The Fetal Center

Congenital Heart Defects

NATIONWIDE CHILDREN'S®

When your child needs a hospital, everything matters.

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Welcome to The Fetal Center at Nationwide Children's Hospital. Your Maternal-Fetal Medicine physician or Obstetrician has referred you to our program.

Your baby has been prenatally diagnosed with an abnormality and may require care at Nationwide Children's. We know this can be a very stressful time for you. Our team of fetal and pediatric medical and surgical specialists are here to guide and support each step of the way. Our goal is to provide you with the information and care you need to prepare for the birth of your baby, as well as what to expect after delivery.

During your fetal center visit the fetal and pediatric specialists will discuss the diagnosis, treatment, recovery and long-term prognosis of your baby. We are also here to provide supportive care, listen to your questions and discuss your concerns.

The Fetal Center Team

Your visit may include physicians from many different specialties depending on your baby's diagnosis.

- Advanced Illness Management
- Cardiology
- Cardiothoracic Surgery
- Clinical Genetics
- Craniofacial Surgery
- Maternal Fetal Medicine
- Neonatology
- Nephrology
- Neurology
- Neurosurgery
- Orthopedics
- Otolaryngology (ENT)
- Pediatric Surgery
- Perinatal Palliative Care
- Plastic Surgery
- Pulmonary
- Urology

Support Team and Additional Services

We understand that this can be a difficult time, and we are here to support you. Our nurse coordinators are available for you to call with questions and concerns. Our intake coordinator will help schedule your appointments at Nationwide Children's to help coordinate your visit to all necessary specialists in one day. To help prepare you for the birth and care of your baby, the nurse coordinator will arrange a tour of one of our Intensive Care Units, which could be the Neonatal Intensive Care Unit (NICU) or Cardiothoracic Intensive Care Unit (CTICU) depending on your baby's needs. We will also make sure you go home with information and educational resources to help you better understand your baby's diagnosis and what to expect after delivery.

A family support coordinator is available to provide emotional and spiritual support to you before and after your baby's birth. Additional support such as social work, psychology, interpreter services and accommodations for families that live outside of central Ohio are available. Please speak with the team about these services and any additional support you need. Please let us know if you have any additional questions or concerns.

For additional information, please contact The Fetal Center at **(614) 722-BABY (2229)**
or visit **NationwideChildrens.org/Specialties/Fetal-Center**

What to Expect at Your Upcoming Cardiology Appointments

Baby Name:____

Heart Condition:____

Date of First Fetal Echo:______________________________________

Fetal Medicine Visit #1

Date and Time:_________________________

Goals of visit:

- Introduction to heart problem and plan
- Introduction to fetal medicine team

Fetal Cardiology Visit #2

Date and Time:_________________________

- Follow up fetal echo and Fetal Medicine Visit
- Meet with cardiologist
- Meet with newborn specialist (neonatologist)
- Meet with Fetal Nurse Coordinator

Goals of visit:

- Further understand the diagnosis
- Review what will happen at delivery hospital and transfer of baby to Nationwide Children's Hospital
- Understand what surgery or intervention is expected before discharge home from the hospital
- Discuss expectations for hospital stay before and after surgery
- Discuss preparing to take your baby home from hospital
- Review resources/additional services to help provide support

Fetal Cardiology Visit #3

Date and Time:______________________________

- Follow up fetal echo
- Meet with cardiologist
- Meet with newborn specialist (neonatologist) if not already done.
- Fetal Nurse Coordinator
- Tour of Nationwide Children's Hospital Cardiac Intensive Care Unit

Goals of visit:

- Review the diagnosis
- Review what will happen at the time of delivery and in the first 1-2 days of life
- Introduce research studies currently being offered at Nationwide Children's Hospital
- Understand long term plan for surgeries
- Review expected long term outcome/prognosis
- Resources on additional services to help provide support

Frequently Asked Questions

Over the course of your fetal medicine visits all of these questions should be addressed in some way. Please feel free to use the list below as a check list to ensure that all topics are covered. Please don't hesitate to contact one of the fetal medicine team members if you have questions/concerns regarding any of the questions below.

Diagnosis

☐ Do I understand the diagnosis and heart diagram?
☐ Is there any uncertainty about this diagnosis?
☐ How/why did this happen? Can anything be done now to help?
☐ What prenatal follow-up can I expect?
☐ When will I meet the heart surgeon? If requested, a meeting or conference call with a heart surgeon can be arranged prior to your baby's birth. Otherwise, you will meet the surgeon once surgical timing has been established.

Delivery Plan

☐ How and where will my baby be delivered?
☐ Can I see/hold my baby after delivery?
☐ How will my delivery be coordinated with Nationwide Children's?
☐ How will my baby be transported to Nationwide Children's and when will this occur?

Time Between Delivery and Surgery

☐ Where will my baby stay prior to surgery?
☐ Will my baby be transported to a different facility or building and how will this occur?
☐ What other testing will be done before surgery?
☐ Will my baby be able to eat prior to surgery?
☐ Will I be able to breastfeed?

Plans for Surgery

☐ What surgeries are required for my baby and when will they happen?
☐ What will my baby look like after surgery?
☐ What are the surgical risks and survival rates?
☐ How long will we be in the hospital before going home?

Common Concerns About Growth and Development

☐ What cardiac and developmental issues should I expect?
☐ What feeding and growth concerns should I expect?
☐ How likely is my baby to be readmitted to the hospital?

Quality of Life and Long-Term Outlook

☐ Will my baby need future surgeries or procedures?
☐ Will my baby have physical limitations?
☐ Are there limitations for school?
☐ Could my other/future children have heart defects?
☐ How likely is it that my baby will need a heart transplant?

Preparing for Care of Baby at Home

☐ How long will we be in the hospital before going home?
☐ How will we know my baby is ready for discharge home?
☐ What plans should I make for childcare?
☐ How will I monitor baby at home?
☐ Where will my baby be cared for when we go home? Frequency of clinic visits?

Research Studies

Nationwide Children's Hospital is a leader in pediatric research. Our hospital is part of multiple network of academic research hospitals across the county. We do research studies to try and learn how to better treat babies with similar types of heart problems. Your baby may be eligible to participate in research trials during his or her hospitalization. Participation in research is entirely voluntary, and will not in any way affect the care your baby will receive once he or she is born.

