



Lurie Children's Heart Center Answers  
to Conquering CHD's

# Guided Questions Tool



# Guided Questions Tool

It's hard to hear the words, "There is something wrong with your baby's heart." Thanks to new and advanced treatments and centers of excellence, your baby has the best chance of surviving and thriving.

After receiving a diagnosis, many families don't know the questions to ask when selecting a care center for their child. To help guide families through this difficult time, Conquering CHD, a parent-led national organization and advocacy group, developed the Guided Questions Tool to help families make more informed care decisions.

To help provide guidance to families, Lurie Children's Heart Center has supplied answers to each of Conquering CHD's questions in the following pages. We've broken down this information into three sections — Information About Our Heart Center, Information About Your Hospital Stay and Looking Ahead. For any additional questions, we encourage you to talk with your care team.

**For more information about Lurie Children's Heart Center, visit [luriechildrens.org/heartcenter](http://luriechildrens.org/heartcenter).**

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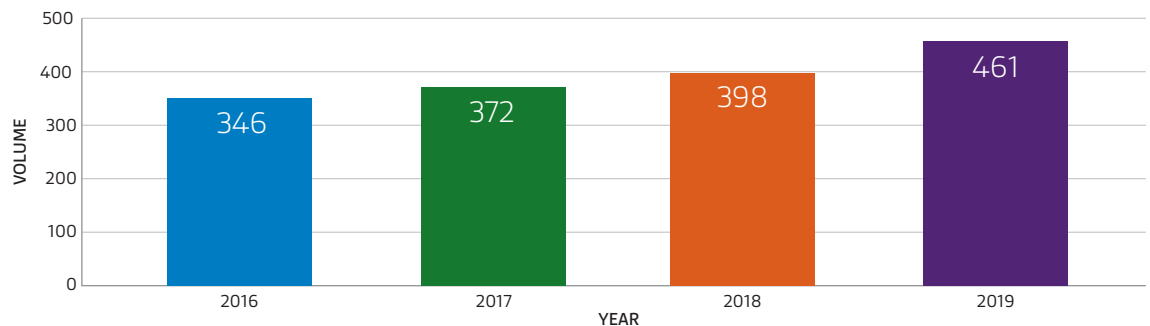
# Information About Our Heart Center

1

How many cardiac surgeries have you performed in the past year? In the past four years? How many cardiac catheterizations have you performed in the past year? In the past four years?

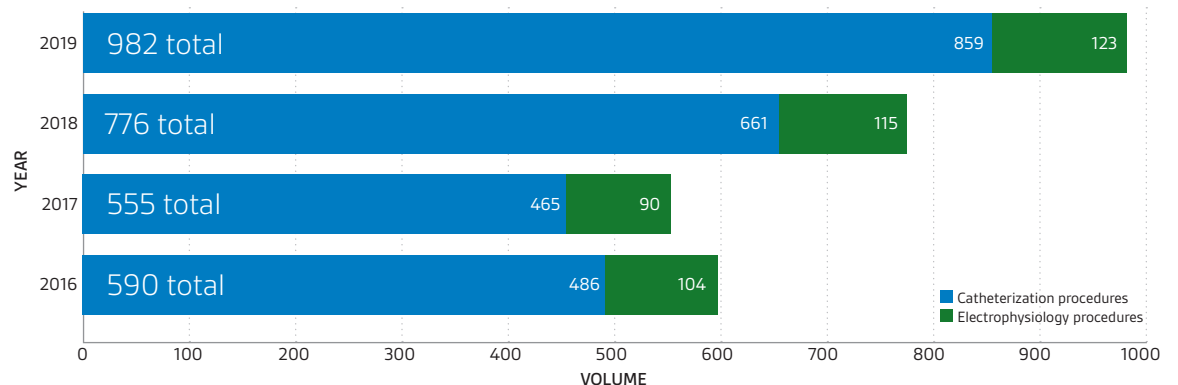
On average, Ann & Robert H. Lurie Children's Hospital of Chicago performs close to 460 pediatric and congenital heart surgeries each year. Lurie Children's is considered a high-volume center by the Society of Thoracic Surgeons (STS). STS created a national database to track patient quality and safety measures. Lurie Children's Heart Center has been reporting volume and outcomes to the STS database since 2004, and consistently ranks among the top programs in the country. Below are our surgical volumes from 2016–19.

