

Summer 2023

RECOVER Newsletter

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

We have created this newsletter to share the latest updates from the RECOVER study with you.



VOICES OF RECOVER



Kawai

Young adult participant, Hawai'i

Born and raised in Honolulu, 24-year-old Kawai has always been active in her community. These days, when she's not playing softball or teaching preschool in her neighborhood, Kawai is busy studying for her law degree at the University of Hawai'i at Manoa, which she wants to use to work in Native Hawaiian rights.

But that hasn't stopped her from making time to help Long COVID research by taking part in the RECOVER pediatric study. "I had COVID and it was brutal," she says, but that's not the only reason she wanted to join. She also wanted to support her friends, one of whom got COVID twice and has been dealing with symptoms of Long COVID. "This pandemic has been like nothing before, at least in my lifetime," Kawai says, "so just to be able to help understand it better is cool."

Invite Your Family & Friends to Join RECOVER

RECOVER is still looking for children and young adults up to age 25 who are interested in helping Long COVID research. We're also looking for people who have been pregnant any time from 2020 onward. Do you know someone who might want to join?

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



WHAT WE'RE LEARNING

In a new paper, RECOVER researchers compared participants who had COVID at least 6 months ago to participants who never had COVID and looked at 37 symptoms that the first group reported more often. Out of these symptoms, they found 12 symptoms that best set apart those who have been infected with COVID-19 from those who have not:



Feeling tired and unwell that gets worse after physical or mental activity (post-exertional malaise)



Symptoms that affect the stomach and digestion (gastrointestinal symptoms)



Loss of sexual desire or ability



Dizziness



Feeling weak and tired (fatigue)



Long-term (chronic) cough



Loss of, or change in, taste or smell



Chest pain



Brain fog



Fluttering or pounding heartbeats (palpitations)



Feeling thirsty



Unusual movements (abnormal movements)

Through this study, researchers also found that participants who had Long COVID were more likely to have had COVID for the first time before the Omicron variant, had it more than once, and not gotten a COVID vaccine.

This research brings us closer to identifying, or figuring out, who has Long COVID based on their symptoms. However, more research is needed, including with children and teens, before this can be used to diagnose or treat patients.

Thank you again for being a part of RECOVER – we couldn't do it without you!

Learn more about this research and see answers to common questions at:

RECOVERcovid.org/updates/recover-research-qa

Read a summary of the paper published in JAMA at: RECOVERcovid.info/JAMApaper

Thanks to participants choosing to securely share their health data, researchers are making new discoveries about Long COVID. Here are 2 of the recent findings:

Possible Explanations for How Long COVID Develops

RECOVER researchers reviewed many published papers of COVID studies and found 4 main explanations in those papers for how Long COVID might develop in different parts of the body:

- **Long-lasting immune reaction:** When someone first gets COVID, it may make their immune system act strangely even after the infection is gone; this may cause symptoms in different parts of the body like the nervous system, the heart, the lungs, and more
- **Viral persistence:** The virus, or pieces of the virus, could stay in different organs even after the immune system tries to fight it off; some researchers believe that a COVID infection can wake up other viruses that are already in a person's body, such as the Epstein-Barr virus (EBV) that causes mono (infectious mononucleosis)
- **Autoimmune disease:** COVID may trigger the immune system to create antibodies that attack the body's own tissues by mistake, like what happens when someone has an autoimmune disease like lupus
- **Microclots:** The virus that causes COVID may cause tiny blood clots that block pathways to the heart

Scientists believe that there may be more than 1 process that causes Long COVID symptoms. By doing more research on these possible explanations, they hope to learn what treatments might be able to help patients.

Read the full paper published in eLife at:
doi.org/10.7554/eLife.86002

Things in the Environment That Increase Risk for Long COVID

RECOVER researchers studied the health records of more than 100,000 people in the New York City area and in parts of Florida, Georgia, and Alabama to find things in their environment that could make them more likely to get Long COVID.

In the New York City area, these things were:



In Florida, Georgia, and Alabama, these things were:



In the future, researching the environment in other cities and states could help scientists find ways to help treat Long COVID symptoms.

Read the full paper published in
Environmental Advances at:
doi.org/10.1016/j.envadv.2023.100352



Upinder Singh, MD, on Rising to the Global Challenge

Upinder "Upi" Singh, MD, describes herself as a "global traveler and citizen." Born in India, she spent time in Europe as a child before moving to the United States as a teenager and eventually going to medical school at The Ohio State University. She now leads a Long COVID research team at Stanford University, which has enrolled nearly 1,000 adult participants as part of the national RECOVER study.



"When I saw the terrible effects of COVID," says Dr. Singh, "I felt I had to get involved." But she's also hopeful about the future of research. "This is an important disease that's affecting the whole world, and by studying it, I think we'll also learn a lot about other post-viral conditions."

Watch a conversation with Dr. Singh and other researchers on the recent RECOVER paper published in JAMA at: bit.ly/JAMAlearninghub

Your participation is not something we take for granted. RECOVER could not happen without you. By coming in for your study visits, you're helping researchers collect data that helps them understand how Long COVID affects the body over time. This means you might be asked to repeat certain tests, to see if your health has changed since your last visit.

As RECOVER keeps growing, we will keep using your data responsibly and share with you what we learn along the way.

Thank you for joining RECOVER. We look forward to another year of discoveries, thanks to your partnership and trust.

Share Your Thoughts!



bit.ly/participantnewslettersurvey

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

A Reminder About RECOVER Policies

While the national Public Health Emergency for COVID-19 has now ended, there are still many people dealing with Long COVID who need help and treatment. That's why the work of RECOVER is really important right now. As a reminder, all RECOVER study visits will still be free.