Family Support

What specialists or other resources are available to me and my family? Please speak with one of the fetal medicine team members about these services and any additional support you may need.

- The Connecting Families Mentoring Program
- Psychology
- Social Worker
- Financial Counselor
- Lactation Consultant
- AIM team / Palliative care team
- Child Life
- Genetics
- Massage Therapy
- Pastoral Care

Overview

A heart defect is when the heart or the heart's blood vessels do not grow (develop) the right way before birth. The words "congenital heart defect" and "congenital heart disease" both mean that the defect happened before the baby was born. The Centers for Disease Control and Prevention (CDC) estimates that nearly 1% of births each year in the United States (or about 40,000 babies) are affected by congenital heart defects.

Causes

Parents often think they did something to make this happen to their baby. This is a normal response. In most cases, parents have no control over their baby's condition and have not done anything to cause the problem. In many cases, the cause of congenital heart defects is unknown. If you have specific questions or concerns about you or your baby, talk with your doctor or nurse practitioner.

Diagnosing the Heart Defect (Before Baby is Born)

During pregnancy, there are many prenatal tests that can tell the doctor if your baby has a heart (cardiac) problem. However, some heart problems cannot be seen until after birth. The following are some prenatal tests that may be done:

- **Prenatal ultrasound:** Complex heart defects are usually found during a pregnancy (prenatal) ultrasound, which would show an abnormally-shaped heart. Your doctor will schedule a fetal echocardiogram to get more information.

- **Fetal echocardiogram:** A fetal echocardiogram is a special ultrasound done by a sonographer and used by a pediatric heart doctor (cardiologist) to look closely at your baby's heart and surrounding blood vessels. The cardiologist will need to assess your baby after birth with an echocardiogram to confirm the diagnosis.

- **Fetal MRI (Magnetic Resonance Imaging):** This type of imaging gives more detailed pictures of your baby's organs, and may be helpful for complicated heart, lung or other concerns.

Postnatal Diagnosis (After Baby is Born):

- **Echocardiogram:** An echocardiogram is a special ultrasound used by a pediatric heart doctor (cardiologist) to look closely at your baby’s heart and surrounding blood vessels.

- **Heart Catherization:** A test to measure pressures in the heart, take pictures (angiography), and/or open a narrowing with a stent or balloon. Heart catheterizations are performed while your child is asleep with medications.

- **Cardiac MRI:** A test that uses radio waves, magnets, and a computer to create detailed pictures of the heart and blood vessels. Cardiac MRI can provide detailed information on the type and severity of heart disease.

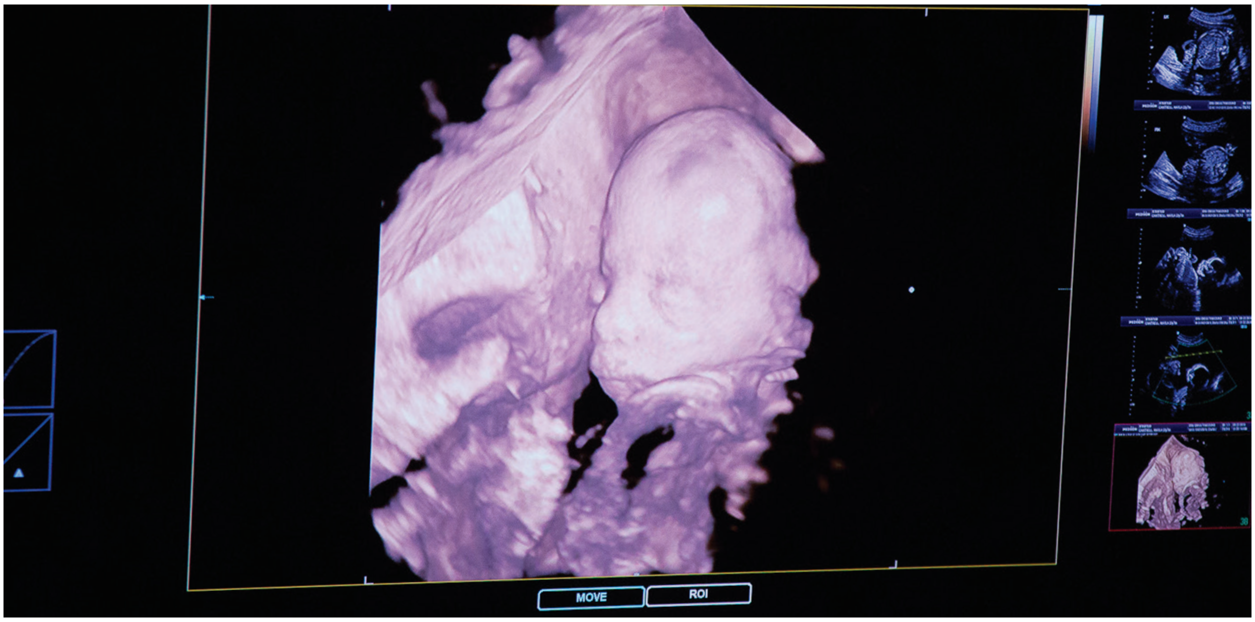
Other Tests

Some congenital conditions are because of changes in DNA, or a baby’s unique genetic make-up. The doctors may suggest genetic testing to find out more about your baby’s DNA. DNA is composed of individual genes that make up chromosomes.

- **Cell-Free Fetal DNA testing:** Your doctor can take a sample of your blood to look for copies of baby's (fetal) DNA. This is only a screening test. A positive result means that there could be problems with the DNA. This should be confirmed with another test to be sure of the result. Other testing can be done before or after birth depending on the needs of the baby.

- **Amniocentesis:** A small sample of the amniotic fluid that surrounds the baby in the womb is taken and tested for DNA problems. This test is usually done in the middle of the second trimester. An amniocentesis can be used to confirm findings on the cell-free fetal DNA test.

- **Testing the baby:** After birth, a test is done with a sample of your baby’s blood to test for DNA problems. This is called either a karyotype (basic chromosome study), or microarray (more detailed look at all genes).



Heart Anatomy and Function

Function of the Normal Heart After Birth

In a normal heart, there are four chambers and four valves. The chambers are divided into the top and bottom. The top chambers are called atria and the bottom chambers are called ventricles.

Atria

The **atria** are the "collecting" chambers. The atria collect blood going back to the heart from the lungs or body by way of veins.

