

Long COVID Tissue Pathology Study: Key Messages for Families

What is Long COVID?

A condition in which a person is still sick many months after getting COVID. It can include:

New or ongoing symptoms, such as:

- Trouble breathing
- Feeling weak and tired
- Trouble thinking or "brain fog"
- Cough
- Multisystem inflammatory syndrome in children and adults (MIS-C and MIS-A)
- Fever
- Anxiety or depression
- Low blood oxygen levels

Problems with certain organs, such as:



Heart



Lungs



Kidneys



Brain

Who can take part in the tissue pathology study?

Deceased adults ages 18 and older who:

Had suspected, probable, or confirmed COVID as defined by the World Health Organization (WHO) criteria and meet any of these:

- Did or did not meet clinical criteria of PASC as defined by WHO
 - The deceased did not have to die of COVID, or have a confirmed case, just suspected or probably
- Died during any of these timeframes:
 - 30 days or more from the time their COVID symptoms began (symptom onset)
 - 30 days or more after a COVID diagnosis, whether still hospitalized or discharged (released)
 - After having fully recovered from COVID (30 days or more from symptom onset), whether hospitalized or not at time of death
 - Had acute COVID (current) infection and died 15-30 days from symptom onset

What is the RECOVER tissue pathology study?

RECOVER is a research project that aims to learn about the long-term health effects of COVID (called Long COVID). It's paid for by the National Institutes of Health (NIH).

The overall goal is to better prevent, test, and treat Long COVID.

As one of the RECOVER studies, the tissue pathology study aims to:

- Identify, evaluate, and characterize the clinical manifestations (signs) of Long COVID in adults who die after COVID infection, with and without Long COVID
- Identify risk factors related to the severity of these clinical manifestations
- Consider differences in the clinical manifestations based on sex and race or ethnicity
- Create accurate and quantifiable measures for Long COVID symptoms to understand how Long COVID happens in the body

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Introduce the idea of tissue pathology

- If your loved one wanted to donate their organs, but doctors said they are unable to, there may be another way your loved one can help people in the future.
- You could agree to a tissue pathology, or research autopsy, to help researchers better understand COVID and Long COVID.



Explain Long COVID and RECOVER

- Long COVID is a health condition in which a person is sick many months after getting COVID. Doctors don't know why some people get Long COVID and others don't.
- There's a large study to learn more about Long COVID called RECOVER. The goal of the study is to better prevent, test, and treat Long COVID – to help people in the future.

Why you might agree to have your loved one in the study

- Tissue autopsy is a way to see how Long COVID affects the body, which cannot be done while people are alive.
- When a loved one dies, this research can be deeply meaningful for grieving family members, as they know their loved one is helping researchers learn how to help others in the future.
- Many people who decided to have their loved ones do similar autopsy research have described it as a positive way to cope with great loss.

If patients have questions, point out how to contact tissue pathology study coordinator for more details.

To learn more about RECOVER and find sites enrolling in the tissue pathology study, visit RECOVERcovid.org

