

# COVID MUSIC STUDY Understanding MIS-C

## ABOUT THE MUSIC STUDY (Long-Term Outcomes after the Multisystem Inflammatory Syndrome In Children)

Multisystem Inflammatory Syndrome in Children (MIS-C) is a rare condition that can affect the heart, lungs, kidneys, brain, skin and eyes after a COVID-19 infection. Because MIS-C is new, we are still learning about its causes and long-term effects. “Long-Term Outcomes after the Multisystem Inflammatory Syndrome In Children”, also called the MUSIC Study, will follow about 600 children with MIS-C at leading children’s hospitals in the U.S. and Canada.

## FREQUENTLY ASKED QUESTIONS

### WHAT IS MIS-C?

MIS-C appears to happen some time after a young person develops COVID-19. While it is normal for the immune system to fight off an infection, children with MIS-C seem to have their immune systems turned on too strongly. Children with MIS-C may have decreased heart function (meaning the heart doesn’t squeeze as well as it should), enlargement of the coronary arteries (the blood vessels that nourish the heart), and heart rhythm problems. We do not know how long these problems last or if there are long-term effects of MIS-C on other organ systems.

### WHAT WILL HAPPEN IN THIS RESEARCH STUDY?

1. The study team will collect data from your/your child’s routine clinical care, including laboratory test results and cardiac testing reports, such as echocardiograms (echo), electrocardiograms (ECG), and cardiac MRIs.
2. If the doctor has ordered tests as part of clinical care, such as an echo, ECG, or MRI, we may ask for these results. If a test or procedure is done for research because it was not a part of regular care, it will be paid for by the study and will not be charged to you or your insurance. You do not have to agree to any testing that is not part of routine care.
3. We will see you/your child at clinic visits that usually occur about 2 weeks, 6 weeks, and 6 months after hospital discharge.
4. One year after discharge from the hospital, we will look at your/your child’s medical chart and contact you to conduct a brief annual medical history form once a year for 5 years. We’ll ask about any operations, tests or times that you/your child were in the hospital, any medicines you/your child is taking, and if you/your child have developed any health problems. These questions should take about 20 minutes to complete.
5. *Optional:* We are trying to understand how differences in DNA (genetic make-up) may make young people susceptible to developing MIS-C. A sample of blood will be collected from you/your child and the biological parents for genetic research. If you/your child are unable to give blood, a sample of saliva (spit) can be given instead (but blood is preferred because it is more reliable for DNA testing). These samples from participants and their parents are optional and can be collected at any time during the study.

### WHO CAN JOIN THIS STUDY?

Anyone less than 21 years old can join this study if doctors believe they have had MIS-C.

### IS THERE ANY COMPENSATION OR COST TO ME?

Participants and caregivers will receive money to help with travel on visit days and to help compensate for time and effort. Most of the tests participants undergo will be part of their routine care. Optional tests that are done for research only and are not part of regular care will be provided free of charge.

### IS IT POSSIBLE TO LEAVE THE STUDY EARLY?

Yes, it is up to participants and their families to decide to be in the study. Once in, they may leave the study at any time. Being in the study will not affect any other medical care now or in the future.

### ARE THERE ANY RISKS TO ME WHEN I PARTICIPATE?

We will do everything we can to make you feel comfortable, schedule visits and times to talk with you around your family schedule and to protect your privacy.

### ARE THERE BENEFITS TO ME WHEN I PARTICIPATE?

We cannot promise any benefits to taking part in this research. It is possible that any tests performed solely for research purposes could reveal important findings. If that happens, results will be shared with you and your doctor.

### WHY SHOULD I PARTICIPATE IN THIS STUDY?

The results of the study will help caregivers, parents, and patients understand important things about the long-term health outcomes after MIS-C. The results may help improve care of children, teens, and young adults with similar problems in the future.

### WHAT SHOULD I DO NEXT?

1. Read the informed consent document where you will learn more details about the study.
2. After reviewing the document, ask your study team member about questions you may have.
3. If you decide to participate, you will be asked to sign the document.