

# Your child has congenital heart disease: What you need to know

Answers to common questions from our pediatric heart experts



**Children's**<sup>SM</sup>  
Healthcare of Atlanta



In an effort to provide clear and transparent information for families who have a child facing congenital heart disease, the Children's Healthcare of Atlanta Heart Center has supplied answers for each of the Pediatric Congenital Heart Association (PCHA) Guided Questions Tool. This tool answers common questions that families ask about their child's heart condition, and provides information about the 10 most widely performed heart surgeries to help families make evidence-based treatment decisions. If you have questions about any information provided in this booklet, we encourage you to ask your cardiologist or care team who can help clarify.

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## Understanding the data

Children's participates in the Society of Thoracic Surgeons (STS) Congenital Heart Surgery Database. In 1989, STS launched a clinical data registry for cardiothoracic surgery that includes a component focused on congenital cardiac surgery. The STS Congenital Heart Surgery Database contains more than 475,000 congenital heart surgery procedure records and currently has more than 1,000 participating physicians, including surgeons and anesthesiologists from 119 pediatric heart programs.<sup>1</sup> The 10 benchmark procedures used in this booklet are common pediatric cardiothoracic procedures used by STS to benchmark the performance of surgical centers across the country.

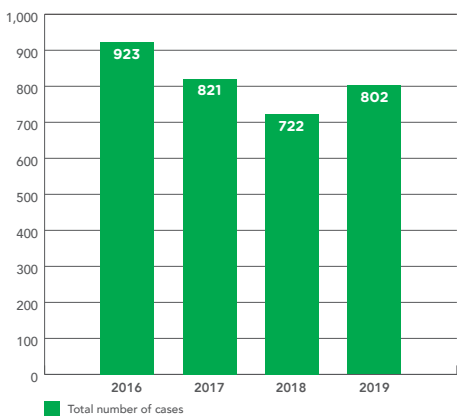
# How many procedures does your program perform each year on average? How many times has your program performed this procedure or ones like it in the last year? How many times has your program performed this procedure or ones like it over the last four years?

Children’s performs hundreds of heart procedures each year. The charts below illustrate volumes based on cardiac procedure and the number of cardiothoracic surgeries performed during the last four years. According to IMPACT, the Children’s Heart Center had 1,002 cath lab visits in 2019. The electrophysiology team performed 188 ablations, implanted 68 pacemakers and cardioverter defibrillators (ICDs), and managed 380 patients in the Pacemaker Clinic in 2019. This information can be found online at [choa.org/heart](https://choa.org/heart).

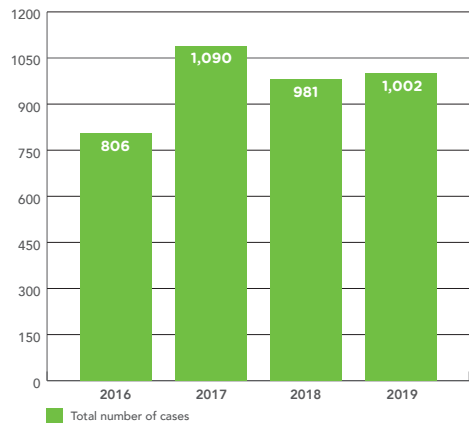
Cardiac surgical procedure volumes\*

	2016	2017	2018	2019
Arterial switch operation (ASO)	6	8	14	8
ASO+ventricular septal defect (VSD)	2	10	8	7
Atrioventricular canal repair	41	34	22	19
Coarctation of aorta repair	38	31	23	42
Fontan	28	20	19	45
Glenn/Hemi-Fontan	43	30	28	25
Norwood	30	15	11	23
Tetralogy of Fallot repair	30	34	27	54
Truncus arteriosus repair	1	2	4	4
VSD repair	45	57	54	41

2016-2019 cardiac surgical cases by year\*



2016-2019 catheterization lab visits by year\*\*



\*The Children’s Healthcare of Atlanta data is based on STS Spring 2019 Harvest Report definitions.  
 \*\*IMPACT

## What is the survival rate for these types of procedures at the time of hospital discharge? How do your results compare to other centers?

