

Winter 2024

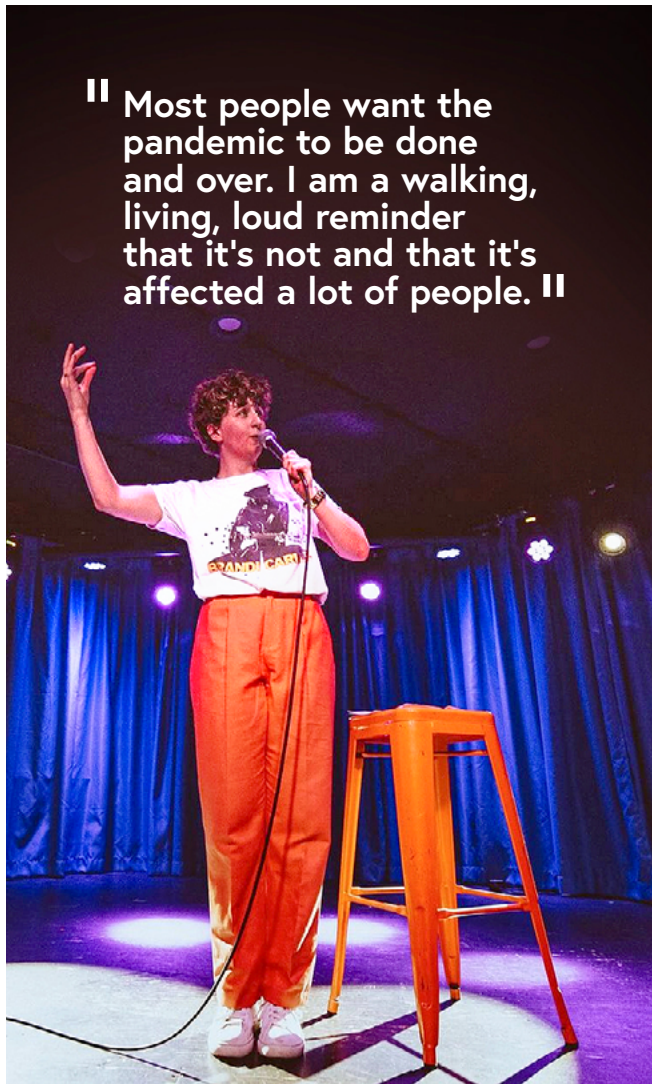
RECOVER Newsletter

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



“Most people want the pandemic to be done and over. I am a walking, living, loud reminder that it's not and that it's affected a lot of people.”

Camrynne

Adult Cohort Participant, Washington

When COVID-19 hit New York City in March 2020, actor and comedian Camrynne was living her dream, studying at the Upright Citizens Brigade comedy school and the Wynn Handman Acting Studio. She may have caught the virus on the subway, or at her busy restaurant job. Her fever lasted for an entire month, and as spring turned into summer, she started to have new symptoms that worried her. Camrynne struggled to stay awake and remember basic words. She could feel her heart racing, especially when she stood up, and was often short of breath. Her joints and muscles hurt all the time.

It was clear she was getting worse and not better, so Camrynne made the difficult decision to move home to her family in Washington. There, she built a new life for herself. She joined different research studies, including RECOVER, to help find answers about Long COVID. She began a career in stand-up comedy, hosting and producing a weekly LGBTQ+ open mic and variety show called Space Queers. Many of her jokes are based on her experiences with Long COVID, which starts important conversations. "Most people want the pandemic to be done and over," Camrynne says. "I am a walking, living, loud reminder that it's not and that it's affected a lot of people."

YOU ARE MAKING A DIFFERENCE

Because of you, we're making important discoveries that help us gain a better understanding of Long COVID. The pictures below show how much the adults and children in the study are doing. These numbers are as of November. 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.



94,201 Adult **19,053 Pediatric**

LABORATORY RESULTS

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



1,235,861 Adult **18,227 Pediatric**

OFFICE VISITS

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



36,473 Adult **4,684 Pediatric**

BLOOD SAMPLES

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



34,714 Adult **21,208 Pediatric**

SMELL TESTS

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



4,875 Adult

CHEST SCANS

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



3,781 Adult

FLEXIBILITY TESTS

This test looks at how far your fingers, thumbs, elbows, knees, and spine can bend.



3,760 Pediatric

THINKING TESTS

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



3,635 Pediatric

Dr. Igbo Ofotokun

RECOVER Principal Investigator (PI) of the RECOVER Atlanta Hub

Finding the answers to Long COVID is no easy task. It takes many years to understand Long COVID and how to treat it, which is why RECOVER is a long-term study. This means that researchers study participants over many years to gather important information. Dr. Igbo Ofotokun is a PI (the lead researcher) at the RECOVER Atlanta hub in Atlanta, Georgia, which has 5 study sites. He is an expert at studying chronic (long-term) illnesses. His background is in researching acquired immunodeficiency syndrome (AIDS) and human immunodeficiency virus (HIV), which are chronic diseases.

When the COVID pandemic hit, Dr. Ofotokun was called on to share his knowledge of chronic illnesses with RECOVER. His experience studying these conditions helps him lead a team of researchers to find the root causes of Long COVID. "These are people's lives," he says. "You need to get it right." Doing research on chronic diseases is more than a job. He says that patients "become part of your work family."