## CARDIOVASCULAR SURGERY VOLUME BY YEAR



[Cardiac catheterizations](#) may be used to assess and/or treat some heart conditions. We perform nearly 1,000 procedures in the cardiac catheterization lab each year, including both cardiac catheterizations and electrophysiology (EP) procedures. During cardiac catheterizations, X-ray equipment, special dye (contrast) and long, flexible tubes (catheters) are used to visualize blood flow through the heart and vessels. These catheters are special in that they allow interventions upon structures within the heart, such as valves or blood vessels. Catheter procedures are less invasive than open heart procedures. Your doctor will let you know whether catheterization is needed for your child's condition. Electrophysiology procedures performed in the catheterization lab also use specialized catheters to help diagnose, map and treat the origin of abnormal rhythms.

## TOTAL CATHETERIZATION VOLUME BY YEAR



# 2

What is the survival rate for two-ventricle operations at the time of hospital discharge? What is the survival rate for single ventricle operations at the time of discharge? How do your results compare to other centers' results?

Below is a list of operations that STS refers to as "benchmark operations." Please note that operations for patients with single ventricle anatomy are part of the benchmark operations but are displayed in their own table. The national survival rate for these operations is shown, based on data from STS.

## SURVIVAL RATE FOR TWO VENTRICLE OPERATION TYPES (2015–18)

Benchmark Operation	Heart Center Operations Included in STS Analysis	In-Hospital Survival Rate (Lurie Children's Heart Center)	In-Hospital Survival Rate (STS Aggregate)
Arterial switch repair	30	100%	98%
Arterial switch + ventricular septal defect repair	11	100%	94.9%
Complete atrioventricular canal repair	28	100%	97.9%
Tetralogy of fallot repair	53	100%	98.8%
Truncus arteriosus repair	8	100%	91.1%
Ventricular septal defect path repair	101	100%	99.5%
Coarctation of the aorta repair	52	98.1%	98.7%

## SURVIVAL RATE FOR SINGLE VENTRICLE OPERATION TYPES (2015–18)

Operation	Heart Center Operations Included in STS Analysis	In-Hospital Survival Rate (Lurie Children's Heart Center)	In-Hospital Survival Rate (STS Aggregate)
Norwood procedure	43	86%	85.6%
Glenn procedure	55	94.5%	98%
Fontan procedure	37	100%	99%

# 3

## What are the most likely complications or outcomes that might make recovery more challenging?

If your child requires surgery, complications are rare. The most common complications are bleeding, infections, abnormal heart rhythms and feeding difficulties.

- Bleeding typically slows down and then stops within the first few hours after surgery. If that doesn't happen, our team will give your child medicine that will help stop the bleeding. In rare cases bleeding will not stop, or will become worse. If this happens, your child may need to be given a blood transfusion and may need another operation to stop the bleeding.
- Infections following surgery are rare. The hospital tracks all surgical site infections very closely and treats them aggressively. All of our patients receive antibiotics before and after surgery to help minimize the possible risk of infection.
- Abnormal heart rhythms, or arrhythmias, can occur after heart surgery if the heart is irritated by the procedure. Most arrhythmias get better in a few hours or days after surgery and do not cause problems later. When an abnormal rhythm persists, our team may use medicine to control it. On rare occasions, a pacemaker may be required. This device helps your child's heart have a regular rhythm. If your child has arrhythmias or needs a pacemaker, he or she will be seen by the Heart Center's Electrophysiology Program. The program is the largest in the state and has electrophysiologists who are specialists in arrhythmias.
- Feeding difficulties occur with some babies who undergo heart surgery. This may be a result of injury to the nerves that control the vocal cords that occurs during the operation, or due to the development of poor motor coordination during hospitalization. We have a specialized team of dietitians, speech therapists and breastfeeding counselors who work with patients to provide nutrition support and help with learning how to feed. Some babies require tubes to be placed through the nose into the stomach for feeding. Occasionally babies may need a tube placed surgically into the stomach for nutrition to be given at home.