Ventricles

The **ventricles** are the "pumping" chambers. The ventricles are muscle chambers that pump blood out to the body or the lungs by way of the great arteries. The great arteries are the pulmonary artery, which pumps blood to the lungs, and the aorta, which pumps blood to the body.

Right Heart

The **right heart** is the right atrium and right ventricle. Its job is to collect used blood (low in oxygen) and pump it to the lungs. The lungs will give the blood oxygen (oxygenate) again.

Left Heart

The **left heart** is the left atrium and left ventricle. Its job is to collect blood from the lungs (high in oxygen) and pump it out to the body. The body uses the oxygenated blood to work the muscles, brain and other organs.

Valves

There are four **valves** inside the heart that separate the chambers. These valves are one-way "doors" in the heart. These valves open and shut between the atria and ventricles and between the ventricles and great arteries. The valves push blood forward and keep it from moving backward.

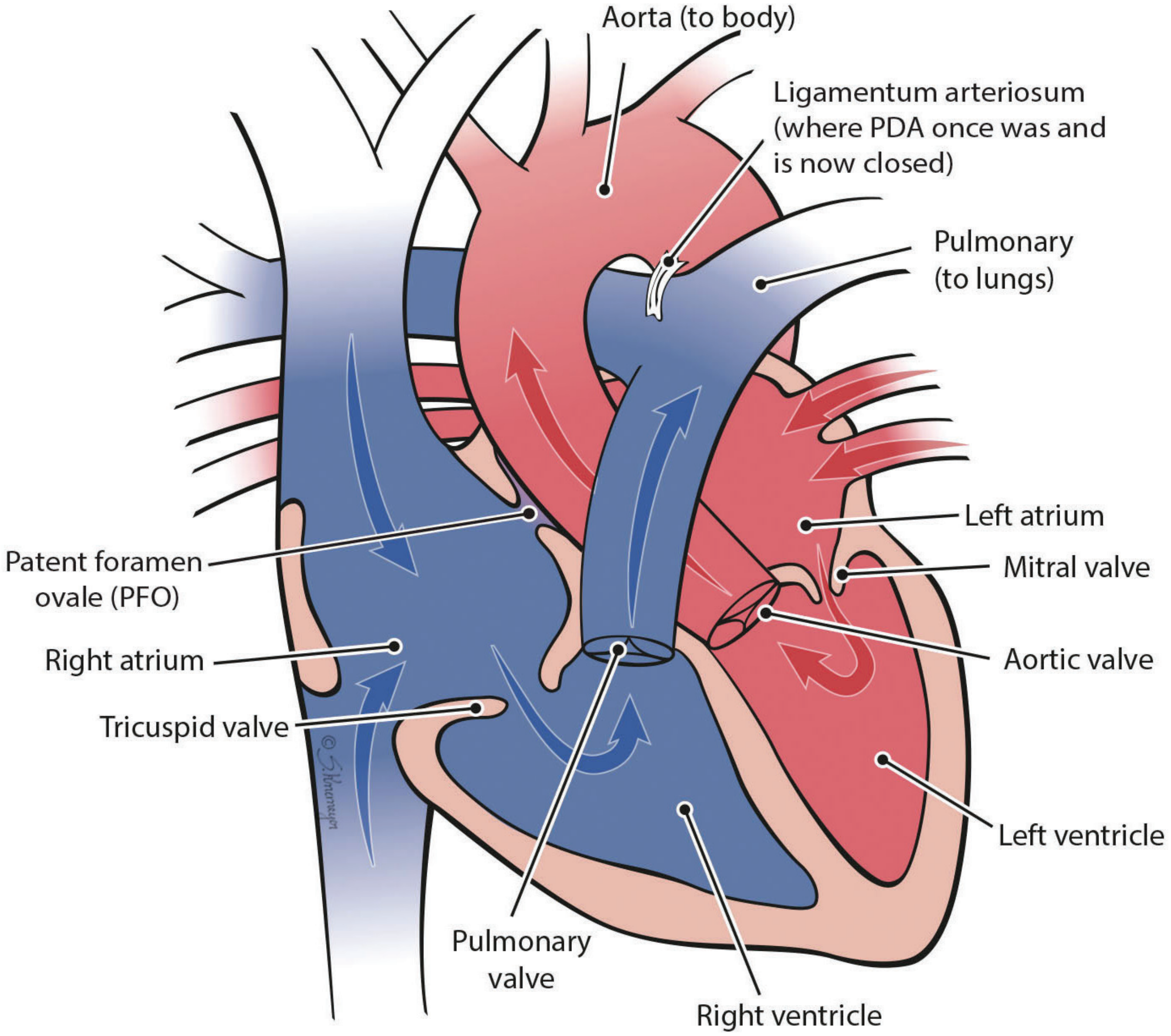
Patent Ductus Arteriosus (PDA)

In a developing fetus, several special "fetal" connections exist. For some babies with heart conditions, these fetal connections become important even after baby is born. The **patent ductus arteriosus (PDA)** is a special fetal blood vessel that sends blood from the mother's placenta directly to the baby's body, past the fetal lungs. In babies with a normal heart, the PDA begins to close within a few days after birth because it is no longer needed. However, babies with certain heart defects need the PDA to stay open for blood flow.

Patent Foramen Ovale (PFO)

The **patent foramen ovale (PFO)** is a normal fetal opening between the two atrial chambers. Typically, the PFO closes shortly after birth because it is no longer needed. However, babies with certain heart conditions need this PFO to stay open for blood mixing.