The quality of care at Children’s is our highest priority. We monitor our cardiac surgical outcomes and volumes to provide the most accurate information to patient families. Below are the survival rates for the 10 benchmark operations the STS includes in their database of reporting hospitals. Our survival rates at the time of hospital discharge, or within 30 days of the procedure if after discharge, are listed below.

### Cardiac procedure

	2015-2018 Children’s data	2015-2018 STS benchmark
Arterial switch operation (ASO)	95%	97.9%
ASO+ventricular septal defect (VSD)	93.1%	94.9%
Atrioventricular canal repair	96.8%	97.9%
Coarctation of aorta repair	95.2%	98.8%
Fontan	97.7%	99%
Glenn/Hemi-Fontan	98.5%	98%
Norwood	75%	85.5%
Tetralogy of Fallot repair	99.2%	98.9%
Truncus arteriosus repair	80%	91%
VSD repair	99.5%	99.5%

## What are the most common complications or things that can go wrong with this procedure, and how often do they happen within one year of this procedure at your center?

The most common complications in the Children’s surgical patient population are unplanned reoperation or reintervention, pleural effusions, chylothorax and feeding difficulties.

- **Unplanned reoperation or reintervention** involves any unplanned reoperation within 30 days after surgery.
- **Pleural effusion** occurs when fluid builds up in thin layers of tissue that line the lungs.
- **Chylothorax** is a condition that causes buildup of fluid in the lungs that can cause a severe cough, chest pain and difficulty breathing.
- **Feeding difficulties** may occur with neonates who undergo surgery for congenital heart defects. Children’s has a specialized team of nutritionists and speech therapists that works with patients to provide nutrition support and feeding skill development.



## Do you share your results with national data programs like the STS National Database or IMPACT Registry to help improve care? Is this information available to the public?

The Children’s mission is to continually improve and help our heart patients live their best lives. We report our outcomes to several databases, and each database is publicly available.

- The **STS Congenital Heart Surgery Database** is for surgical outcomes. We compare our outcomes to other STS pediatric heart surgery centers. This information is publicly available on our website.
- The **Pediatric Cardiac Critical Care Consortium (PC4)** data registry is for all medical and surgical patients in a cardiac intensive care unit (CICU).
- The **Pediatric Acute Care Cardiology Collaborative (PAC3)** data registry is for all patients in a cardiac acute care unit.
- The **National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC)** is comprised of clinical process and outcome data on the care of infants with single ventricle congenital heart disease from prenatal diagnosis through 1 year old.
- The **Improving Pediatric and Adult Congenital Treatment (IMPACT)** data registry is for pediatric and adult CHD patients who undergo diagnostic catheterizations and catheter-based interventions.
- The **Clinical Cardiac Neurodevelopmental Outcome Collaborative (CNOC)** clinical registry is a multicenter, multinational, collaborative data resource to optimize neurodevelopmental outcomes for individuals with pediatric and congenital heart disease.

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

Our surgeons at Children’s are all certified by the American Board of Medical Specialties in congenital cardiothoracic surgery and trained in their field of expertise. For more information, the individual bios of each surgeon can be found online at [choa.org/heart](http://choa.org/heart). Many of our cardiologists have received advanced specialty training in areas such as critical care, cardiac imaging, arrhythmia care and cardiac catheterization. Newly hired clinical nurses complete a three-to four-month orientation in their specialty area. Annual nursing competencies that show task proficiency are required by each nurse in the Heart Center to promote the best clinical outcomes for our patients.

