Children's Wisconsin

Herma Heart Institute

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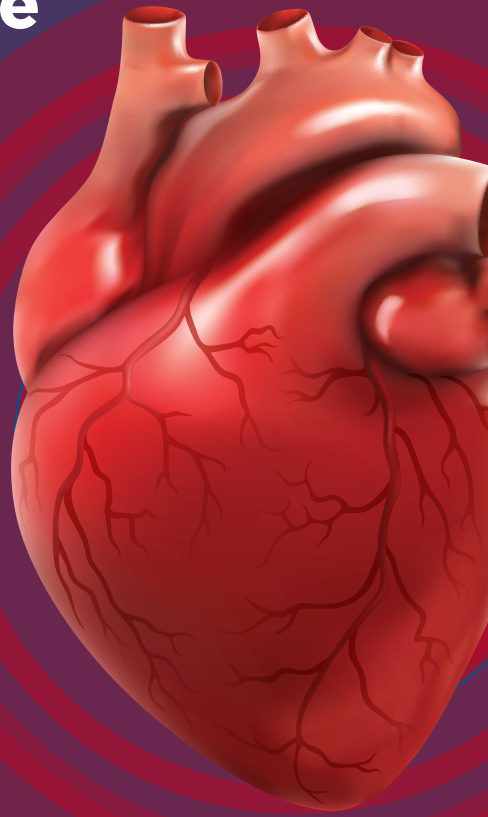
childrenswi.org/heart

Understanding pediatric heart failure

The importance of screening and specialized care



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The importance of screening for heart failure

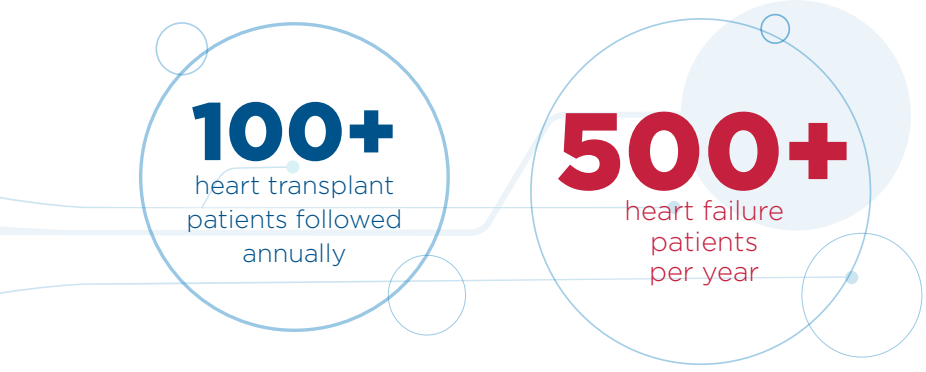
It is crucial that children who are at risk for heart failure be screened as early as possible. Screening can be a lifesaving measure, as children who present *in extremis* have a higher mortality rate. When children reach the point of severe damage to the heart, it is less likely that medication alone can lead to a long-term remission or recovery.

Screening allows doctors to catch heart failure early, when appropriate treatment may prevent the progression to severe disease.

Identifying high-risk pediatric patients

The Herma Heart Institute sees more than 25,000 patients each year. **Steven Kindel, MD,** program director of the Pediatric Heart Failure and Heart Transplant Program at the Herma Heart Institute at Children's Wisconsin, estimates that the program sees at least 500 heart failure patients per year and manages a panel of 100+ heart transplant patients.

In children, the causes for heart failure are diverse, and certain demographics of patients have increased risk of developing heart failure in childhood.

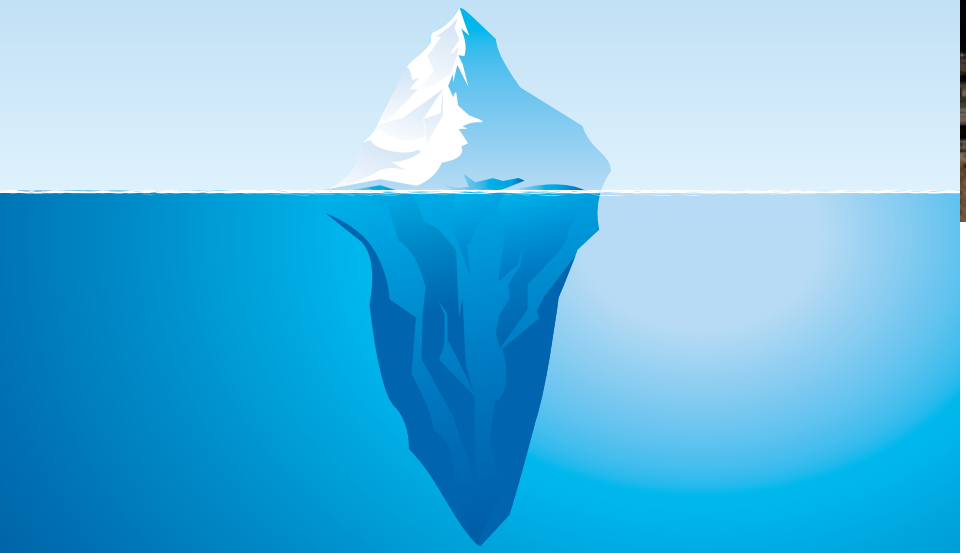


High-risk populations include:

