Conquering CHD

GUIDED QUESTIONS TOOLKIT

QUESTIONS ANSWERED BY

Children's® MINNESOTA

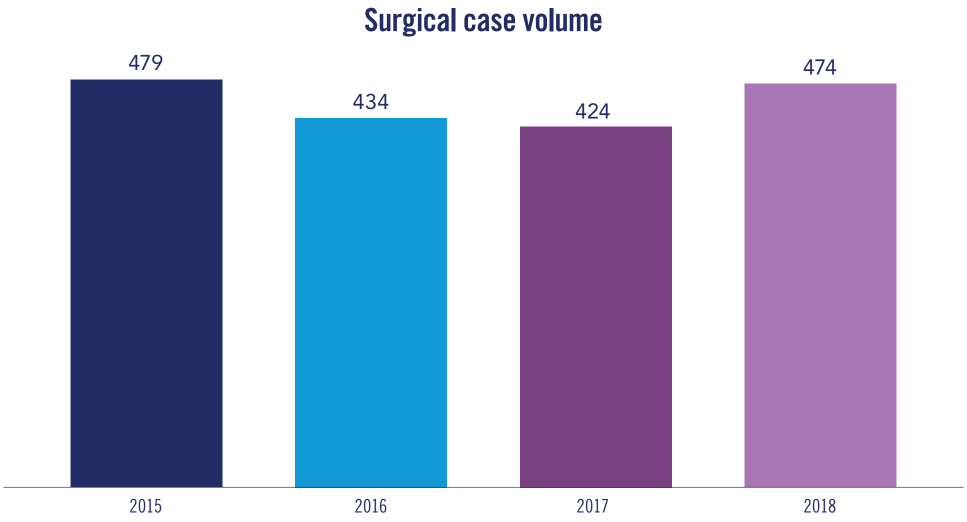
The Children's Heart Clinic

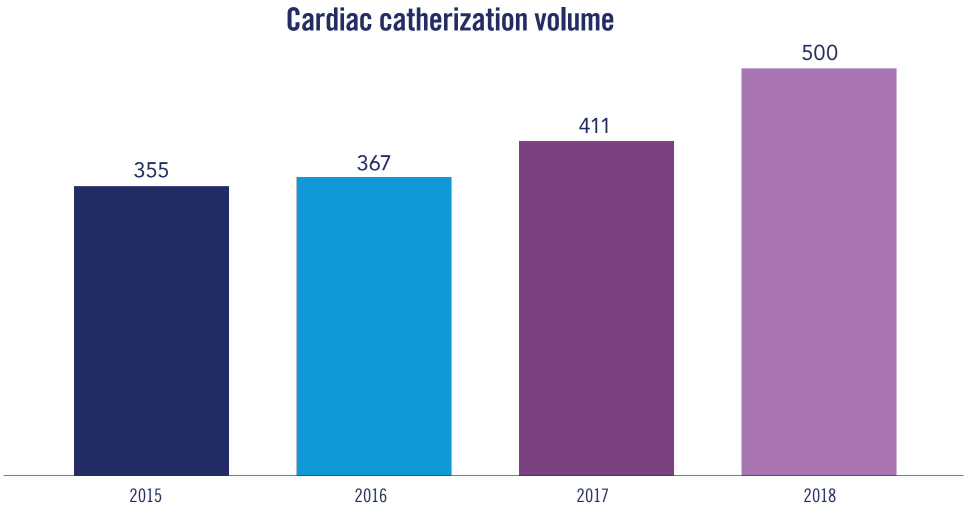
ABOUT YOUR CARDIAC CENTER

How many procedures do you perform each year? How many times have you and your program performed this procedure or ones like it in the last year? Over the last 4 years?

ANSWER:

At Children's Minnesota we perform both surgical and interventional catheter-based heart procedures on infants, children and young adults with heart disease. Our surgical and interventional physicians are all board certified and subspecialty trained in their field of expertise. Our surgeons perform more than 400 surgeries per year. Our program's total cardiac catheterizations and surgeries from 2015 and 2018 are presented in the graphs below.





Treating more patients is associated with higher quality care and better outcomes for patients.

What is the survival rate for this type of procedure at the time of hospital discharge? How do your results compare to other centers' results?

ANSWER:

One benchmark of any pediatric cardiovascular surgery program is the surgical mortality: the percent of babies and children who die after a surgical procedure and before they go home. The table below compares the surgical mortality at Children's Minnesota with other major pediatric cardiovascular surgery centers that report their results to the Society for Thoracic Surgeons.