**There are some risks specific to the type of procedure. Your cardiologist or surgeon will discuss this with you further.**

# 4

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? What else are you doing from a research and innovation perspective to improve care?

## STS DATABASE AND IMPACT REGISTRY

[Lurie Children's Division of Cardiovascular-Thoracic Surgery](#) participates in public reporting of our outcomes as posted on the Society of Thoracic Surgeons' (STS) website. STS updates outcomes data for congenital heart surgery only once yearly, after the Spring data analysis is completed. To learn more, visit [sts.org](https://sts.org).

The IMPACT Registry is the first national registry designed to track outcomes for pediatric and adult patients undergoing a cardiac catheterization procedure for congenital heart disease (CHD). The collection and analysis of the data collected is used to learn more and improve treatment of CHD.

We also participate in multiple other national registries to share data with other institutions to improve outcomes.

## RESEARCH AND INNOVATION

Lurie Children's Heart Center is making a tremendous drive in research to identify safer, more effective ways to diagnose, treat and prevent complex cardiac conditions. Better diagnostic methods and therapies will save lives and guide us to the best medical treatments for each child.

### Dissolvable Heart Stents for Children

Our physician-scientists are breaking the boundaries of pediatric heart medicine with their expertise and bold thinking. [Alan Nugent, MBBS](#), Medical Director of Interventional Cardiac Catheterization, is focused on creating bioresorbable stents.

Metal stents in children create difficulties as their bodies outgrow the stent, resulting in distorted vessels, infection or highly invasive surgery to remove them. During promising early-stage development, Dr. Nugent has created stents made from a polymer that will be well tolerated by young patients. The stents are coated with microscopic drug fibers so the devices biodegrade and disappear once they are no longer needed. The team continues to perfect the stent's design and ability to control inflammation. Currently, there are no bioresorbable stents approved for use in the U.S.

### Clinical Stem Cell Trials

The clinical stem cell trials conducted by Sunjay Kaushal, MD, PhD, Division Head, Cardiovascular-Thoracic Surgery, are among the first for congenital heart disease patients. He is the principal investigator for a national Phase II clinical trial sponsored by the National Institutes of Health (NIH). The purpose of this trial is to determine the efficacy of using stem cells in complex congenital heart disease patients by using allogeneic mesenchymal stem cells, injected during the Glenn operation into patients with hypoplastic left heart syndrome (HLHS). The hope is that this strategy will prove effective in strengthening the right, and stronger, side of the heart with the end result being increased length of survival and longer-term stability and durability to an otherwise fatal condition. In total, Dr. Kaushal has four active NIH grants and two pending NIH grants.

# 5

## Do your surgeons have special training in congenital heart surgery? What other types of special training does your team have?

Led by Division Head [Sunjay Kaushal, MD, PhD](#), the Heart Center's renowned [cardiovascular-thoracic surgery team](#) provides comprehensive surgical care for all congenital and acquired cardiac defects.

The surgical team has particular expertise in valve sparing aortic root replacement; neonatal repairs; coronary artery problems; vascular rings; tracheal abnormalities; mitral valve repair; arterial switch for transposition of the great arteries; tetralogy of Fallot; palliative and reparative operations; and the Fontan, Norwood and Glenn procedures. The team is also specialized in procedures such as low birth weight surgery and complex biventricular reconstructions, including the neonatal double switch operation, Senning Rastelli operation and aortic root translocation operation.

With high volumes and strong outcomes, the team leads the nation in arrhythmia surgery, integrating this technique into the repair of congenital heart defects in infants and children as well as adults.