- **Patients with congenital heart disease.** Children with high-risk forms of congenital heart disease who received surgical palliation should be screened. According to Dr. Kindel, this is especially important for single ventricle patients who progress through to Glenn palliation or Fontan palliation.
- **Patients with infectious or inflammatory myocarditis.** Myocarditis is the most common form of acquired heart failure in children. These patients benefit from long-term follow-up care to ensure they have durable recovery of their heart function.
- **Survivors of pediatric cancers.** Many patients who require chemotherapy or have survived childhood cancer can have acute or persistent injury to the heart. They also remain at increased lifelong risk of cardiac complications.
- **Patients with genetic, metabolic or other inherited cardiomyopathies.** Common types are hypertrophic cardiomyopathy, dilated cardiomyopathy, restrictive cardiomyopathy and left ventricular noncompaction cardiomyopathy. All these forms of cardiomyopathy require long-term treatment and monitoring to prevent heart failure or sudden death.
- **Patients with muscular dystrophy and other neuromuscular diseases.** Children with skeletal muscle disease are at long-term risk of injury or degeneration of the cardiac muscle. The most common forms that affect the heart are Duchenne and Becker muscular dystrophies, where nearly all children will develop heart failure in their lifetime.

Addressing heart failure early

“The population of children with heart failure can be thought of like an iceberg,” said Dr. Kindel. “The kids who have significant heart failure and are symptomatic are the tip of the iceberg that sits above the water. By the time patients are this sick, our therapeutic options may be rather limited. At the same time, the largest part of the iceberg is the ice under the water. Those are the children who don’t have symptoms or haven’t shown us that they are sick. Our hope is that by finding them in the early stages of disease and monitoring them and managing them with medications when needed, we may prevent progression to severe disease, or at least catch it before it is too late. In some kids, we will even see their heart recover to normal.”



Philosophy of care

When we find that a patient has dysfunction or risk of heart failure, the next step is to educate the family and patient about the problem and discuss our options for care, including starting medications or observing over time. Dr. Kindel emphasized that treatment decisions should be made through a collaborative process called shared decision-making between families and providers. “We as a team believe that we need to get the family on board with the treatment plan,” explained Dr. Kindel. “Forcing medications, treatments or testing on families before we gain their trust and understanding doesn’t build a positive therapeutic alliance.”

The Herma Heart Institute offers a full range of treatments and support, including mechanical circulatory support and heart transplantation. These clinics provide close follow-up, education and coordination of care through a large team of specialists that ensures the best outcomes for each family.

Learn more on the following pages.

Herma Heart Institute's advanced heart failure subspecialties and related programs

As diverse as the causes for pediatric heart failure are, so are the treatment options, subspecialties and related programs at Children's Wisconsin. The clinics and programs at the Herma Heart Institute bring care closer to home, seeing patients throughout Milwaukee, Kenosha and the Fox Valley.

Cardiomyopathy Screening Clinic

In this clinic, patients and their families meet with a genetic counselor who coordinates and explains their genetic testing options. Genetic testing may help identify a cause for a child's cardiomyopathy and allow for further screening to identify other at-risk family members. The Children's Cardiomyopathy Foundation has recognized this program as a **Cardiomyopathy Center of Care.**

Neuromuscular Clinic

Neuromuscular disorders can weaken a patient's heart. At this clinic, run by neuromuscular disease specialist **Matthew Harmelink, MD,** a comprehensive team of neurologists, cardiologists, pulmonologists, genetic counselors, physical medicine and rehabilitation providers and others work to provide coordinated care in a single clinic to improve care delivery and convenience for families.

Cardio-oncology Clinic

The Herma Heart Institute collaborates with Children's MACC Fund Center for Cancer and Blood Disorders to monitor heart function and provide therapy for children and young adults who are or have previously received cardiotoxic medications. In addition, cardiologists provide education, evaluation and monitoring of childhood cancer survivors for the long-term effects of chemotherapy through the **Next Steps Survivorship Program.**

Fontan Survivorship Program

This program provides focused care for patients with single ventricle congenital heart disease following their Glenn and/or Fontan palliation. Within the first 10 years, 30% to 50% of these patients have at least one significant chronic complication, which may include heart failure. The Fontan Survivorship Program coordinates care among cardiology, endocrinology, gastroenterology, psychology, pulmonology and palliative care for each patient with Fontan circulation. **Children's is one of the few hospitals in the Midwest, and the only one in Wisconsin,** with this kind of program and is a founding care center of the Fontan Outcomes Network.

Mechanical Circulatory Support (VAD and ECMO) Program

Cardiologists at Children's have a long-standing history and successful track record of using ventricular assist devices (VAD) and extracorporeal membrane oxygenation (ECMO) to support children's hearts until they can get a transplant. These mechanical pumps can provide long-term support when needed, and patients in this program are managed closely by specialized experts.

Heart Transplant Program

The Herma Heart Institute is the largest pediatric cardiac care center in the state of Wisconsin. Surgeons at our center have performed more than **240 heart transplant procedures.**

"We're very fortunate that Children's Wisconsin has strength in all of the necessary subspecialties to provide excellent care to children," says Steven Kindel, MD, program director of the Pediatric Heart Failure and Heart Transplant program at the Herma Heart Institute. "In the coordinated clinics, patients get to see multiple specialists all in one clinic."

Access Center

Access coordinators at Children's assist families from out of town with coordinating visits to the hospital, gathering medical records, connecting with specific medical teams, scheduling appointments and getting financial approvals. They serve as the go-to resource prior to arriving in Milwaukee or the Fox Valley for scheduled appointments.

Connect with us

To consult with a cardiologist at Children's, send inquiries to CardiologySecondOpinion@chw.org, or reach out directly to Dr. Kindel at skindel@chw.org or (414) 266-7423. Virtual care options are also available for some services.