	Total Volume of Surgeries at Children's Minnesota Heart Institute	Children's Minnesota Heart Institute In-Hospital Mortality %	STS In-Hospital Mortality %
Off CPB Coarctation Repair	81	2.5%	1.3%
Ventricular Septal Defect (VSD) Repair	73	0.0%	0.5%
Tetralogy of Fallot Repair	60	0.0%	1.2%
Atrioventricular Canal (AVC) Repair	54	5.6%	2.1%
Arterial Switch Operation (ASO)	27	0.0%	2.0%
ASO + VSD Repair	14	7.1%	5.1%
Glenn/HemiFontan Operation	60	3.3%	2.0%
Fontan Operation	49	0.0%	1.0%
Norwood Operation	47	19.1%	14.4%

January 2015 to December 2018

This graph shows the risk of mortality for different types of surgeries. A lower value is better.

What are the most likely complications or things that can go wrong following a heart procedure?

ANSWER:

Infection – Children that undergo a surgical procedure or have a central venous line are at risk of infection. We have a low rate of hospital acquired infections and follow strict care protocols to ensure that your child's risk of infection is as low as possible.

Feeding difficulties – Babies with congenital heart disease may need surgery during their first week of life — a time when they normally would be learning how to eat. Many babies with congenital heart disease have feeding difficulties and we have a feeding team who helps them learn how to eat. Some babies require placement of a feeding tube into their stomach to provide nutrition while they work on feeding by mouth.

Heart rhythm disorders – Some types of heart disease cause children to have problems with their heart rhythm. Some children will need to go home on medicine, and rarely some children may require a pacemaker, to help their heart rhythm be normal. We have a team of heart rhythm experts (called Electrophysiologists) who help guide decisions and management for patients with heart rhythm concerns.

Do you share your results with national data programs such as the STS Database or IMPACT Registry to help improve care? Is this information open to the public?

ANSWER:

Yes, we report our outcomes to the Society of Thoracic Surgeons (STS) Congenital Heart Surgery Database (CHSD), the Pediatric Cardiac Critical Care Consortium (PC4), the Pediatric Acute Care Cardiology Collaborative (PAC3), the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) and the IMPACT Registry, to name a few. The STS database includes a total of 118 North American cardiac surgical centers. We compare our surgical outcomes to other STS pediatric heart surgery centers and we participate in public reporting of outcomes. You can find this information on the STS website (sts.org). Our cardiac catheterization team reports to the IMPACT registry, which helps us compare the outcomes of cardiac catheterization procedures to other pediatric cardiac catheterization centers.

Do your surgeons have special training in congenital heart surgery? What other types of special training do your doctors and nurses have?

ANSWER:

Each of our surgeons has subspecialty training in pediatric congenital heart surgery. Subspecialty training includes a residency in general surgery lasting 5–7 years, a fellowship in cardiothoracic surgery lasting 2–3 years and additional training in pediatric cardiothoracic surgery training lasting 1–2 years. All our surgeons have been awarded a Subspecialty Certificate in Congenital Cardiac Surgery by the American Board of Thoracic Surgery. Beyond their training, each of our heart surgeons has many years of practical experience.

In addition to our cardiac surgical team, children with congenital heart disease are cared for by a multidisciplinary team of pediatric heart experts. These pediatric cardiac specialists include cardiac intensive care physicians, interventional cardiologists, cardiac imaging specialists, electrophysiologists, an advanced heart failure and transplantation team, advanced practice providers specializing in pediatric cardiology and cardiovascular surgery, perfusionists, respiratory therapists, cardiac nurses, nutritionists, cardiovascular pharmacists and social workers.

How are family members included in the decision-making process? How will the care team give me information or reports, before, during and after the procedure?