Surgeon	Special training	Focus of practice
Paul Chai, MD	<ul style="list-style-type: none"><li>• American Board of Thoracic and Cardiac Surgery</li><li>• American Board of Thoracic Surgery (congenital cardiac surgery)</li></ul>	<ul style="list-style-type: none"><li>• Pediatric congenital heart surgery</li></ul>
Kirk Kanter, MD	<ul style="list-style-type: none"><li>• American Board of Thoracic and Cardiac Surgery</li><li>• American Board of Thoracic Surgery (congenital cardiac surgery)</li></ul>	<ul style="list-style-type: none"><li>• Pediatric congenital heart surgery</li></ul>
Subhadra (Subi) Shashidaran, MD	<ul style="list-style-type: none"><li>• American Board of Surgery (general surgery)</li><li>• American Board of Thoracic and Cardiac Surgery</li></ul>	<ul style="list-style-type: none"><li>• Pediatric congenital heart surgery</li><li>• Adult congenital heart surgery</li></ul>
Fawwaz Shaw, MD	<ul style="list-style-type: none"><li>• American Board of Surgery (general surgery)</li><li>• American Board of Thoracic and Cardiac Surgery</li><li>• American Board of Thoracic Surgery (congenital cardiac surgery)</li></ul>	<ul style="list-style-type: none"><li>• Pediatric congenital heart surgery</li><li>• Adult congenital heart surgery</li></ul>

## How will our family be involved during our child's heart surgery?

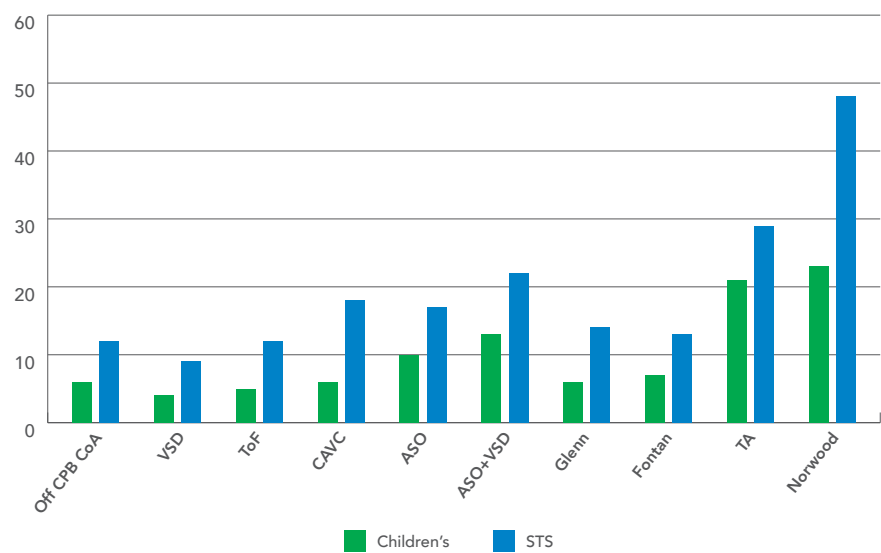
- Children's encourages a family's involvement in their child's care and practice. The family-centered approach to care recognizes that families and patients are partners with our healthcare team. We encourage parents to ask questions, tour the facility prior to admission and participate in family-centered rounds.
- In pediatrics, family-centered care is based on the understanding that the family is a child's primary source of strength and support. This approach to care recognizes that the information provided by families, children and young adults is an essential component of high-quality clinical decision-making, and that patients and families are integral partners with our healthcare team.
- Parents are encouraged to attend and participate in medical rounds, because this is a great opportunity to ask questions and have their opinions heard. Our team begins by reviewing a child's medical history, as well as important events or issues from the past 24 hours. Rounds are a time for the medical team to review information about each child in our CICU. Rounds begin on 7 a.m. on weekdays and 8 a.m. on weekends. During this time, a staff member will ask a parent what questions they have. Parents are updated by our operating room staff at the beginning of any surgical procedure and every one to two hours thereafter. Once the procedure is completed, a member of our surgery waiting room front desk will escort you to a consult room, where the surgeon will give you details about your child's procedure.
- Morning rounds usually include the following team members:
  - Cardiologist
  - Respiratory therapist
  - Nutritionist
  - Cardiac fellow(s)
  - Pharmacist
  - Bedside registered nurse
- Our team reviews each child's current medications, vital signs, lab values, chest X-rays and other important information. They make a medical plan of care for the next 24 hours. This is a time for parents to ask our medical team any questions they may have.