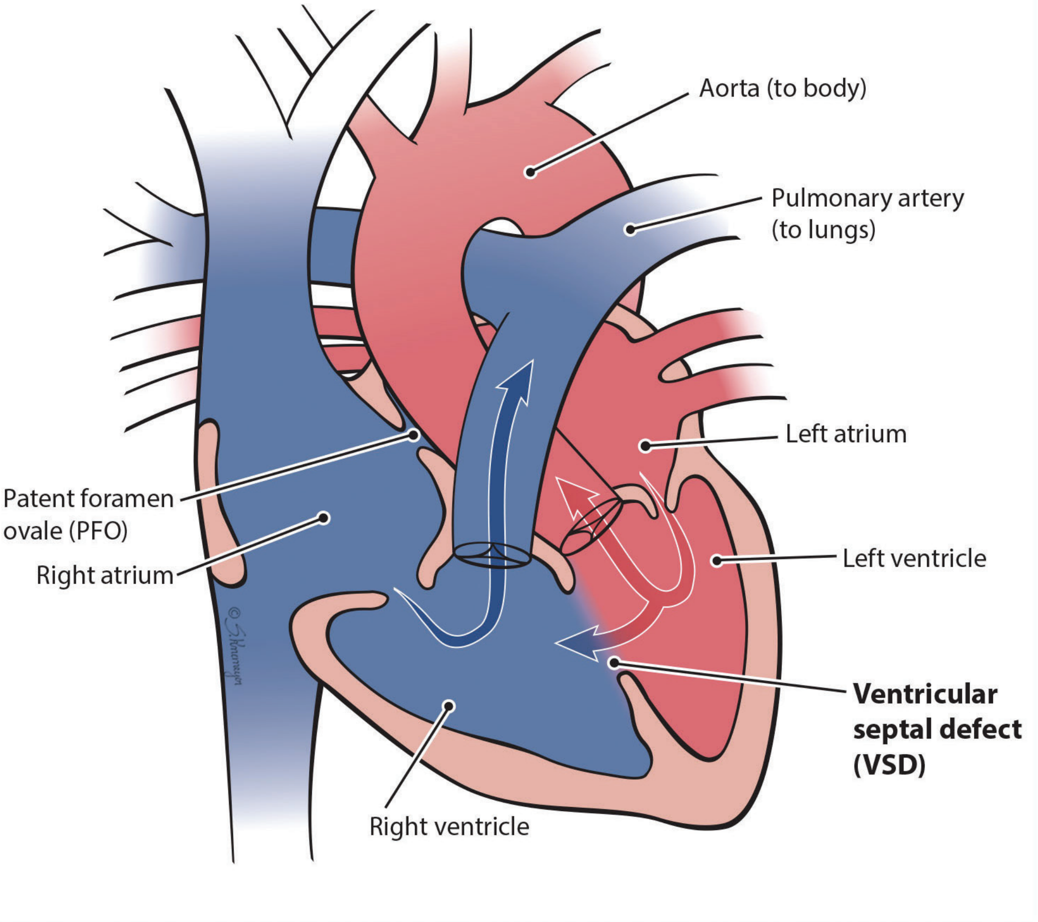
Normal Heart After Birth



Types of Congenital Heart Defects Diagnosed Prenatally

Ventricular Septal Defect (VSD)

A VSD is a hole in the wall (septum) that separates the right and left bottom pump chambers (ventricles) of the heart. Blood can flow across the hole as the heart pumps. Most times, a baby born with a VSD has no symptoms. However, if the VSD is a large hole, the blood flowing across the hole causes extra blood flow to go to the lungs. This can cause lung problems, trouble breathing, and problems with eating and growth over time.

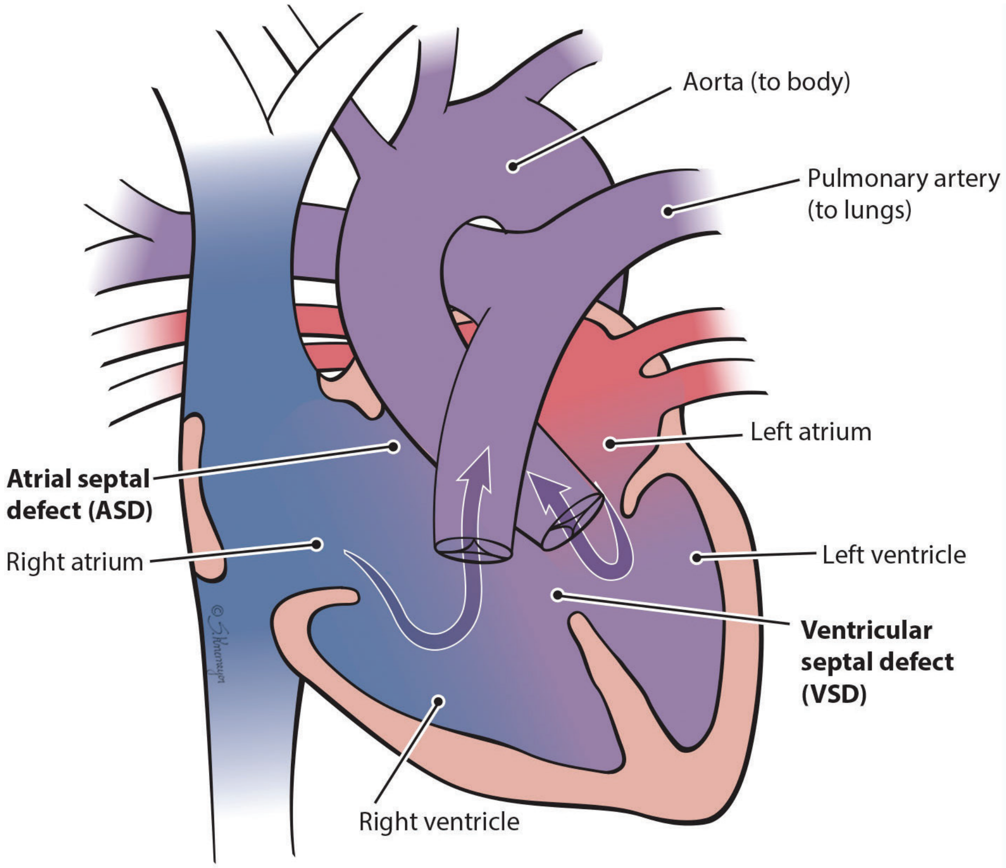


Treatment for VSD

Most VSDs are small in size and will close on their own as the baby and the heart grow. Large holes need to be closed (repaired) to prevent lifelong complications, particularly growth problems and lung and heart damage. Surgery is usually done by 1 year of age. If a VSD does need to be closed, most patients will need open heart surgery. In surgery, the surgeon will close the VSD with stitches or a patch. Some holes can be closed during a cardiac catheterization ("heart cath"). During this procedure the cardiologist guides a catheter through the blood vessels and goes up to the heart. Once the catheter is in the heart, the VSD is closed with a device called a "septal occluder".

