

Fall 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

Jessi

Participant, Washington

Jessi led a fast-paced life, balancing her job as a high school English teacher and starting the school's theater program. But everything changed when she got COVID in 2020. It started with a high fever, bad headache, and the feeling that her organs "just kind of hurt." She thought the worst was over after 2 weeks of being sick. So, she returned to work, only to find herself falling asleep at her desk. For 8 months, Jessi had many medical tests, went to the emergency room often, and even had 2 heart surgeries. The heart surgeries were to try and fix an arrhythmia, which is an abnormal rhythm of the heart. Doctors finally said she had postural orthostatic tachycardia syndrome (POTS). POTS makes your heart beat too fast when you stand up. It can make you feel dizzy or cause you to faint.

Since the day she got COVID in 2020, Jessi's life changed. She started needing aids, like a wheelchair, to help her get through each day. After work, she had to sleep instead of doing daily tasks. She couldn't do things she was used to always doing because she had so little energy. So, she made the difficult decision to leave her job. She now thinks of her energy like a battery and carefully plans how to use it each day. "I

do about half as much [as I would normally do], and sometimes that's too much. But whatever percentage I have to give, I'm giving 100%, because that's what I have," she explains.

"I am very different now than I was," she says, "but I like to think that's for the better. This experience has made me more empathetic [and] recognize my boundaries." Her advice for others living with Long COVID is, "to not be afraid to advocate for yourself." It might be hard to explain Long COVID to people who haven't experienced it. But it's important to speak up about how you are feeling to help others understand.



*Jessi and
her daughter, Fia*

YOUR PARTICIPATION MAKES A DIFFERENCE

Thanks to you, we're making important discoveries that help us gain a better understanding of Long COVID. The infographic below shows how much the adult and pediatric cohort participants are doing. As the study continues, these numbers will grow. We encourage you to continue completing study activities so we can make a big difference together.

SYMPTOM SURVEYS

These surveys ask about how you are feeling. Everyone completes the surveys, whether you've had COVID in the past, currently have COVID, or never had COVID.



83,846 Adult **17,596 Pediatric**

LABORATORY RESULTS

Lab tests study the samples taken during procedures like biopsies for adults or saliva for kids.



1,186,280 Adult **16,632 Pediatric**

OFFICE VISITS

Check-ups on your weight, height, blood pressure, heart rate, how your body reacts to standing up, and other tests.



31,374 Adult **3,815 Pediatric**

BLOOD SAMPLES

RECOVER researchers look closely at the cells in the blood for things that may be related to Long COVID.



32,350 Adult **16,346 Pediatric**

SMELL TESTS

This test helps RECOVER researchers understand your sense of smell using scratch and sniff cards.



4,428 Adult

CHEST SCANS

This test uses x-rays to see if your lungs are healthy or if you have trouble breathing.



3,196 Adult

FLEXIBILITY TESTS

The flexibility tests look at how your joints move, by checking how far fingers, thumbs, elbows, and knees can bend.



2,348 Pediatric

THINKING TESTS

A checkup for your thinking skills, like memory, focus, & problem-solving, to see how well your brain is working.



2,443 Pediatric

RESEARCHER SPOTLIGHT

Dr. Monica Verduzco-Gutierrez, MD

RECOVER Researcher and Director of the Long COVID Clinic at the University of Texas Health Science Center at San Antonio

Dr. Monica Verduzco-Gutierrez has a strong connection with her patients and understands the challenges they face on a personal level. She works in physical medicine and rehabilitation. Her goal is to help people recover and get their abilities back after injuries to the brain, spinal cord, muscles, bones, and joints. As someone who used to be a runner and is still very active, she relates to patients who were athletes but now can't do what they love because of their conditions.

"I see patients who know their bodies well," Dr. Gutierrez says. "They tell me things like, 'I used to be able to go out and run marathons, and now I can barely walk down the street without having a hard time breathing or my heart racing.'" By working with doctors from different specialties, Dr. Gutierrez aims to treat the whole patient, not just one symptom. She wants to help people with Long COVID do everyday tasks again. This will let them enjoy their hobbies and passions, even if they can't do everything the same as before they got sick.

Dr. Gutierrez is passionate about making sure that people with Long COVID get the care they need. This led her to speak before the U.S. Congress about access to healthcare.

Read more about Dr. Gutierrez's speech to the U.S. Congress at: RECOVERcovid.info/SpeechToCongress



"As I advocate for people with Long COVID, I can only do so much for them when I see them one at a time. Congress has a role in ensuring they get the services they need."



UNDERSTANDING THE RESEARCH

Characterizing Long COVID in Children and Adolescents

This RECOVER study is one of the first to look at Long COVID symptoms in children across age groups. Researchers for this study created a new research tool to help find children who are most likely to have Long COVID. The study asked about long-lasting symptoms in both school-age children (ages 6 to 11) and teenagers (ages 12 to 17). Researchers then compared symptoms between those who had COVID before and those who did not.

For school-age children with Long COVID, the most common symptoms were trouble with

memory or focus, back or neck pain, stomach pain, headache, fears, refusing to go to school, skin rashes, trouble sleeping, nausea or vomiting, and feeling dizzy. For teenagers with Long COVID, the most common symptoms were changes in or loss of smell or taste, pain in bones, muscles or joints, back or neck pain, feeling tired all day or after walking, low energy, trouble with memory or focus, headache, and feeling dizzy.

The study showed that Long COVID symptoms can affect almost every part of the body. It also found that, while many of the symptoms were similar for both age groups, there were some differences. Understanding why these differences happen can help create future Long COVID treatments for children based on their age.

Read the full paper at:
[doi:10.1001/jama.2024.12747](https://doi.org/10.1001/jama.2024.12747)



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NewsletterFeedback](https://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.

