RECOVER
Researching COVID to Enhance Recovery

An Initiative Funded by the National Institutes of Health

Spring 2024

RECOVER Newsletter

Thank you for being a part of the RECOVER study! We are so grateful to our participants for helping us learn more about Long COVID.

This newsletter has been created to share the latest updates from the RECOVER study with you.

VOICES OF RECOVER

Robin

Participant, Texas

In her 23 years working as a research nurse, Robin liked to describe herself as a "juggler-in-chief" who did many different kinds of tasks at the same time. Always quick to learn and help, she spent 2020 supporting some of the first studies testing COVID treatments. In 2021, she helped start one of RECOVER's first study sites in San Antonio, Texas, where she had the honor of signing up RECOVER's very first participant. Now, happily retired, Robin has come full circle with RECOVER, becoming the study's very last participant to join the adult cohort!

Robin (middle) participates in a RECOVER study visit with Dr. Thomas Patterson (left) and nurse practitioner Cheryl Farner

RECOVER FUNDING UPDATE

The National Institutes of Health (NIH) recently announced that it will fund RECOVER with another $515 million over the next 4 years. This means more research and opportunities to work with participants, patient and community representatives, researchers, and doctors to find answers for people living with Long COVID.

Read the full announcement at:
RECOVERcovid.info/funding

Take the Next Step with a Free Fitbit from RECOVER

As a RECOVER participant, you or your child (13 years or older) may receive a free Fitbit that you can wear like a watch or wristband. With a RECOVER wearable device, you'll learn new things about yourself like:

- Your heart rate and how it changes when you do activities
- How long and well you sleep each night
- How many steps you walk each day

By sharing this information with researchers, you can help them learn more about how your body works every day, not just during your study visits.

Being part of this program is up to you—you can choose to take part or not.

You can request a Fitbit for yourself or your child in 1 of 2 ways:

1. **Tell the study team that you or your child want to join the RECOVER Digital Health Program.**
2. **Next time you or your child fill out study surveys, click the option to join the RECOVER Digital Health Program (option only available at some study sites).**

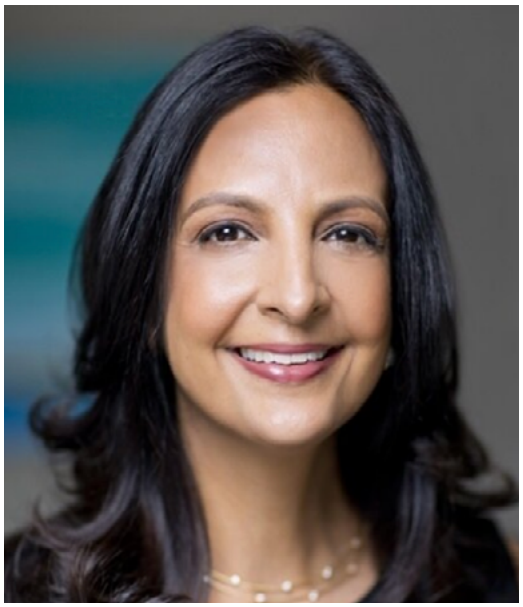
AN ENROLLMENT MILESTONE

In October 2021, RECOVER signed up its very first participants to join. Now, just over 2 years later, the adult and pregnancy studies have finished recruiting a large group of adults and pregnant people of different ages, races, and backgrounds. Thank you to all the participants who have made this possible!

The adult and pregnancy studies are now finished enrolling people, but RECOVER is still looking for children and young adults up to age 25 who have symptoms of Long COVID. Do you know someone with Long COVID who might want to join?

To find a cohort study site in their area, tell them to visit: studies.RECOVERcovid.org

RESEARCHER SPOTLIGHT



"We are actively working with data from patients who have enrolled in the study to try to better understand their symptoms and the right course of treatments required."

Rainu Kaushal, MD, on the Power of Big Data

When it comes to Long COVID, there is still so much to learn, says Rainu Kaushal, MD. A few questions she's working to answer are: Who gets it? How long does it last? What treatments might help prevent it or improve symptoms? One way RECOVER researchers are working to answer these questions is by looking at data, or information, from people's electronic health records, or EHRs.

An EHR is a digital medical chart that has health data like doctor visits, lab results, and other health history. RECOVER researchers like Dr. Kaushal can link data across the U.S. from different EHRs used by healthcare providers, hospitals, and other medical centers. This allows them to study more than 60 million patients, including people who are participants in RECOVER.

Dr. Kaushal has built her career studying big data, which involves using special software to look for patterns in health information about symptoms, diagnoses, and medications. She is excited about the things she and her team can learn by using big data. "We are actively working with data from patients who have enrolled in the study to try to better understand their symptoms and the right course of treatments required."

HOW PARTICIPANTS HELP RECOVER

RECOVER could not happen without you!

Completing surveys and going to study visits helps researchers collect data and better understand how Long COVID affects people over time. If you missed a survey for yourself or your child, make sure to contact your study site or check your email inbox for your last survey to see if there's still time to complete it.

There are also lots of new resources for participants on RECOVERcovid.info/participants including research questions, timelines of study activities and visits, and what to expect while in the study.

UNDERSTANDING THE RESEARCH

The following summaries are short overviews of published scientific papers and discuss 2 ways that Long COVID can happen in our bodies.

Immune Mechanisms

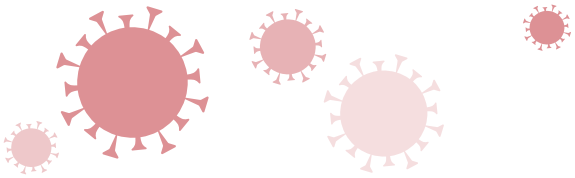
People who had COVID may develop Long COVID, which is when someone may experience various health issues after having COVID. Many of these problems are due to a strong reaction to the SARS-CoV-2 virus by the immune system (the body's defense system that fights infections). This reaction can happen a long time after the virus is no longer in the body. A healthy immune system can tell the difference between our body's healthy cells and the harmful ones that make us sick. However, an overactive immune system can make mistakes and cause harm because it may attack healthy organs and tissues. This paper talks about what scientists know so far about how this happens after getting COVID and how it can lead to both short-term and long-term problems.

Read the full article in *eLife* at:
doi.org/10.7554/eLife.86014

Viral Persistence

This paper explains how long SARS-CoV-2, the virus that causes COVID, stays in the body and whether it might become dormant (inactive) and then reactivate as part of its natural lifecycle. The authors write about whether the amount of time the virus stays in the body, known as the "persistence" of the virus, could be related to people developing Long COVID. They also describe what researchers know so far about this topic, what they still need to find out, and the types of research studies that may help answer these questions.

Read the full article in *eLife* at:
doi.org/10.7554/eLife.86015



Share Your Thoughts!

RECOVERcovid.info/NewsletterFeedback

We want to learn more about you! Take this brief survey to tell us about yourself and what you think about this newsletter.

YOUR DATA MATTERS

Your privacy is important to us. We will continue to follow all laws to protect your personal information, including the Health Insurance Portability and Accountability Act (HIPAA), which is a federal law that requires researchers and healthcare providers to follow specific privacy rules when handling patients' information.