## How many days will my child remain hospitalized before and after a procedure?

- The number of days your child is hospitalized depends on how soon he is able to get back to a healthy baseline.
- The graph below shows the median number of days children with various heart conditions stay in the hospital. On average, children treated at Children’s have shorter hospital stays than the STS benchmark for each procedure.

Median hospital length of stay at Children’s



\* CPB (cardiopulmonary bypass); CoA (coarctation of the aorta); ASO (arterial switch operation); VSD (ventricular septal defect); ToF (tetralogy of Fallot); CAVC (complete atrioventricular canal); TA (truncus arteriosus)

## What are the options for when, where and how to deliver a baby born with a congenital heart defect? How does your team work with my OB-GYN and midwife to prepare for a delivery and care right before and after delivery?

The Sibley Heart Center Cardiology team will work closely with your obstetrician and perinatologist to determine the best delivery plan for your baby. If a certain hospital location or mode of delivery is indicated, we will work with your family to make sure this process goes as smoothly as possible. Based on your prenatal imaging, our fetal cardiologists will make recommendations regarding the timing of cardiology evaluation of delivery. This recommendation is communicated to your obstetrician, specialist and delivery center.

## **How does Children's work with a baby's pediatrician after birth and following the procedure?**

Children's will provide your baby's pediatrician with regular updates while your child is in the Heart Center. These updates are communicated in emails or over the phone. Prior to discharge, our surgeons will also work closely with your baby's pediatrician to coordinate care. In addition, cardiologists in our City Call Program are available to be present at your birthing hospital. We believe it is very important to maintain these relationships.

## **If a baby needs to stay in the hospital after delivery to prepare for a procedure, where will he be? Where will he stay after the procedure? Does your program have a CICU that cares mainly for children with congenital heart defects?**

If your baby's heart requires a procedure, we will care for them in the Children's CICU. We have one of the largest dedicated CICUs in the country with 32 total beds, in addition to 35 beds in our Cardiac Acute Care Unit (CACU).

Once your baby is medically stable, he will be moved from the CICU to the CACU, where our specially trained cardiac nurses and cardiology team will provide care. Parents are strongly encouraged to stay overnight in their child's CACU room. During this time, you can provide emotional support to your child, while also receiving the training required to safely care for your child at home.

If there are times when you can't stay with your child, parents can always call the CACU to speak with their child's nurse and get a medical update.

## **Can parents hold their baby before or after a procedure? If so, when and how?**

Children's understands how important bonding is for newborn babies and their parents, as it is essential to the baby's health and development. We encourage new parents to hold their babies whenever possible. If your baby is too unstable to be held before or after a procedure, our nursing staff can assist you with finding ways to bond with your baby.



## **Can mothers breastfeed their baby after delivery and again after a procedure? Do babies require a special diet before or after a procedure? Should parents expect their baby to take a bottle or breastfeed without problems before or after a procedure?**

Children's provides consistent, research-based information, instruction and support, as well as necessary supplies to breastfeeding mothers of hospitalized children.

Under the guidance of our lactation consultants, we will assist mothers with initiation and maintenance of milk production. Nurses will also provide ongoing support to lactating mothers throughout a patient's admission by monitoring for problems, providing supplies and encouraging continued breastfeeding when appropriate.

Depending on your baby's medical status, he may be able to take a bottle or breastfeed before or after surgery. If your baby is unable to take a bottle due to their medical status, they may need a feeding tube or be supplemented with formula. Our specially trained therapists are available to help your baby with feeding from a bottle or breastfeeding if he requires assistance.