As the surgical core of the region's largest pediatric heart transplant program, the team collaborates closely with referring pediatric cardiologists.

Our cardiovascular-thoracic surgeons are also faculty in the Division of Cardiac Surgery at Northwestern University Feinberg School of Medicine.

Surgeons are supported by a Heart Center team of specially trained pediatric caregivers with experience treating congenital heart disease in children. These specialists include [cardiac anesthesiologists](#), [intensivists](#), [advanced practice nurses](#), physician assistants, cardiac-trained nurses, [perfusionists](#) and technologists.

# 6

## 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?

Families are not just visitors, they are a part of our team. Giving families the best possible experience is the core of our mission — something we strive for each and every day. We follow a family-centered care principle where the family is the patient's biggest source of support, and we actively include parents in their child's care.

Parents are welcome at the bedside 24/7 and we encourage their participation during rounds. We make decisions together with parents and communicate in a manner that works best for them.

Our Heart Center has several cardiothoracic nurse coordinators. These clinicians will meet with you upon arrival, walk you through where to go, assure that you are acclimated to the [Cardiac Care Unit](#) and provide you with updates throughout the procedure. In addition, you will see the cardiothoracic coordinators after surgery as they will continue to check in and be available to answer questions and help facilitate communication with the surgical team.

In the Cardiac Care Unit, we welcome our patients and families to participate in multidisciplinary rounds. These rounds take place twice a day where your care team will come to your bedside and discuss the plan. We consider our patients and families an essential part of the team and value their input. You know your child best and we recognize how important that is.



# Information About Your Hospital Stay

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If my child has a complex congenital heart disease, how many days do you think he/she will be in the hospital, both before and after the procedure? If my child has a less complex congenital heart disease, how many days do you think he/she will be in the hospital, both before and after the procedure?

The time of hospitalization varies by complexity of the defect, as well as other factors such as how small or ill the patient is prior to surgery.

Operation	Volume 2016–19	Median Postoperative Length of Stay	Median Hospital Length of Stay
Arterial switch operation	35	12.0	17.0
Arterial switch + ventricular septal defect repair	8	13.5	23.0
Atrial septal defect repair	69	4.0	4.0
Complete AV canal repair	38	10.0	11.0
Glenn procedure	54	8.5	12.0
Norwood procedure	32	40.5	45.0
Tetralogy of Fallot repair	56	7.0	7.0
Total anomalous pulmonary venous return repair	16	13.5	16.5
Ventricular septal defect patch repair	106	5.0	5.0
Off-bypass coarctation of the aorta repair	48	6.0	8.5

# 8

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

If an abnormality is identified on prenatal screening, a comprehensive fetal care consultation to discuss anticipated surgery or other care after birth can be arranged at Lurie Children's through [The Chicago Institute for Fetal Health](#). This consultation will be arranged with the cardiac specialists who will be involved in your child's care after birth. In addition to a cardiologist, this team may include a cardiac surgeon, cardiac critical care specialist and neonatologist. The specialists will discuss and coordinate the best treatment plan for your baby after birth, and may review anticipated procedures, expected length of stay and anticipated surgical results. Our specialty programs offer a multi-disciplinary team of specialists committed to the best outcomes. Learn more about the Fetal Cardiology Program at [luriechildrens.org/fetalcardiology](http://luriechildrens.org/fetalcardiology).

Your options may be to deliver where initially planned and your baby is then transferred to Lurie Children's, or to deliver at Northwestern Medicine Prentice Women's Hospital. We may or may not schedule induction or a C-section within the 39th week of pregnancy. By delivering at Prentice Women's Hospital, we have the ability to transfer your baby safely to our Regenstein Cardiac Care Unit by way of a patient- and staff-only bridge. Being close to the Cardiac Care Unit allows you to visit your baby after your nurse and doctors feel it is safe for you to come over as well.