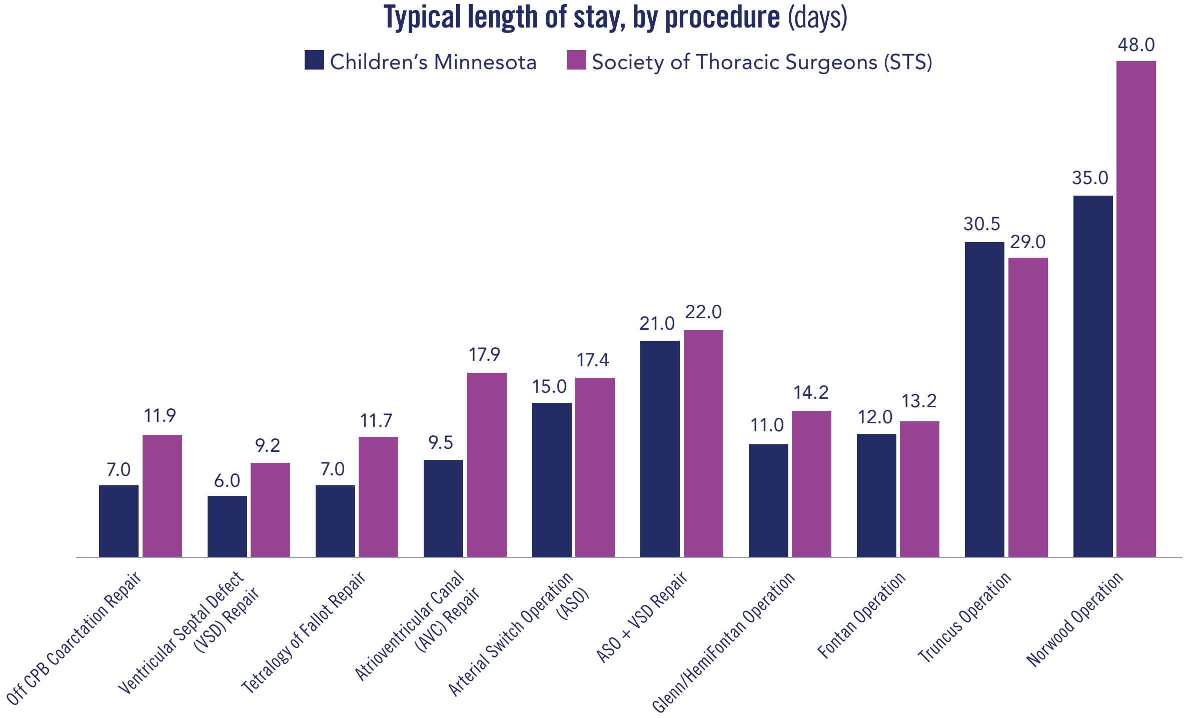
ANSWER:

Family involvement is very important in every phase of your child's care at Children's Minnesota. Patient and family centered care, expressed by direct, open and consistent communication, was a core value at our institution's founding, and has remained so throughout its history. For children who require a heart surgery or catheterization procedure, we meet with each family in advance to discuss the procedure. We always encourage families to ask questions, review our outcomes, tour our facility and meet our care team. If your child requires hospitalization at Children's Minnesota, families are encouraged to participate in daily rounds with the inpatient care teams. Our goal is to make sure that families, primary care doctors and other cardiologists are updated frequently on each child's care plan and progress.

ABOUT YOUR HOSPITAL STAY

How many days do you think my child will be in the hospital, both before and after the procedure?

ANSWER:



Typical length of stay, by procedure (days)

Keeping length of stay down for patients means less time in the hospital, and more time at home growing and thriving. These usual length of stay numbers help your family set expectations for how long you can anticipate to be in the hospital after your child's procedure or operation.

What are my options for when, where and how to deliver my baby? How do you work together with my OB/GYN/midwife to prepare for my delivery and my care right before and after delivery?

ANSWER:

When your child receives a prenatal diagnosis of congenital heart disease, our fetal cardiology team contacts your primary OB provider to discuss the best and safest delivery location for you and your baby. If your baby's heart requires a procedure right after birth, we often recommend delivery at The Mother Baby Center at Abbott-Northwestern Hospital which is directly connected to Children's Minnesota where our pediatric cardiology team is located. Our goal is to keep you and your baby under one roof, while providing optimal cardiac care for your baby.

You will continue to see your primary OB provider throughout pregnancy in addition to follow-up visits with fetal cardiology to monitor your baby's heart. We will partner with your primary OB provider and they will receive updates throughout the pregnancy from our team.

How do you work together with my baby's doctor after birth and after the procedure?

ANSWER:

We work closely with pediatricians, family practice providers and pediatric cardiologists both here in Minnesota and in the surrounding states. Our team provides your child's doctors with regular updates when your child is staying here in the hospital or when they are seen in cardiology clinic.

If my baby needs to stay in the hospital after delivery to prepare for a procedure, where will he/she be? What about after the procedure? Do you have a cardiovascular intensive care unit (CVICU) that cares mainly for children with heart defects?