## **What does your program do to help prepare parents to take their babies home from the hospital?**

Each patient's discharge needs, such as nutrition, respiratory care, physical therapy and medication therapy, are assessed. A plan for addressing these needs will be created by the attending physician with input from the Children's interdisciplinary team, which includes a registered nurse, social workers, case managers, therapists, dietitians, child life specialists and other caregivers. Prior to discharge, we will make sure you have educational materials, teaching tools and phone numbers to call if you have questions or concerns about your child's health.

Before your child goes home, parents are required to attend the following classes:

- CPR class
- Car seat class (if your child is a newborn)
- Cardiac surgery discharge class

All classes are free to parents and caregivers. We require that at least one parent take each class if your child has had heart surgery. The car seat class is required if your child is a newborn and has never been home. You must bring your child's car seat and base for inspection.

## What support is available to cardiac patient families, such as introductions to families who have children with heart defects, as well as financial, nutritional and mental health support?

Children's understands that having a child in the hospital can be a stressful and difficult time for every family. Our family support team includes social workers, psychologists, chaplains, child life specialists and family experience liaisons who can help navigate emotional, financial, familial and spiritual challenges you may encounter during your child's time in the hospital.



### **Fetal team**

The Fetal Cardiology Program provides complete consultative services for parents with suspected or known heart problems in their unborn child.



### **Financial services**

Children's provides resources to assist patients and/or their families that have an emergent financial need due to a patient's healthcare status. The goal of the Children's Assistance Program is to connect patients and families to community resources that can assist with their financial needs. Children's offers a number of options and services for paying for your child's hospital bill. Financial counselors are also available to screen for Medicaid eligibility, as well as assist families with the application process. Applications for financial assistance with medical bills are also available through the financial counseling office.



### **Social workers**

Our social workers provide emotional support during your child's admission and can refer you to further counseling and support. They are knowledgeable about financial and community resources, and connect families with resources that are available. Social workers also assist with lodging and transportation needs, and can provide school and work excuses.



### **Child life specialists**

Certified child life specialists provide developmentally appropriate interventions like therapeutic play that help reduce fear, anxiety and pain in children of all ages. These specialists have received education and training in the developmental impact of illness and injury.



### **Chaplains**

The chaplains at Children's are trained to respond to the spiritual needs of pediatric patients in the hospital setting and provide support and guidance to patients and families as they seek healing, meaning and hope in the face of illness or injury. Chaplains are available 24 hours a day, seven days a week.



### **Psychologists**

Our Cardiac Neuropsychology Program provides mental health support to our cardiac patients. Our lead cardiac psychologist oversees inpatient screening and treatment of medically related trauma and stress in patients and families. In addition, outpatient screenings are conducted to assess developmental skills for infants and toddlers with congenital heart defects. It is important to treat development issues early on. Our neuropsychologists can create a plan to help your child develop necessary communication, thought and motor skills.



### **Family experience liaisons**

Family experience liaisons visit all newly admitted patients each day to discuss hospital services. They share basic education on patient rooms, units, services Children's offers, parking and cafeteria-related questions. During your child's hospital stay, the liaison is a resource to help coordinate needs for you. They may connect patients, families and visitors to a variety of support services available at Children's, as well as advocate for the needs of patients, families and visitors during their stay at Children's.

In addition to our specialized cardiac care, Children's offers family-centered support programs for families while they are in our care and in the community.



### **Kids at Heart**

Sponsored by the Children's Heart Center, Kids at Heart offers parents, families and caregivers of kids with congenital heart defects a chance to come together and share their experiences.



### **Camp Braveheart**

We believe it is important that every child feels special, and a child with congenital or acquired heart defects is no different. At Camp Braveheart, we promote positive self-esteem with fun and learning. This summer camp is for children and teens that have heart conditions or have undergone a heart transplant. We give every child between the ages of 7 and 17 a chance to experience camp, build friendships and make memories to last a lifetime.