Atrioventricular Septal Defect (AVSD, Endocardial Cushion Defect, Also Called Atrioventricular Canal Defect or AVCD)

An atrioventricular septal defect (AVSD) is a heart defect in which there is a hole between both the top collecting chambers (atria) and bottom pumping chambers (ventricles). The valves between the chambers (the tricuspid and the mitral valves) are involved in the hole and do not form separately. Instead, one large valve is formed. Blood can flow across the holes and cause extra blood flow to the lungs. There are multiple forms of AVSD – partial, complete, transitional. In a complete AVSD, the hole in the center of the heart is large. In partial and transitional types the hole is smaller. This is seen more commonly in children with Down syndrome, but happens frequently in other children as well.

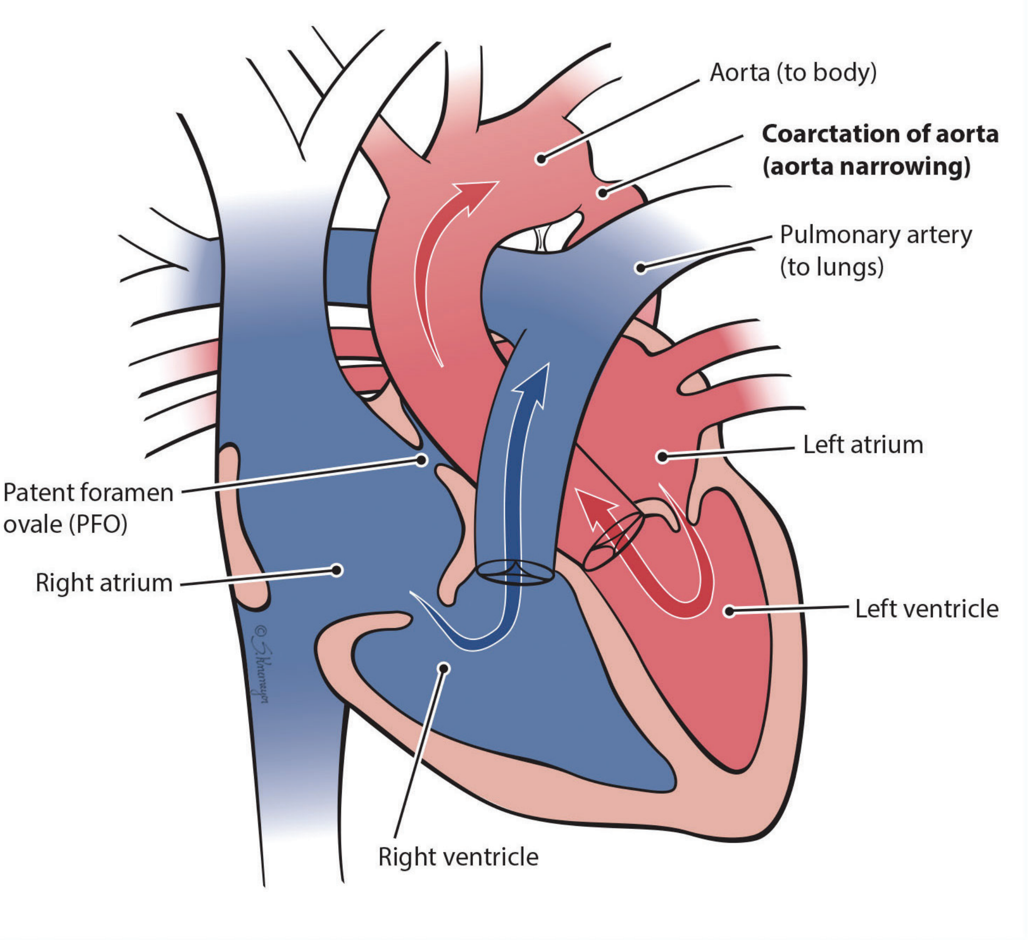


Treatment for AVSD

All forms of AVSD will need surgical repair at some point with open heart surgery. Large holes need surgery early, in the first year, but other types can be done later. During surgery, any holes in the chambers are closed using patches. The valves usually require repair during surgery. Closing the holes will prevent lung damage from the extra blood flow to lungs across the holes. Your baby's cardiologist will decide the best time for surgery based on your baby's specific heart defect.

Coarctation of the Aorta

A coarctation of the aorta is a narrowed part of the aorta, the large vessel that carries blood to the body. The narrowing causes decreased blood flow to the lower body. The left ventricle of the heart must work harder in order to pump blood through the narrowed aorta. A "critical" coarctation means the aorta is so narrowed that blood cannot flow out to the body.



Treatment for Coarctation of the Aorta

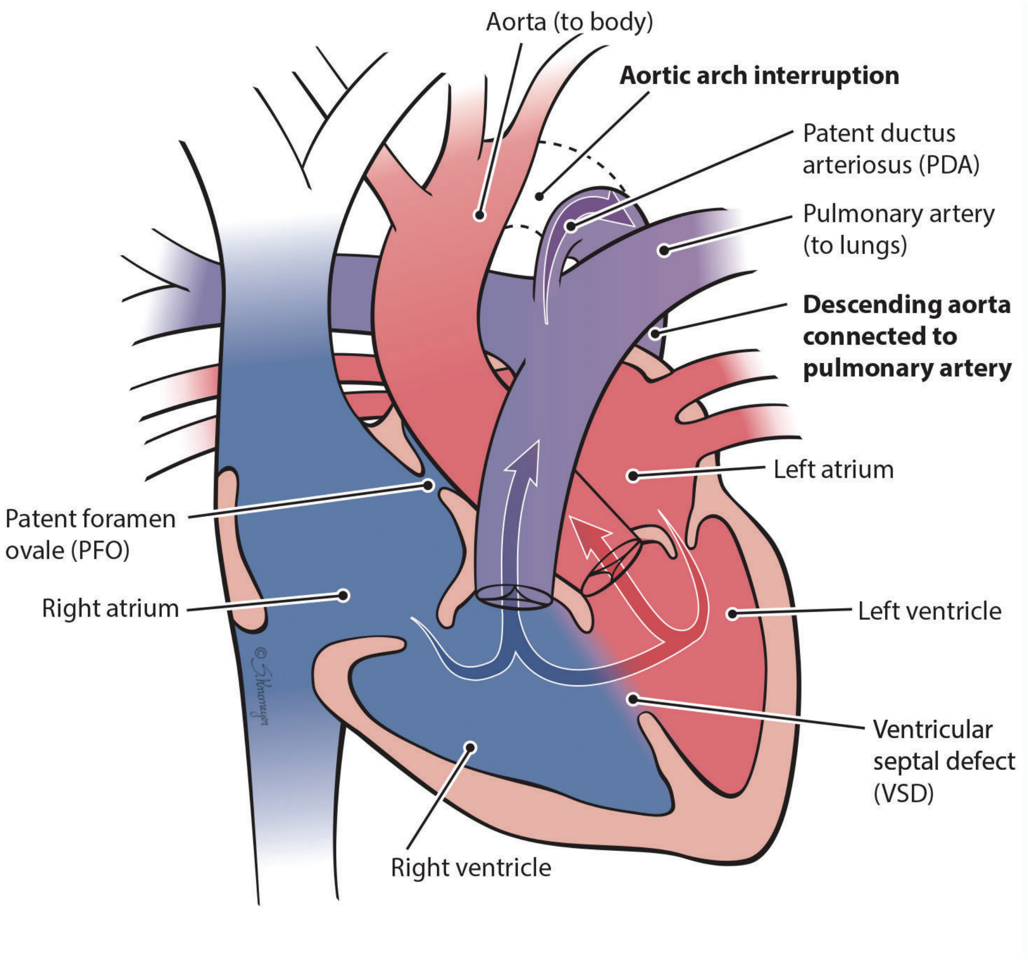
Most children with an aortic coarctation, unless very mild, will need repair soon after birth. Coarctation of the aorta can be treated either with surgery or a cardiac catheterization ("heart cath"). The choice for surgery or catheterization is dependent on the age of the child and the exact details of the heart defect. While older children and young adults can be treated with a catheterization, most young children will need surgery.

