UNIVERSITY OF
MICHIGAN HEALTH
MICHIGAN MEDICINE

Cystic Fibrosis Patient Registry

What is the Cystic Fibrosis Patient Registry?

The **Cystic Fibrosis Patient Registry** collects information on the health status of people with cystic fibrosis (CF) and cystic fibrosis-related metabolic syndromes (CRMS). The registry includes patients who receive care in CF Foundation (CFF)-accredited care centers like Michigan Medicine and who agree to participate in the registry.

The registry information is used to create CF care guidelines, help teams provide care to patients with CF or CRMS, and guide quality improvement projects at care centers. Researchers also use this registry to study CF treatments and outcomes and to design CF clinical trials. More information about the registry can be found on the CFF website: CFF.org/medical-professionals/patient-registry

How do I join the registry?

A member of the Michigan Medicine CF care team will talk with you about the CF Patient Registry during a clinic visit. If you agree to participate in the registry, they'll ask you to sign a consent form. By signing the form, you are giving us permission to enter information into the registry about your health and treatment. One of our coordinators will submit this information electronically to the CFF.

How long will I be in the registry?

If you give your permission, we will continue to enter your health information into the registry as long as you are cared for at our CF center or until you decide you don't want to participate in the registry.

Are there any risks to participating in the registry?

There are no expected physical risks or discomforts for participating in the CF Patient Registry, since we're simply sharing information about your health and treatments. The main risk of taking part in the registry is that, if there is a data breach, someone not involved in the registry would have access to your information. This risk is very low, as the CFF keeps patient information in a very secure online database that is protected with passwords and encryption codes.

Are there any benefits to participating in the registry?

There may or may not be benefits for you personally. We hope the information learned from the CF Patient Registry will help researchers, doctors, and other care providers better understand CF and CRMS, including how it develops, progresses, and affects patients. If you'd like, the CF care team can provide you with a health summary report from the registry. The registry may also help our CF care team tell if you may be eligible for CF-related research studies.

Do I have to participate in the registry?

Taking part in the CF Patient Registry is your choice. If you decide you don't want to participate, you will not be treated differently, and your health care will not be affected. You can stop taking part in the registry at any time without any issue. Feel free to ask the CF care team any questions you might have about the CF Patient Registry.

Who do I contact if I still have questions about the registry?

E-mail cf-research@umich.edu.

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