If you plan to deliver at Prentice, we will ask that you be seen by the high-risk obstetrics (OB) team at Prentice so that they can plan your delivery. Your fetal cardiology team meets regularly with Prentice's high-risk OB team, as well as your neonatology team, to ensure the care is coordinated for both mom and baby.

We anticipate a vaginal delivery in most cases. However, in rare cases, babies with certain congenital heart diseases will need immediate intervention for stabilization, and in that case we may recommend a C-section. Your provider will talk with you if that is the case.

# 9

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

Normal developmental support with immunizations and screening locally with your primary care provider is very important in your child's care. We partner with your child's primary care provider (PCP) to support developmental care when it comes to all cardiac care (inpatient and outpatient). Our team will inform your local provider of updates when hospitalized and after discharge. If additional supports are needed, we will ensure you have access to these resources.

# 10

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? If my child requires a procedure after birth, how will your team communicate with me?

## BEFORE AND AFTER SURGERY

We assess every child individually to ensure he or she is in the appropriate place to meet his or her needs. Your child could be placed in one of three locations: the Regenstein Cardiac Care Unit at Lurie Children's, the [Neonatal Intensive Care Unit \(NICU\)](#) at Lurie Children's or the NICU at Northwestern Medicine Prentice Women's Hospital (which is connected by a bridge to Lurie Children's).

## REGENSTEIN CARDIAC CARE UNIT

Our Regenstein Cardiac Care Unit (CCU) is a state-of-the-art 44-bed unit devoted to the care of young patients with cardiac disease. We have one of the only acuity-adaptable CCUs in the country.

With an acuity-adaptable model, the Regenstein CCU is one of the few cardiac units of its kind in the nation, allowing each child to stay in the same private room from admission to discharge. The high-tech rooms adapt to the level of care the patient needs, and eliminate the need to transfer the patient to other units in the hospital. Our rooms are technologically equipped for intensive care while providing the family amenities of a regular acute care patient room. Cardiac patients have the same healthcare team throughout their hospital stay.

Our cardiac intensive care team is available 24/7, so your child will receive prompt medical attention. With our knowledgeable staff, family-centered care and advanced technology, the Regenstein CCU gives young patients with heart disease an exceptional place to heal.

### Cardiac Nursing

The nurses at Lurie Children's have received their fifth Magnet® designation by The American Nurses Credentialing Center (ANCC). According to the ANCC, Magnet® designation is widely accepted as the gold standard of patient care, which recognizes excellence and professionalism in nursing. ANCC distinguishes an outstanding environment for professional nursing practice which includes a strong nursing governance structure, innovation and nursing research, interdisciplinary collaboration and engaged nursing professionals.

Lurie Children's is one of less than five percent of all hospitals to have received Magnet® recognition five times, and is the first hospital in Illinois and the first free-standing pediatric hospital in the nation to achieve five designations.

Our nurses are all trained in critical cardiac care, which translates to you having a nurse with the highest level of expertise. Our nurses go through a rigorous orientation program with cardiac-specific curriculum, and all of our nurses participate in ongoing education to assure that their skills and abilities facilitate the best clinical care being provided to your child.

## BABY CARE CONNECT/TELEMEDICINE

[Baby Care Connect](#) allows moms who are still recovering after childbirth to have a video visit with their infants at Lurie Children's Neonatal Intensive Care Unit (NICU) and Regenstein Cardiac Care Unit (CCU). Using iPads with a secure Polycom app, these moms can participate in family-centered rounds and discussions with the care team while also visiting with their child.

Baby Care Connect is currently available at:

- Northwestern Medicine Prentice Women's Hospital
- Regenstein Cardiac Care Unit at Lurie Children's
- Mercy Hospital and Medical Center
- Silver Cross Hospital
- Swedish Covenant Hospital
- West Suburban Medical Center

In addition to Baby Care Connect, we also offer other telemedicine capabilities to connect with your child if you cannot be on site.