During surgery the narrow portion of the aorta is removed, and the aorta is patched and reconnected. This opens the narrowing, fixing the blood flow through the vessel to the lower half of the body, though more treatments may be needed over time.

A heart catheterization uses a thin, flexible tube, called a catheter, which has a balloon and/or stent inside it. The catheter is inserted into the leg blood vessel and passed up to the narrow part of the aorta. When the catheter reaches the narrow area of the aorta, a balloon is inflated to open the narrowing. Sometimes a stent is required to keep the vessel open. Both the balloon and stent treatments are effective, but more treatments may be needed over time.

Interrupted Aortic Arch (IAA)

The aorta is the large vessel that carries blood from the left ventricle out to the body. An interrupted arch happens when the aorta does not form correctly - a section of aorta is missing so that the part coming off the heart and the part going out to the body are not connected. When this happens, blood cannot get from the heart to the lower body without an extra blood vessel called a patent ductus arteriosus (PDA). IAA usually involves a hole in the lower heart chambers called a ventricular septal defect (VSD).

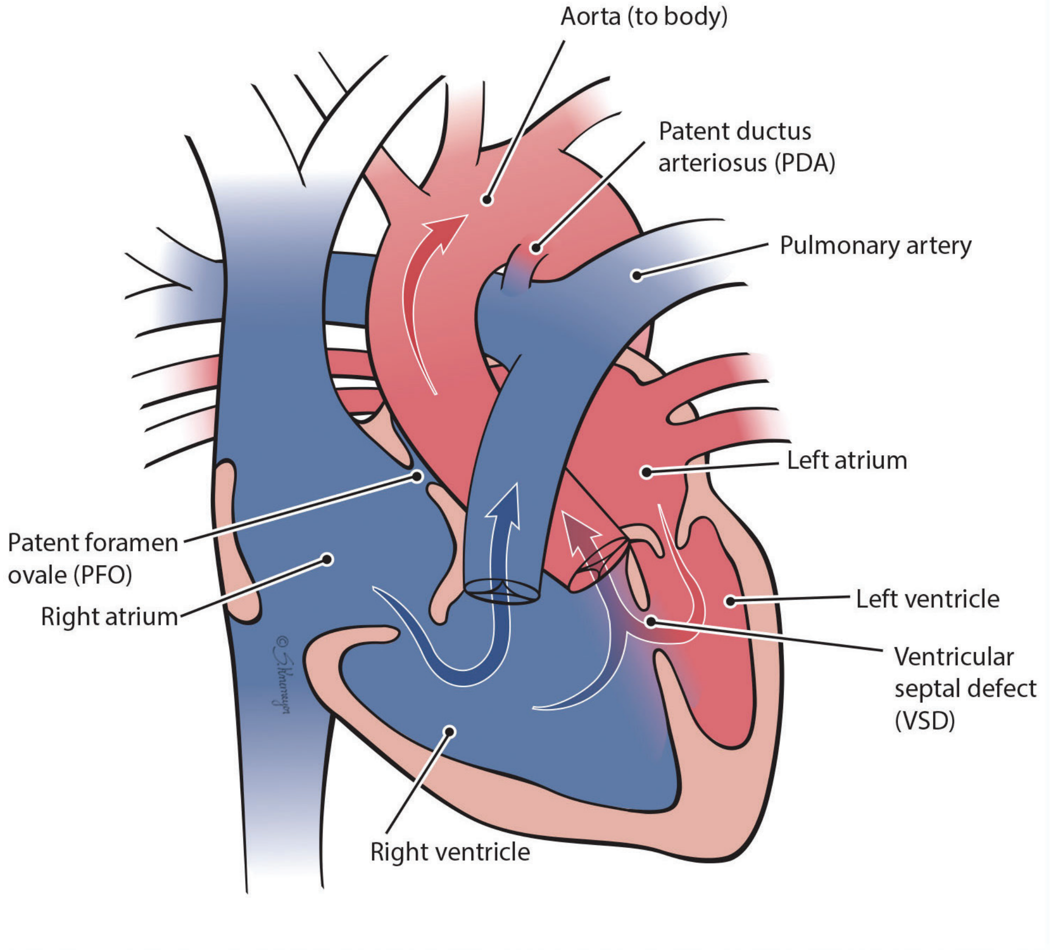


Treatment for Interrupted Aortic Arch

All forms of interrupted arch will need surgical repair (open heart surgery) soon after birth, typically done in the first week. This heart defect is most commonly found in the newborn period, when the baby is small, so sometimes more than one surgery is needed. The surgery will connect the two parts of the aorta together, and close any large holes (VSD) if present. The aorta repair can be a direct connection of the two parts, or sometimes artificial tissue will need to be placed if the gap is large.

