

An Initiative Funded by the National Institutes of Health

Spring 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



Carla & Sofia Participants, New Mexico

Carla and her daughter Sofia joined RECOVER to be part of the search for answers to Long COVID.

Sofia is 7 and loves science.
She is excited to learn more about the effects of Long COVID and what happens during a study. Carla is hoping that taking part in RECOVER will show Sofia that anyone, no matter how small, can help improve people's health in the future by taking part in research.

Stuart Katz, MD, on Getting to the Heart of the Matter

Stuart Katz, MD, has always been fascinated by the heart. As a cardiologist, he has spent his career trying to understand what causes the heart to fail.

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WHAT WE'RE LEARNING

Every person's health tells a story.

RECOVER researchers studied data from people's electronic health records (EHRs) and found 4 types of Long COVID. The 4 types are based on symptoms and health problems that happen together and are related to:

- Heart and kidneys
- Breathing, sleep, and anxiety
- Muscles and nerves
- Digestive tract and breathing

Read the full paper published in *Nature Medicine* at: doi.org /10.1038/s41591-022-02116-3

Patients, caregivers, and community members are a key part of RECOVER.
They work side by side with researchers to:

- Advocate for their community
- Provide feedback on study plans
- Share important research with the public

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But it wasn't until after he had COVID and continued to feel sick that he understood what it was like to be a patient searching for answers.

Today, Dr. Katz leads the team of hundreds of researchers that make up RECOVER.

"My personal experience with Long COVID gave me a unique perspective on the research. I spent 30 years researching heart failure but never experienced it. However, having experienced Long COVID, I now have a deeper understanding of what it's like to feel these symptoms, which helps inform my work as a doctor and a researcher."

As RECOVER completes participant enrollment this year, Dr. Katz hopes the study will discover what causes Long COVID and how different parts of the body are affected. This will help to create a clearer definition of Long COVID and inform possible treatments.

RESEARCH RESULTS

Symptoms Associated with COVID Infection in Children, Teens, and Young Adults

RECOVER researchers found that children younger than 21 years old who had COVID (tested positive) were more likely to have certain symptoms 1 to 6 months after their infection compared to children who didn't have COVID. These symptoms included:



Changes in taste or smell



Loss of smell



Inflammation (swelling) in the heart muscle (myocarditis)



Trouble breathing (acute respiratory disease)



Inflammation in the muscles (myositis)

These findings could help doctors better diagnose and treat Long COVID in children.

Read the full paper published in JAMA Pediatrics on August 22, 2022 at: doi.org/10.1001/jamapediatrics.2022.2800

Chance of Long COVID in Adults

Researchers in Scotland did a survey to ask over 96,000 people, ages 31 to 56 years, about their experiences with COVID. Among the people who had symptoms when they had COVID:

- Almost half (42%) reported only partially recovering, which means their symptoms improved but didn't go away
- Some (6%) reported not recovering at all

Compared to people who never got COVID, people with ongoing symptoms after COVID were more likely to have:

- Breathlessness
- Chest pain
- Palpitations (feeling that their heart is racing, pounding, or skipping a beat)
- Confusion



Read the full paper published in *Nature Communications* on October 12, 2022 at: doi.org/10.1038/s41467-022-33415-5

RESEARCH RESULTS (continued)

Risk factors for Long COVID in Adults

Risk factors are things that raise a person's chance of having a health condition. RECOVER researchers found that risk factors for Long COVID include:

Had a hospital stay of any length due to COVID

About 4 times more likely to get Long COVID

Had a hospital stay longer than 30 days

About 3.5 times more likely to get Long COVID

Being middle aged (40-69 years old)

About 2.5 times more likely to get Long COVID

Read the full paper in *medRxiv* on August 17, 2022 at: doi.org/10.1101/2022.08.15.22278603

Share Your Thoughts!



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 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.

RECOVER RESOURCES

Thanks to participants like you, researchers are starting to learn more about how to prevent and treat Long COVID.

We understand you might also have questions, and we want to help answer them. RECOVER has put together a list of FAQs to share what we know about Long COVID.

To learn more, visit: bit.ly/longCOVIDFAQs

Many parents have questions about the COVID vaccine. Getting the vaccine is a great way to keep kids healthy. Millions of children and teens have already gotten their COVID vaccine, which is how doctors have learned that COVID vaccines keep kids from getting very sick with COVID.

To learn more, visit: bit.ly/kidsvaxFAQs

