

An Initiative Funded by the National Institutes of Health

# Spring 2025 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.



## ENROLLMENT COMPLETE FOR RECOVER'S OBSERVATIONAL STUDY



On December 31, 2024, RECOVER finished enrolling children and teens into the pediatric cohort. We completed enrollment for adults and pregnant people at the end of 2023. Now, the RECOVER observational study has all the people we need!\*

Even though we're done signing up participants, our work isn't finished. Researchers will keep studying Long COVID with information from your study visits and tests. By looking at data from participants, researchers can better understand what can cause Long COVID, look for new ways to treat it, and find ways to stop people from getting it. This research will help doctors take better care of everyone in the future. Thank you for being part of this historic journey!

\* The tissue pathology cohort continues to honor tissue donations.

## YOU ARE MAKING A DIFFERENCE

March 15, 2025 is Long COVID Awareness Day—a time to support the millions of patients, caregivers, and community members living with Long COVID. RECOVER stands with you. Our project will continue sharing how Long COVID has changed lives and why research studies like RECOVER are so important.

To learn more about Long COVID Awareness Day, visit: recoverCOVID.info/LCAwareness-Spring2025



#### **VOICES OF RECOVER**

#### The Peterson Family Pediatric Cohort Participants, Rhode Island

Millions of families around the world have seen and felt the impact of the COVID-19 pandemic. For some, like the Petersons, those effects have lasted much longer than expected. Before getting COVID for the first time in 2020, the Petersons were a busy, active family. Olivia, the oldest child, loved organizing games with neighbors like water soaking contests and races. Will enjoyed science and playing outside. Both kids excelled at karate and earned their brown belts. But everything changed once they got COVID. Olivia and Will started to feel tired all the time and couldn't play outside like before. Some days, they were so tired that they slept all day and night. Their muscles hurt, and they had bad headaches. Their symptoms were so bad that they had to stop going to school.

Although Amy, their mom, did not get Long COVID, she developed myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS) a few years ago after getting sick with a different virus. ME/ CFS makes her body and brain very tired, so she has to stay in bed a lot. Long COVID and ME/CFS share similarities because some people with Long COVID also feel exhausted for long periods of time. ME/CFS can also happen to people who've had COVID. Even though Amy's experience with ME/CFS wasn't related to Long COVID, it helped her family understand what was happening when the kids developed Long COVID.

RECOVER recently found that Long COVID symptoms can look very different in each person, especially in kids. This means families coping with Long COVID often have many different needs at once. The Petersons have found ways to make their home comfortable for everyone. Olivia sometimes needs to sleep while others are eating dinner, but when she wakes up at 3 a.m., she finds a fridge stocked with food so she can easily fix herself a meal. Will struggles to eat vegetables because of his stomach problems, so he snacks on fresh basil and mint that the family grows.



These days, everyone sleeps at different times. The Petersons have a sleep zone and an awake zone. The sleep zone is cool and dark. The awake zone has a TV, big sunny windows, a computer, and healthy snacks. This setup helps everyone rest while making sure whoever is awake can enjoy fun activities, like playing Legos or folding Origami. "We build our lives to make things easier," Amy explains. "We also try to keep calm and be kind to each other." Life is very different now for the Petersons, but they work together to support and care for one another.

## RECOVER's Digital Health Program is Closing

Thank you to everyone who has been a part of the RECOVER Digital Health Program (DHP).

Because of you, we're getting closer to having enough digital health data to help us better understand Long COVID. The DHP has given RECOVER important information about how Long COVID can affect someone over time. Now, RECOVER's leaders have decided to focus its limited time and funding on other studies, like ones that explore treating Long COVID. Because of this, the DHP will end soon.

#### Please continue using your RECOVER Fitbit until April 7, 2025 to help us reach our goals!

You can keep your Fitbit and use it once the program ends—there's no need to return it. Remember to keep going to your regular RECOVER visits and completing your surveys. Your participation continues to make a difference in understanding Long COVID by helping researchers collect important data.

## Long COVID and ME/CFS in Adults

A new RECOVER study found that adults who had COVID were more likely to develop a condition called myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) compared to those who didn't have COVID. ME/CFS can be very severe and is similar to many forms of Long COVID. Even small amounts of effort can lead to days or weeks of physical and mental exhaustion in people with ME/ CFS. Researchers studied about 13,000 RECOVER participants and found that 4.5% of adults who had COVID in the study later developed ME/CFS, while only 0.6% of those who didn't have COVID got ME/CFS. These findings highlight the need for healthcare professionals to be aware that ME/CFS can develop after a COVID infection.

"Showing the increased risk of ME/CFS after getting COVID is important. It can help us understand and find solutions for ME/CFS, Long COVID, and other chronic (long-lasting) illnesses that can happen after getting sick with a virus." — Emily Taylor, RECOVER Representative, and co-author of this paper

Read the full article in the Journal of General Internal Medicine at: recoverCOVID.info/MECFS-Spring2025

For more information about ME/CFS, visit: recoverCOVID.info/MECFSFacts-Spring2025



## **Discover RECOVER Video Series**

Explore RECOVER's video series, **Discover RECOVER**, which features short videos that highlight study findings.

Explore the videos here: recoverCOVID.info/DiscoverRECOVER-Spring2025

#### **RESEARCHER SPOTLIGHT**

#### Dr. Jessica Kosut, on Hawaii's Unique Role in Pediatric Long COVID Research

Dr. Jessica Kosut is the Division Chief for Pediatric Hospital Medicine and Medical Director of Inpatient Pediatrics at the Kapiolani Medical Center for Women & Children in Honolulu, Hawaii. She's working to understand and improve care for children with Long COVID. Growing up in Cupertino, California, she learned how seeing different points of view can help solve tough problems—a skill she uses in her work as a RECOVER researcher.

Hawaii is one of the most ethnically diverse places in the US, and Dr. Kosut believes this is important for Long COVID research. Studying Long COVID in children is challenging, especially since younger kids may not know how to explain their symptoms. Surveys can help, but they don't give the full picture of someone's health. By including children from many backgrounds, her site helps RECOVER learn how Long COVID affects kids in new ways.

Dr. Kosut's team makes sure families at their site feel welcomed and valued. They create newsletters for the local community with thoughtful details, like drawings that show holiday events around Oahu that might interest participants. Families in focus groups shared that they don't usually get study results, so her team made sharing updates a priority. By celebrating community diversity and building connections, her work helps research for children across the country while keeping families informed and part of the process.



"We want the research to reflect the experiences of every child," says Dr. Kosut

## 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.