Long-term studies go on for many years, but Dr. Ofotokun says it's important to share findings with participants and the research community throughout the study. He explains, "We've put a lot of time into this together, and RECOVER is working hard to help people who are suffering."

At the Demystifying Long COVID North American Conference 2024, Dr. Ofotokun shared important findings from the research paper called, "Development of a Definition of Post-Acute Sequela of SARS-CoV-2 Infection." The paper highlights that RECOVER researchers found 12 main symptoms in people with Long COVID. This study is important because it is the first to explain what Long COVID is by looking at the symptoms people feel after a COVID infection. Other scientists have used this information to help with their own research, including finding new ways to treat Long COVID.

To learn more about the research, visit: recoverCOVID.info/AdultPASC-QA

To read the paper, visit: recoverCOVID.info/AdultPASC



"We've put a lot of time into this together, and RECOVER is working hard to help people who are suffering."



SHARING THE SCIENCE

A New Definition for Long COVID

A group of scientists that are part of the National Academies of Sciences, Engineering, and Medicine (NASEM) recently published the following new definition of Long COVID: "Long COVID is an infection-associated chronic condition that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems." This means that Long COVID can happen after getting sick with COVID and may get better, or go away and then come back again. It may also get worse over time. This new definition is an important step toward improved medical care, research, and support services for people living with Long COVID.

To learn more about the new definition, visit recoverCOVID.info/NASEMReport

Discover RECOVER Video Series



The Discover RECOVER video series is now live! These short videos talk about the study's Long COVID research in a way that is easy to understand. Hear from researchers and Patient, Caregiver, and Community Representatives who are helping find the answers to Long COVID.

The first video about Long COVID in children and adolescents is available at: recoverCOVID.info/PedsPASCVideo

UNDERSTANDING THE RESEARCH

This section gives an overview of published scientific papers about how well the vaccine works to help prevent Long COVID.



How Well the COVID Vaccine Works

RECOVER researchers found that adults who were vaccinated before getting COVID were less likely* to develop Long COVID. They also studied millions of electronic health records (EHRs) to discover that, in some children, COVID vaccines help lower the chance of getting Long COVID within the first 6 months of vaccination. After 6 months, the vaccines do not protect against COVID as well. This means that if a child gets sick with COVID, their risk of getting Long COVID is higher. It is important to get kids vaccinated for COVID every year to help prevent Long COVID.

Read more about how well COVID vaccines work in adults here:

doi.org/10.1038/s41467-023-38388-7

Read more about how well COVID vaccines work in children here:

doi.org/10.1542/peds.2023-064446

*These studies show that the COVID vaccines lower the chances of developing Long COVID in most people, but not in everyone. People that cannot get vaccinated because of other medical conditions should continue masking and practice safe social distancing in large gatherings.

STAYING SAFE THIS HOLIDAY SEASON

RECOVER Wants to Wish You a Happy and Safe Holiday Season

With more indoor celebrations happening this time of year, remember to get your COVID vaccine if you can, wear a mask in crowded indoor places, and get tested if you were exposed to COVID or have symptoms. Let's do our best to protect each other.

For more information on mask use, visit: recoverCOVID.info/Masking-CDC

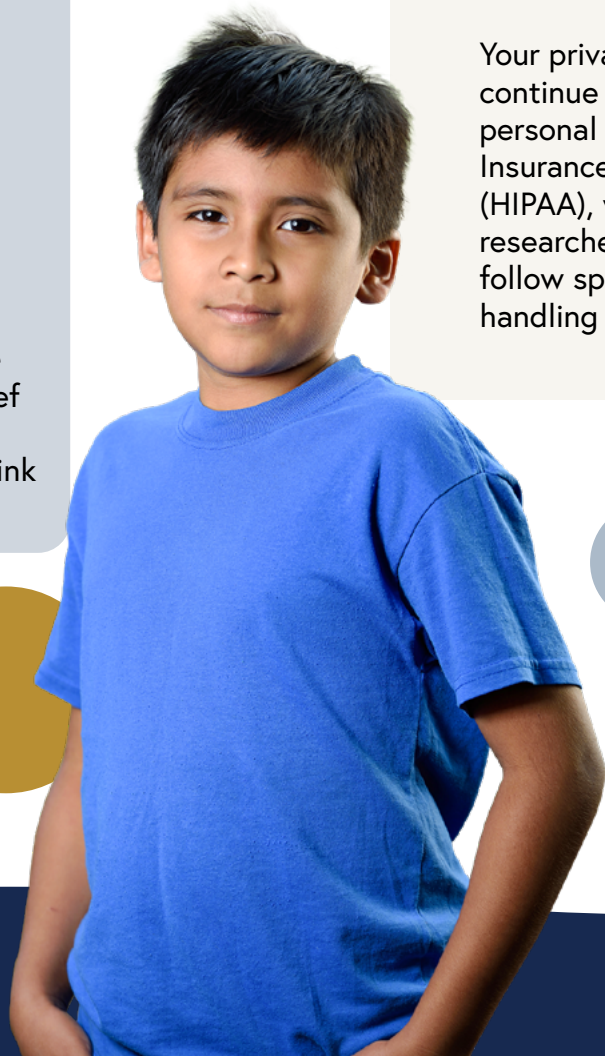


Share Your Thoughts!



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.