ANSWER:

If your child requires intervention (surgery or cardiac catheterization) in the newborn period, he or she will be cared for in the Cardiovascular Care Center (CVCC). Our CVCC is a 25-bed unit located on the 4th floor of Children's Minnesota that is right next to our cardiac operating rooms and cardiac catheterization lab. Children are cared for in the CVCC from admission to discharge, with care provided by specialty trained nurses, advanced practice providers and cardiology physicians.

Babies who are premature, who have other organ system problems, or who are not expected to need intervention right after birth may be cared for in the Neonatal Intensive Care Unit (NICU) or the Infant Care Center (ICC) with close monitoring by the cardiology team.

Will I get to hold my baby before or after the procedure? If so, when and how?

ANSWER:

We aim for all parents to hold their child as we know that bonding between parents and children is very important. Rarely, babies may be too unstable to be held in their parent's arms prior to a procedure. In these cases, we encourage families to sit close to their baby and place your hands on them for comfort.

Will I be able to breastfeed my baby after delivery and again after the operation? Will my baby require a special diet? Should I expect my baby to take a bottle or breast feed without problems?

ANSWER:

We strive for babies to breastfeed before and after surgery. We have specialized lactation specialists who help babies and mothers learn how to breastfeed and pump breastmilk successfully. Nutrition is very important in babies, particularly those who have heart disease, and we work closely with dietary specialists to ensure that all children are receiving optimal nutrients for their bodies. Feeding can be a frequent challenge in children with heart disease and we have a team of feeding experts to help support these children with tools to learn to eat.

What do you do to help prepare parents to take their babies home from the hospital?

ANSWER:

Our primary goal at the time of hospital discharge is for families to understand their child's medical condition and feel comfortable caring for their child at home. From the time of your child's admission, our team will involve family members in medical rounds and helping with daily cares. We feel that being involved in daily care helps parents achieve confidence with their child's needs. Our nursing staff is skilled in educating families at the bedside so that parents are comfortable and confident at the time of discharge.

Some children have more complex needs than others upon discharge. In these circumstances a case manager will work closely with you to coordinate home care, home nursing and home therapies. Additionally, throughout your hospital stay there will be opportunities for educational classes that are provided by Children's Minnesota. You can expect to leave the hospital with written materials, teaching tools and scheduled appointments, as well as 24/7 contact information should questions arise when you are at home.

What support is available for me and my family? For example, can I talk to other families that also have children with heart defects? Do you provide financial, nutritional and mental health support?

ANSWER:

Nutrition services – Registered dieticians with expertise in cardiac nutrition work in both inpatient and outpatient cardiology areas. They are part of the interdisciplinary team and are available to answer questions related to general nutrition, growth, tube feeding and IV nutrition.

Family support – We have a team from social work, child life and spiritual care to help support our cardiac families. Social workers help families cope with and adjust to social, financial and psychological needs associated with their child's illness, lengthy hospitalization and transition to outpatient care. Child Life specialists utilize therapeutic play, age-appropriate education and coping techniques to help children and their families (including siblings) adjust and cope with the hospital or clinic setting, chronic illness and treatments. Chaplains offer support to children and families of all faith traditions and spiritual expressions.

Connecting families – For interested families, we can connect families together with other parents that have a child with a heart defect. For those with a child in the hospital, weekly parent coffee time is offered to provide time to connect with other families. Depending on your family's unique needs, we may be able to refer or connect you with other hospital and community resources.

LOOKING AHEAD

What are the expected long-term results for this heart defect and its procedure? What is my child's life expectancy or how long is my child expected to live? Are there other possible life-long problems that I need to watch out for?

ANSWER:

You child's life expectancy and their need for additional cardiac interventions are closely related to their heart anatomy and the type of heart repair that is needed. Also, some children with heart problems have additional problems with other organ systems or have a genetic abnormality that might affect life expectancy. Overall, the outcomes of children with heart disease have dramatically improved over the past 30 years. Most children with congenital heart disease are living to be adults. Most will enjoy an excellent quality of life. However, newer research does show that some children with heart defects have neurodevelopmental delays and may need additional help in school. We aim to help your child live life to the fullest and our team will fully support your child in order to achieve this goal.

As my child gets older, does your medical care provide a plan for transitioning from pediatric to adult care?

ANSWER:

Yes, we have a team who specializes in caring for adolescents and adults with congenital heart disease and they are called Adult Congenital Heart Disease physicians. This team will help ensure that your child continues to receive comprehensive and excellent care when your baby becomes an adult.

If you have any questions related to your child's care, please talk to your cardiology team.

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