# 11

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

Often parents can hold their baby prior to the procedure and within a few days after the procedure. We recognize how critically important the bond is between you and your child. There are several ways that we work to support that bond between you and your baby and prioritize kangaroo care, which includes holding and skin-to-skin contact whenever it is clinically safe to do so. Kangaroo care is a 50-year-old strategy that has shown to improve outcomes in premature babies, and it is encouraged for all hospitalized babies. We will make every effort to support your vision for bonding after birth, including holding.

Our priority is your baby's safety. There may be special medical lines and tubes to navigate in addition to phases of your baby's recovery that may not be appropriate for safe holding. The Cardiac Care Unit uses the Care Partnership Pyramid, which offers guidance as to what types of care parents can provide during different phases of your stay. Our team will guide you and provide this support throughout the entirety of your time with us, and we encourage you to discuss this with your care team often.

During times of restricted holding, there are other ways we will work with you to make the interaction as meaningful as possible. This could include touching your baby (stroking your baby's head, or holding their hand or foot), talking or reading to your baby and using video visits. Forming a strong relationship with your baby is important to our team's goals, and together we can help you understand the best methods to engage and thrive.

# 12

## 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 feeding without problems?

If your goal is to breastfeed your baby, that is our team's goal as well. We work one-on-one with families to be able to safely provide breast milk for their babies — whether through direct breastfeeding, bottle feeding expressed breast milk or expressed milk through a feeding tube.

Many of the nurses in the Cardiac Care Unit are Certified Breastfeeding Counselors. They will be there to help you reach your breastfeeding goals and answer any questions you may have along the way.

Our team has helped develop a helpful video series to guide you through the breastfeeding process. To watch the videos, visit [luriechildrens.org/breastfeeding](http://luriechildrens.org/breastfeeding).

# 13

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

Our goal is to educate families well in advance of hospital discharge, so that there is a safe and smooth transition to home. Each baby is provided with a care plan unique to their medical and developmental needs. Our care providers work with families, educating them on the many aspects of cardiac care so that parents feel empowered and comfortable caring for their baby in the home setting.

### BEFORE DISCHARGE

From the moment your family becomes part of the Heart Center, our cardiac team will find ways to involve you in every aspect of your child's care. We prioritize parental involvement because it helps families become more confident and builds a positive environment for everyone involved.

Our nursing staff partners with you, teaching you necessary skills required to care for your baby at home. They will give your family hands-on guidance and practice so you are well prepared to take care of your baby's daily needs, like feeding and giving medicine.

While your baby is here, you will learn about their care, nutrition, safe sleep, CPR and how to use a car seat. You may also be approached to participate in research studies or quality-of-care projects. We ask for participation from our families so we may continuously strive to provide excellent care. Our [Sarah and Peer Pedersen Family Learning Center](#), located on the 12th floor of the hospital, is a resource space where all patients and families can access educational resources, learn more about our services and read through consumer health materials..

Before you go home, you may also have time to "room in." This may be a part of the discharge process. During this time, you will manage all of your baby's care for 12–24 hours. This will help you become more comfortable with your baby's needs while the care team is nearby to answer questions and assist.

When you go home, we will assure that you will be fully supported. We will provide you with teaching sheets, a medicine list and a visit summary which clearly explains how to reach the Heart Center team if you have any questions or concerns.

### AFTER DISCHARGE

During your stay, we will work to coordinate care with your baby's primary care provider. Any follow-up appointments will be scheduled and shared with you before discharge. You will receive a printed list of these appointments.

### CARDIAC FOLLOW-UP CARE

In addition to the main hospital, we offer cardiac services at 10 [Lurie Children's outpatient centers](#) around the Chicago area, offering families the same quality care closer to home. Our goal is to provide care close to home if at all possible to avoid the burden of travel time. Please familiarize yourself with our outpatient centers and ask your provider for a local center near you.