### **Feed the Heart Program**

Cardiac staff members serving on the Patient Family Advisory Council and parents serving on the Cardiac Family Advisory Council created the Feed the Heart Program to provide weekly meals for heart patients and their families.

## **What are the potential long-term results for a child born with a heart defect? What is a child's life expectancy as a result of being born with a heart defect? Are there other potential lifelong problems for a child born with a heart defect?**

Your child's life expectancy and their need for additional heart interventions are closely related to their heart anatomy and the type of heart repair that is needed. Some children may also have other health challenges that are unrelated to their heart defect.

Overall, the outcomes of children with heart disease have improved dramatically over the past 20 years. Children typically go on to live full, meaningful lives. However, some children with congenital heart disease experience developmental and learning differences, and may benefit from extra help to succeed in school, social relationships and future employment. Be sure to talk with your doctors if you think your child is not developing important skills or experiencing other problems that raise concern.

## **What should a parent expect from their child as a preschooler, school-age child, teenager and adult?**

Research indicates that children with heart conditions are at risk for motor and language delays, learning difficulties, attention problems and social challenges. This is why the American Heart Association and the American Academy of Pediatrics recommend children with some heart conditions, such as those needing surgery in the first months of life, be seen in a cardiac neurodevelopmental program.

Children's is also a founding member of the Cardiac Neurodevelopmental Outcome Collaborative, which is an international group of healthcare professionals committed to partnering with families to optimize neurodevelopmental outcomes for congenital heart disease through clinical and research initiatives throughout a patient's lifetime.

The Cardiac Neurodevelopment Program at Children's includes experts in cardiology, social work, neuropsychology and rehabilitation therapy. They work with parents and other specialists to provide complete developmental support, such as:

- Comprehensive assessments of developmental skills during critical phases between infancy and age 21.
- Recommendations for support, intervention, community resources and guidance with school planning.
- Consultation for caregivers regarding ways to support development during hospitalizations.
- Education during the prenatal period about neurodevelopmental concerns associated with congenital heart disease.



### **Infants to preschool**

We recommend scheduling the first appointment to assess your child's neurodevelopment when he is between 6 and 9 months old. At that time, a pediatric psychologist will conduct developmental testing to help assess your child's early thinking, communication and motor skills. Reassessment should occur when your child is a toddler, or around 18 to 24 months old. You will also need to complete questionnaires about your child's development and any parenting challenges you may have. Based on the results of this evaluation, we will recommend a course of action to support your child's specific developmental needs. This may include a referral to our Rehabilitation Program, which includes feeding, physical therapy, occupational therapy and speech-language pathology, Babies Can't Wait or the Early Intervention Program in your area.



### **School-age to young adults**

Starting in preschool, your child will meet with a pediatric neuropsychologist to complete written, oral and picture-based tests. Information is also gathered from parents and teachers. The neuropsychologist will review medical and school records, and meet with you to learn about your child's family and social background. We will also provide forms for your child's teacher to complete about learning, attention and behavior in the classroom. The results from this assessment will lead to specific recommendations about ways to support your child's learning and social-emotional progress. Follow-up visits during the school-age years are determined based on your child's progress.

## **Does your program provide a plan for transitioning from pediatric to adult care?**

Kids at Heart provides teen programming for heart patients ages 13 to 20, preparing them for transitioning to an adult cardiologist.

In addition, Children's partners with the Emory Adult Congenital Heart (EACH) Center, which specializes in the lifelong care and monitoring of adults with congenital heart disease. As the only adult congenital heart program in Georgia and one of the largest programs in the country, the center identifies any problems related to congenital heart disease and provides the most effective treatment and management options.

The EACH Center has a multidisciplinary team that includes adult and pediatric cardiologists, congenital cardiac surgeons, electrophysiologists, interventional cardiologists, nurses, social workers and imaging specialists. This program also offers the assistance of a nurse practitioner who provides transition liaison services.



## Notes

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