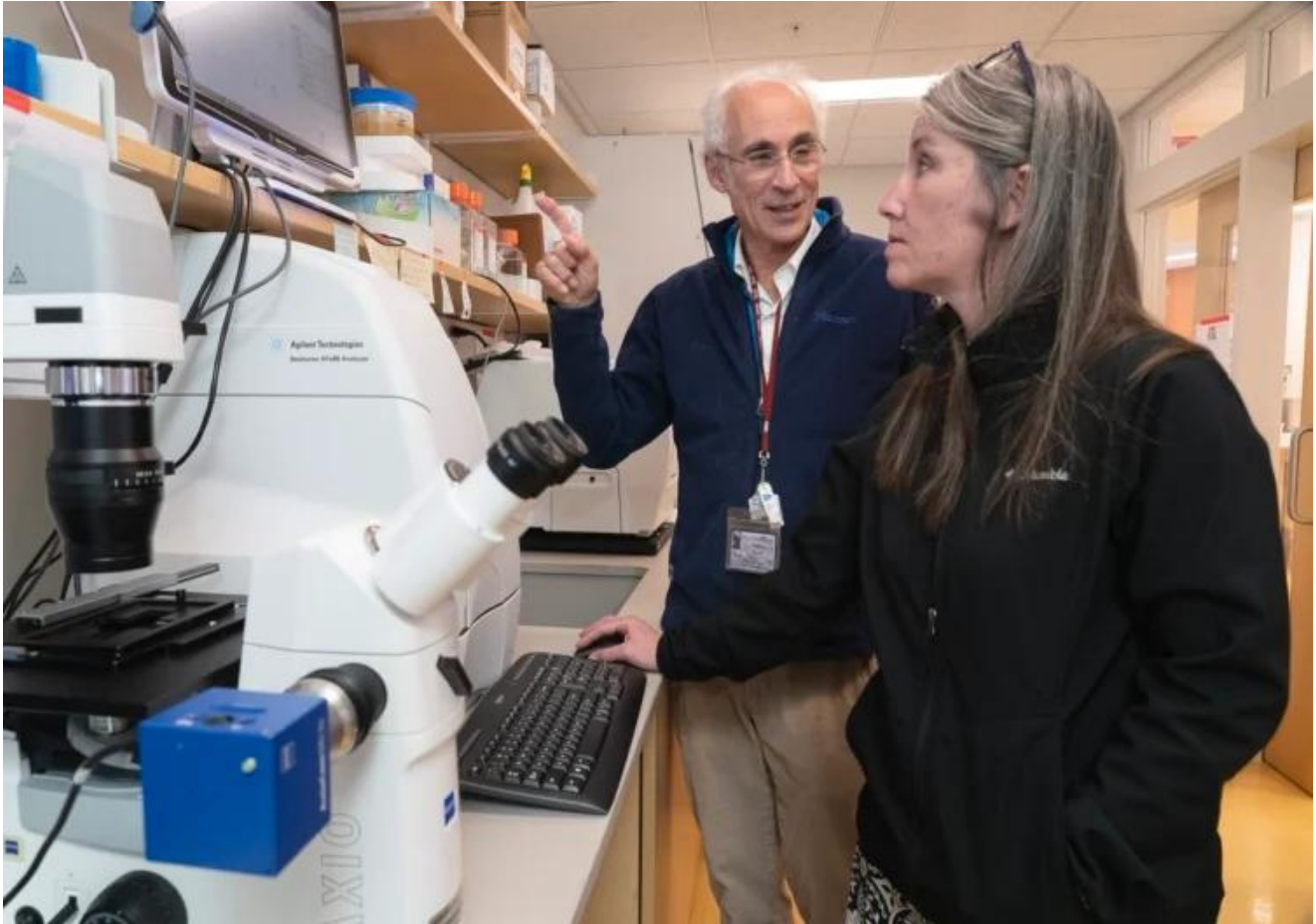
Rosen said there still is a lot of disinformation out there about the COVID-19 vaccines and long COVID. He said one thing is certain: The vaccines do not contribute to long COVID. Side effects from the vaccines, he said, are rare, almost always benign and resolve quickly.

TREATMENT RESEARCH

On the treatment front, the Maine institute is participating in two national medication studies, of immulina and paxlovid.

Paxlovid is an antiviral that’s currently given within five days of infection, but Rosen said it has potential for people suffering from long COVID. Immulina is a natural supplement – derived from an extract of blue-green algae – that aims to reduce inflammation and could potentially ease symptoms, Rosen said.

“For people who have long COVID, there are these new research trials being started all the time,” he said. “There is hope.”



Dr. Cliff Rosen, of the Maine Health Institute for Research, discusses Long COVID research with MIHR Manager of Physiology Care, Victoria DeMambro in the Scarborough lab. *Carl D. Walsh/Staff Photographer*

Another medication, naltrexone, showed promise this year in a small National Institutes of Health study of 52 patients who took a low dose, and will be researched further. Naltrexone is currently used to treat opioid and alcohol use disorders.

Koski said she has been cleared to take a low dose of naltrexone starting in January, and she hopes it improves her symptoms. Naltrexone is not part of the MaineHealth research.

One myth that is still out there, Rosen said, is that ivermectin can ease long COVID symptoms. He said ivermectin, which is used to treat intestinal parasites – does not work and can be harmful.

WAITING FOR RELIEF

While patients wait for effective treatments, their lives remain upended.

Dawn Summers-McDonald, 52, who is from Westbrook but has moved to Florida, said the long COVID symptoms she has had since 2020 have “destroyed my plans for my future.”

“I love to cook and I was thinking of opening up a catering business,” she said. Not only did she drop that plan but she’s isolated. She doesn’t socialize much, afraid of catching COVID-19 a second time.



Gretchen Drown of Portland holds a self portrait she painted when she was very sick with COVID-19. Drown has been struggling with long COVID for two years and has improved but still suffers with many symptoms. *Gregory Rec/Staff Photographer*

Summers-McDonald does immunoglobulin therapy at the Mayo Clinic, and that has helped, but she still suffers from many symptoms, including blurred vision, numbness, a burning sensation on the skin and gastrointestinal problems.

“I pretty much have had a sore throat every day for two years,” said Gretchen Drown, a 57-year-old Portland resident who is part of the RECOVER study. “It will flare up and reduce, but it almost never goes away.”

Drown, who has suffered from long COVID since 2020, said her symptoms have improved over the past several months, but it’s still rare that she goes a full day without having any. They include feelings of euphoria and depression, nerve pain, insomnia and cognitive problems.

Drown believes the RECOVER study will be key to restoring her health. But she expects individualized treatments, not one that works for everyone, will yield the best results because people with long COVID have such a wide range of problems.



Gretchen Drown of Portland has been struggling with long COVID for two years and has improved but still suffers with many symptoms. *Gregory Rec/Staff Photographer*

“There’s not yet an understanding of what is driving these symptoms. This is going to be so important,” Drown said. “This is going to be the data set that all of our providers end up relying on for years to come.”

For people with long COVID who live in Maine and want to share their experiences, there is a support group on Facebook called “C19 Long Haulers Maine.”

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