Double Outlet Right Ventricle (DORV)

In a normal heart, the aorta comes off the left pumping chamber (ventricle) and the pulmonary artery comes off the right pumping chamber (ventricle). In DORV both the pulmonary artery and the aorta (the “outflow vessels”) come from the right ventricle. This defect usually also has a large ventricular septal defect (VSD), a hole between the bottom chambers. DORV frequently will have additional heart defects and is very unique to each child.

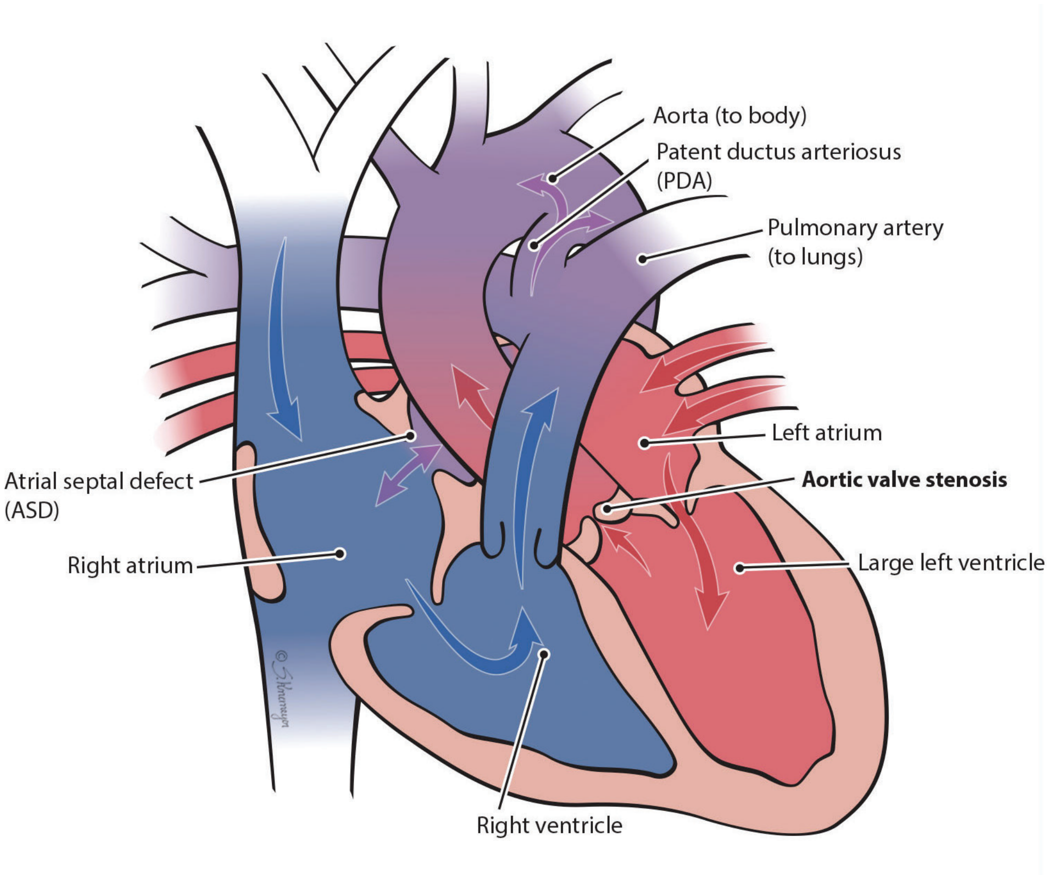


Treatment for Double Outlet Right Ventricle (DORV)

All forms of DORV will need some form of heart surgery to correct the normal flow of blood. Most forms of DORV are able to have a “complete repair,” where the blood flow is restored back to normal and the hole in the bottom chambers (VSD) is closed. The timing of surgery will depend on the exact anatomy of the DORV, but can vary from the newborn period to 1 year of age. Some infants with DORV will need more than one surgery.

Aortic Stenosis

In the normal heart, blood flows from the left ventricle through the aortic valve to the rest of the body. Aortic valve stenosis is when the aortic valve is more narrow than normal and does not open properly. This blocks flow to the body. Aortic stenosis can be mild, moderate or severe. When a baby has severe aortic stenosis, the left pumping chamber (left ventricle) gets enlarged and weak.



Treatment for Aortic Stenosis

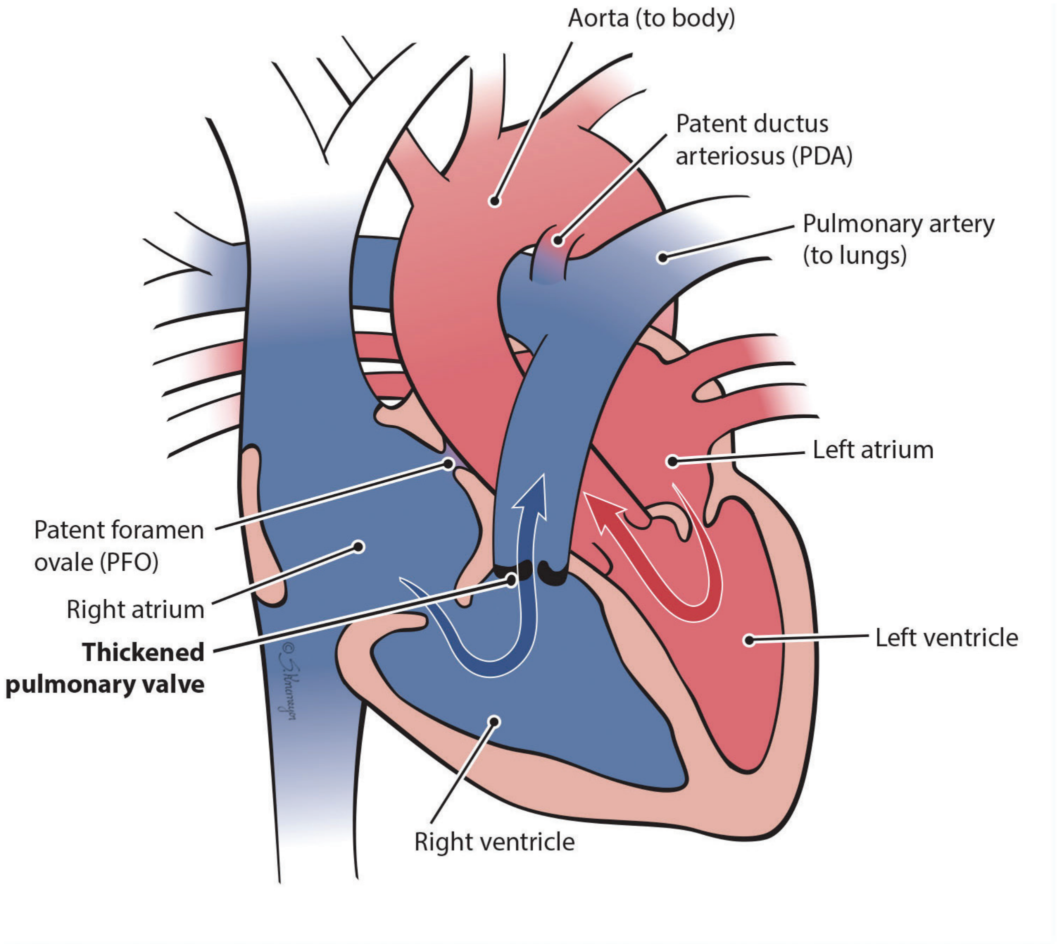
Mild and moderate aortic stenosis often does not need treatment. If the aortic stenosis progresses to severe, then treatment to improve the body blood flow will be needed.