Additional locations include:

- Lurie Children's Outpatient Center in Arlington Heights
- Lurie Children's Outpatient Center in Grayslake
- Lurie Children's Outpatient Center in Huntley
- Lurie Children's Outpatient Center in Lake Forest
- Lurie Children's Outpatient Center in Lincoln Park
- Lurie Children's Outpatient Center in New Lenox
- Lurie Children's Outpatient Center in Northbrook
- Lurie Children's Outpatient Center in Skokie
- Lurie Children's at Northwestern Medicine Central DuPage Hospital Pediatric Outpatient Center
- Lurie Children's Outpatient Center in Westchester

# 14

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

This can be an incredibly stressful time in a family's life and we want to be as supportive and share as many resources as we can to help you through the unknown. Many parents find it helpful to connect with other parents who have children with heart conditions, and so we often connect families with each other. There are also many local and national parent groups that focus on families affected by congenital heart defects, including Conquering CHD ([conqueringchd.org](http://conqueringchd.org)) and Mended Little Hearts ([mendedhearts.org](http://mendedhearts.org)). These groups offer peer-to-peer support services, share information and promote awareness and advocacy. Our providers and care staff are actively involved in both organizations.

### A TEAM OF SUPPORT

We offer resources and a variety of teams built to support your family mentally, emotionally and spiritually.

- **Case managers:** Our case managers can suggest resources to help with your family's specific physical, emotional and financial needs. They work with the Heart Center's social workers and your baby's heart team to coordinate any services you may need after discharge. This may include home nursing, medical supplies, home therapies or specialty services.
- **Social workers:** Our team of social workers support you and your family by helping you to understand how your child's illness or condition affects the entire family. Your social worker will provide emotional support, assist to solve problems that may result from your child's illness and connect you with Lurie Children's and community resources due to financial stressors, challenges with coping or other life stressors.
- **Registered dietitians:** As part of the feeding team, our dietitians provide a wide range of services for patients of all ages, including assessment, developing care plans, monitoring and education. For children with special healthcare needs, a good nutritional status helps to minimize complications from illness, medical treatments and surgery.
- **Psychologists:** Our psychologists support your child and family's well-being. They can do assessments and provide therapies for children with developmental and behavioral concerns.
- **Child Life specialists:** Our Child Life specialists assess, support and advocate for each child's physical and emotional needs. They are there to help your child understand their diagnosis or procedure in an age-appropriate way whether through play, teaching materials or other activities.
- **Chaplains:** Our chaplains provide emotional and spiritual care to people of all faith traditions, as well as those with no religious affiliation.
- **Music therapists:** Our board-certified music therapists design highly individualized interventions using patient and family-preferred music to promote comfort and work on developmental, physical and expressive goals. In the hospital setting, music therapy can offer an outlet for feelings about illness and hospitalization and reduce a child's perception of pain and anxiety.
- **Art therapists:** Our art therapists are clinically-trained professionals who use a variety of art materials at the bedside or in a group setting to help improve the physical and emotional well-being of patients and families.
- **Teachers:** Lurie Children's offers various education programs to our patients and their siblings to make sure a stay at our hospital doesn't disrupt a child's learning.

- **Interpreters:** All patients and families have the right to have complete information regarding diagnosis, prognosis and treatment in a language you understand. We strive to provide our services in the languages of our patients and families. Our Spanish language interpreting services are especially strong; we employ 16 full-time Spanish interpreters to meet your and your child's needs.
- **ParentWISE®:** Our trained ParentWISE® (Parent Wisdom In Shared Experience) volunteers are available in person or by phone to offer hope and practical support to families. As parents of children who have received specialized care or treatment, ParentWISE volunteers have a unique ability to connect with parents of current patients and offer support in a variety of ways.
- **PeerWISE®:** PeerWISE® volunteers are former patients over 18 who can mentor teen patients, and sometimes even their parents, as they go through the treatment process. PeerWISE volunteers talk with patients and families about what it's like to go through treatment, and about daily life after treatment.

For more information about the resources available to families, visit [luriechildrens.org/heartfamilyguide](http://luriechildrens.org/heartfamilyguide).

