

Fall 2023

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

Thomas, Tommy, Katie, and Kammy *Participant family, Texas*

5-year-old Thomas loves airplanes—both the real kind that his dad, Tommy, flies for his job as a pilot and the toy kind that turn into alien robot superheroes through the power of imagination. But Thomas' Transformers aren't the only heroes in this story.

After Thomas had COVID, he got sick again, this time with a bacteria called C diff., which causes upset stomach and is very rare in children. With the help of special treatment, he got better, but his parents still have a lot of questions. Could Thomas' stomach illness have been related to his COVID infection? If not, what else could have played a role? Are there other kids like Thomas who have gotten rare infections after COVID?



Tommy (top left), Katie, Thomas, Kammy, and pups Lady and Buster



"Be brave"
– Thomas

Thomas and his family joined RECOVER together so they could help scientists get one step closer to solving these mysteries. Thomas may be young, but he knows he's part of something important. When asked if he has any advice for other kids who might be nervous about participating in research, he says, "I'd tell them to be brave." As for Tommy's advice to other parents, he says, "Trust your gut and continue to speak up for your child."

RECOVER RESOURCES

Talking About Long COVID with Your Child's Doctor

Working with patient, caregiver, and community representatives, RECOVER has put together a tip sheet to understand what Long COVID looks like in kids and the steps you can take to learn more and get the help you need.



Download it at:

RECOVERcovid.info/KidsTipSheet

Conversation About Long COVID in Kids

For more information on Long COVID in kids, including common symptoms, what parents should do if they think their child might have Long COVID, and where the study is headed, watch a recent conversation with RECOVER researchers at:

RECOVERcovid.info/KidsLearningHub

WHAT WE'RE LEARNING

Keeping the Focus on Long COVID

Around the world, there have now been more than 770 million cases of COVID. While ranges vary, in the United States, it's estimated that approximately 7% of adults have experienced Long COVID. "We must keep the virus, and Long COVID, center stage," write 3 people working on RECOVER—a patient representative, researcher, and community engagement leader—but there are things we can all do to make a difference.

Read the full article at

medpagetoday.com/opinion/second-opinions/106296

What Comes Next

People with Long COVID need solutions, including treatment. Now, thanks to everything we've learned from participants like yourself, RECOVER is starting to test possible treatments for Long COVID through studies called clinical trials. These trials are only enrolling adults, but researchers know that trials for children are also needed in the future.

To find out more, visit:

trials.RECOVERcovid.org

On this website you can sign up for email updates and find information about the study design, project leaders, and frequently asked questions.



How Patients and Researchers Work Together on RECOVER

Long COVID patients, caregivers, and community members contribute to all parts of RECOVER, including scientific research. A team of patients and researchers recently published a paper on why they chose to work together and how their partnership has improved the study.

The term "Long COVID" was created by patients who got sick during the early days of the pandemic. They connected with each other through social media and online support groups, but struggled to find doctors who understood what they were dealing with. "It literally felt like no one could hear us, even though we kept trying," writes Krista Coombs, one of the authors of the paper.

"I learned that it is ok for me to demand a space to tell my story in whatever way I am comfortable, and that I have things to offer as well as a new outlet for expressing my challenging experiences."



Krista Coombs,
RECOVER Representative

Some of these first patients went on to publish newspaper articles and one of the first scientific papers on the long-term effects of COVID. However, because not everyone from that time could prove that they'd had COVID with a test result, some research studies didn't include them. In response to this, patients worked with RECOVER researchers to ensure Long COVID patients could be included in the study—whether or not they had a positive test.

Many people with Long COVID have been sick for years now, and for patients, participating in research and advocacy can be a way to serve as a voice for those who are suffering.

Read the full paper published in *eLife* at:
doi.org/10.7554/eLife.86043

How COVID Affects Children with Type 1 Diabetes

Type 1 diabetes is a chronic, or long-term, condition that causes a person's immune system to make a mistake by harming the cells that produce insulin, a hormone that the body needs to turn sugar into energy. About 1 in 400 children in the United States have type 1 diabetes.

RECOVER researchers wanted to know how getting COVID affects young people with type 1 diabetes and whether it could cause their condition to get worse. They checked the electronic health records of 2,404 children and compared those who had COVID to those who did not have COVID during the same period of time.



The researchers looked at both groups of children's blood test results to compare their levels of a blood sugar called hemoglobin A1C. People who are being treated for diabetes usually get this test done twice a year to measure how well their condition is being controlled.

The RECOVER researchers found that children who've had COVID had higher levels of A1C for the first 3 to 6 months after their infection. This means their diabetes was less well controlled than in children who didn't have COVID. This finding suggests that doctors should continue to keep a close watch on children with type 1 diabetes after they get COVID, to make sure they are getting the care they need.

Read the full paper published in *Pediatric Diabetes* at:
doi.org/10.1155/2023/8798997

Hector Bonilla, MD, on a Lifetime of Learning from Patients



"Long COVID is a real problem," Dr. Bonilla says. "What you are experiencing is very real, and we are working as hard as we can to find answers."

Hector Bonilla, MD, has spent his career studying new viruses and diseases that doctors don't fully understand. As a young doctor, his first job focused on patients with human immunodeficiency virus (HIV), many of whom were very sick and had been stigmatized, or treated badly by society, because of their illness. In addition to working directly with patients, he helped test new HIV treatments through clinical trials.

Eventually, Dr. Bonilla's interest in HIV led him to study another disease called myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS), which often starts with a viral illness such as mononucleosis (mono). People with ME/CFS can struggle with many symptoms, including extreme tiredness, brain fog or trouble thinking clearly, muscle pain, joint pain, and dizziness.

When people with Long COVID first started speaking out about their symptoms, Dr. Bonilla noticed that some of their symptoms sounded very similar to the symptoms of ME/CFS. Dr. Bonilla recognizes how much doctors can learn from hearing patients' stories in their own words, and he wants people with Long COVID to know that researchers are listening.

Watch a conversation (in Spanish) with Dr. Bonilla and another RECOVER researcher about what they're learning at: RECOVERcovid.info/videoUNIDOS

Take the Next Step with a Free Fitbit from RECOVER



As a RECOVER participant, you or your child can 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).

Invite Your Family & Friends to Join RECOVER

RECOVER is still looking for children and young adults up to age 25 who are interested in participating in Long COVID research. The RECOVER observational cohort study will not give anyone a treatment or medicine for COVID.

Do you know someone who might want to join?
To find a cohort study site in their area, tell them to visit:
studies.RECOVERcovid.org



Looking for Patterns in Participants' Data

Your participation is not something we take for granted. RECOVER could not happen without you. When you come in for your study visits, you're helping researchers collect data, which helps them find patterns in how Long COVID affects the body over time. This means you might be asked to repeat certain surveys and tests so doctors can see if your health has changed since your last visit.

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.



YOUR DATA MATTERS

Your privacy is important to us. We will 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.

