



**RARE
DISEASE**
CENTER OF EXCELLENCE

Rare Disease

WE WILL BE WITH YOU
EVERY STEP OF THE WAY.



Starting your care journey



Some patients and their families come to the Rare Disease Program with a diagnosis, while others are just beginning their diagnostic journey. Your pathway to answers and the right treatment may be unpredictable and complex, but your care team will walk this journey with you and will support you by listening, providing timely information, and collaborating to provide world-class care.

Where we are



Most patients with a possible or confirmed rare disease diagnosis are seen in our Explorer Clinic, on the 12th Floor of the East Building. The street address is 2450 Riverside Avenue, Minneapolis, MN 55454. Other pediatric specialty clinics are nearby on this campus and are connected to or near M Health Fairview Masonic Children's Hospital.

Next steps



For patients with undiagnosed conditions, the amount of time it takes to arrive at a diagnosis will vary. Our promise to you is that we will keep you informed, even if that means calling to say the care team has not found an answer yet. We will provide you with a time frame for next steps whenever that is possible.

Seeking support



While our team looks for answers, you may wish to investigate information on rare diseases.

The National Organization for Rare Disorders, or NORD, is a good place to start: rarediseases.org.

M Health Fairview Masonic Children's Hospital has been named one of only 31 Rare Disease Centers of Excellence by NORD. Their database of information on rare disorders and patient advocacy may be helpful.

The National Institutes of Health hosts the Genetic and Rare Disease Information Center: rarediseases.info.nih.gov

As you get closer to a diagnosis you may wish to search for disease-specific information and advocacy groups online.

Your care team

A patient navigator or care coordinator will be your main point of contact during your journey, but providers and staff in the roles described below may also be part of your team.

- A **patient navigator** will coordinate with other staff to schedule appointments, address financial needs and insurance questions, help arrange accommodations and travel, and answer questions.
- A **care coordinator** who is a registered nurse works with the Rare Disease Program to help make sure everything goes smoothly. The care coordinator can interpret clinical information and answer your questions.
- **Specialty care doctors** (often referred to as providers) The first provider you meet will depend on what is already known about the patient's health. Because a genetic difference often causes rare diseases, your first encounter may be with a geneticist. That doctor may refer you to others on the multidisciplinary team, including a neurologist (brain), endocrinologist (glands/hormones), cardiologist (heart), and pulmonologist (lungs), among others. Doctors from many specialties will work together to identify a diagnosis and treatment.
- A **genetic counselor** is a health care professional who gathers family medical history, facilitates and interprets genetic tests, and provides information and support to the patient and family. Patients see them during the diagnostic phase and for follow-ups.



RARE DISEASE

IS A CONDITION THAT AFFECTS FEWER THAN **200,000 AMERICANS** AT ANY POINT IN TIME

7K
RARE DISEASES
WORLDWIDE

25-30
MILLION

AMERICANS ARE LIVING WITH A RARE DISEASE

- A **social worker** will likely meet with your family, especially if you have any barriers to care such as need for short-term housing or financial challenges.
- A **registered dietician** may be part of your care team. Some rare diseases require special diets to improve long-term outcomes for the patient, so the dietician has an important role.
- **Child-family life specialists** work in our clinics and hospital to help children cope with medical routines, fear, anxiety, and pain. Play sessions and other activities help children learn about medical tests and treatments and normalize their health care experience.
- A **financial case manager** may work with you and your insurer to help you plan for covering the cost of care.

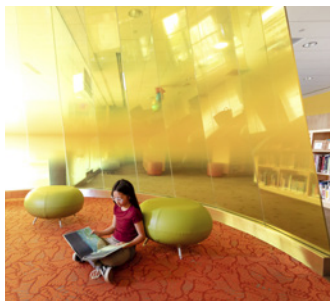


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Welcoming spaces

M Health Fairview Masonic Children's Hospital was designed to provide the very best in patient and family programs, and we have many fabulous spaces dedicated to fun, distraction, and enrichment during clinic visits and hospital stays. These spaces are located on the lobby level of the hospital. You are invited to visit:



The family resource center: A library and so much more! You'll find reading materials for babies through adults. Borrow a video game system, iPad, or movie. Use the library computers to do some work or print documents on the free printer/scanner/fax machines. Check out the weekly programming, such as story times and coffee hours in this space. It's a great place to just sit and relax.

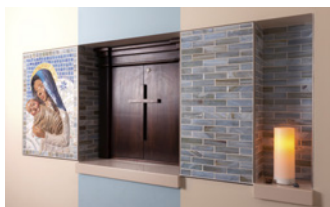


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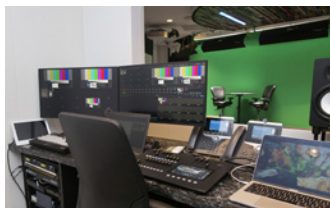
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Kyle Rudolph's end zone: A therapeutic play space open to pediatric patients and their families. Enjoy the sports simulator, indoor mini basketball court, bubble hockey table, quiet play area for young children, themed craft activities and more.



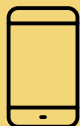
Quinn Seymour chapel: A quiet space that is always open for prayer or meditation. The design is pleasing to children and families. Many people stop by to write their hopes and prayers on slips of paper and tuck them into the branches of the chapel "tree."



Zucker family suite and broadcast studio: The studio hosts live and recorded content for pediatric patients and families.



Outdoor play spaces: Our Sullivan Playground and Sport NGIN Sport Court offer a place to get some fresh air and exercise.



If you have questions about your diagnostic journey, please reach out to a member of your care team or call 612-672-4009.

Thank you for entrusting your care with us!

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