# Looking Ahead

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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 lifelong problems that I need to watch out for?

Long-term outcomes vary based on your child's specific condition. Some heart defects can be fixed with one operation, while for other defects additional surgeries may be needed as children get older. This will depend on your child's diagnosis.

## **UNDERSTANDING YOUR CHILD'S HEART DEFECT**

To have the best understanding of long-term outcomes, it is important to talk with your cardiologist. It is also important to understand the limits of prenatal diagnosis. Unfortunately, we do not always have all of the answers about your child's diagnosis before birth. While we can find many issues in utero, the way the blood flows through the heart changes after your child is born and starts to breathe. For certain heart conditions, it can be difficult to predict how the heart will handle those changes. More testing may be needed after birth to understand all the details of your child's condition.

## **FOCUSING ON QUALITY OF LIFE**

For children with complex heart defects, movement, play, feeding and language skills may develop more slowly. Some children with heart defects may need extra help in school or have emotional or behavioral challenges.

Because the outcomes of surgery for heart disease have greatly improved over the past 20 years, the goal of the Heart Center has moved beyond survival after surgery. We now focus a great deal of effort on making sure that heart kids experience a high quality of life.

## **IMPROVING OUTCOMES THROUGH ADULTHOOD**

More and more, children with congenital heart defects are living longer into adulthood. New complications can occur as a result of the original heart defect. Our Adult Congenital Heart Disease Program is dedicated to responding to these new challenges. **Learn more at [luriechildrens.org/ACHD](http://luriechildrens.org/ACHD).**



# 16

Thinking about how my child will grow and develop, what should I expect from them as a preschooler, school-age child, a teenager and as an adult?

Our team is devoted to helping your baby grow into a healthy adult and have lifelong success. Our NICU-Cardiac Neurodevelopmental Program is dedicated to improving quality of life for children and their families.

### **NICU-CARDIAC NEURODEVELOPMENTAL PROGRAM: CHILD AND ADOLESCENT CLINIC**

Research shows that high-risk neonatal intensive care unit (NICU) graduates and children with complex heart conditions are at a greater risk for neurodevelopmental issues when compared to healthy children. Many of these children experience one or more mild to severe deficits across a range of areas. The NICU-Cardiac Neurodevelopmental Program (NCNP): Child and Adolescent Clinic at Lurie Children's is one of only a few programs in the country that provides individualized care designed to help these children reach their full potential. The NCNP works with families to:

- Offer developmental assessment of infants, toddlers and preschoolers to maximize school readiness
- Identify school difficulties, such as problems with reading, writing and math
- Address speech and language difficulties experienced by infants, toddlers, pre-schoolers and school-age children
- Detect feeding or nutritional problems
- Attend to attention, behavioral and emotional problems
- Provide intervention for difficulties with social relationships with peers and family members
- Recognize challenges with task management and organization
- Diagnose delayed fine and gross motor skills

Learn more at [luriechildrens.org/NCNP](http://luriechildrens.org/NCNP).

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

Our Adult Congenital Heart Disease (ACHD) Program is designed to care for the growing population of adolescents and adults who were born with congenital heart defects (CHD), providing continued care to CHD patients ranging from simple to highly complex. Our providers have specialty training in ACHD, are well prepared to provide life-long follow-up care, and are here to help alleviate the stress and confusion that can come with being an adult with congenital heart disease. We provide treatment, education and support in order to offer the highest quality of care throughout the teen years and adulthood. Our team's background in pediatric and adult cardiology makes our program the right place for your ACHD needs.

We also offer a comprehensive Transition Program, which provides education for CHD patients 15 and over. This care coordination from pediatric cardiologist to ACHD cardiologist provides a seamless continuity of care and reduces risks of problems from multiple hand-offs to different physicians.

Learn more at [luriechildrens.org/ACHD](http://luriechildrens.org/ACHD).



All,  
for  
your  
one.®



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