Treatment choices include:

- **Balloon dilation or valvuloplasty.** This procedure is done as a cardiac catheterization. A heart catheterization uses a thin, flexible tube (catheter) with a balloon inside of it. The catheter is inserted into the leg blood vessel and passed up to the heart. When the balloon-tipped catheter reaches the narrowed aortic valve, the balloon is inflated to stretch the valve open.
- **Surgery.** Open heart surgery may be necessary to open the valve.
- Many babies with severe aortic stenosis also have other issues in the heart. The left ventricle and mitral valve can be affected and multiple complex procedures may be required.

Pulmonary Stenosis

In the normal heart, blood flows from the right ventricle through the pulmonary valve to the lungs. Pulmonary stenosis is when the pulmonary valve is more narrow than normal and does not open properly. This makes it harder for the right ventricle to pump blood to the lungs. If severe, the blood cannot be pumped into the lungs well and the baby may have low oxygen levels.



Treatment for Pulmonary Stenosis

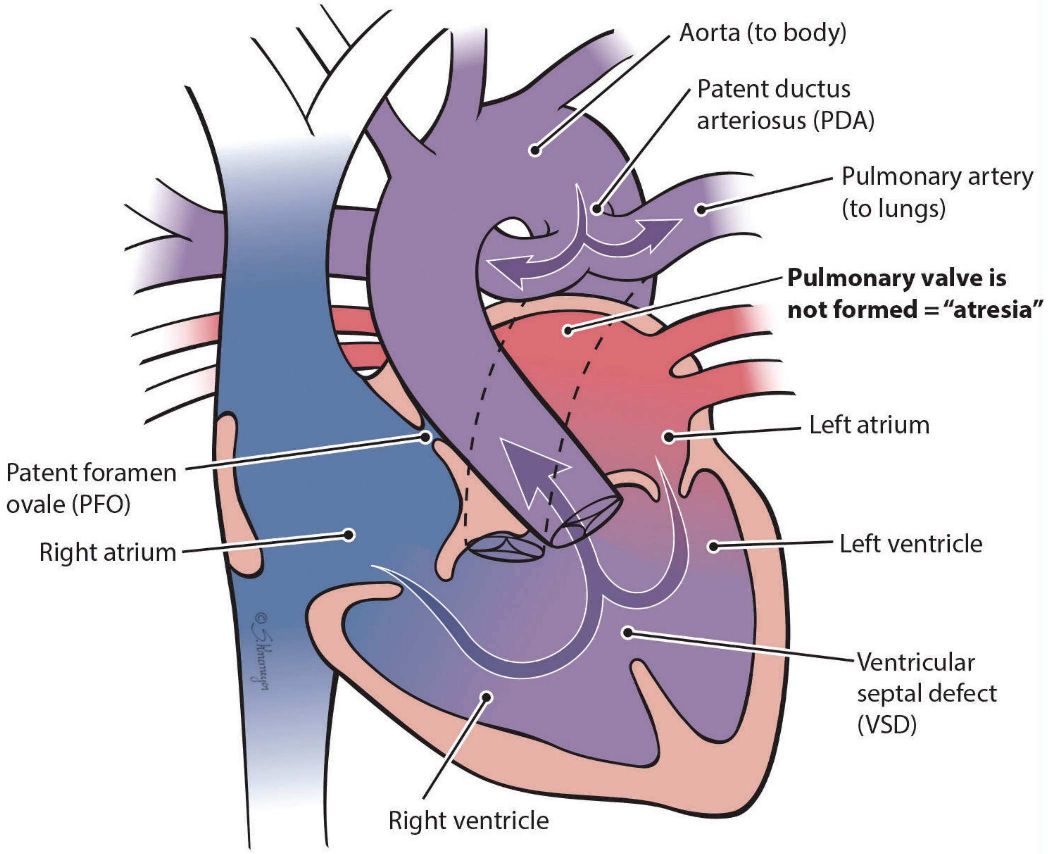
Mild and moderate pulmonary stenosis often does not need treatment. If the pulmonary stenosis progresses to severe, then treatment to improve the lung blood flow will be needed.

Treatment choices include:

- **Balloon dilation or valvuloplasty.** This procedure is done as a cardiac catheterization. A heart catheterization uses a thin, flexible tube (catheter) with a balloon inside of it. The catheter is inserted into the leg blood vessel and passed up to the heart. When the balloon-tipped catheter reaches the narrowed pulmonary valve, the balloon is inflated to stretch the valve open.
- **Surgery.** Open heart surgery may be necessary to open the valve and the lung arteries. Sometimes a "pulmonary valve replacement," a new pulmonary valve, can be placed.
- Most children are able to have an initial catheterization / balloon procedure, although if the stenosis progresses, additional surgery later on may become necessary.

Pulmonary Atresia/VSD

The pulmonary valve is a “door” that opens and closes between the right lower pumping chamber (the right ventricle) and the lungs. The condition known as pulmonary atresia happens when the pulmonary valve does not form, so that no blood can go from the heart into the lungs. When babies have this defect, blood cannot flow normally to the lungs to pick up oxygen for the body, and baby will have low oxygen levels. Immediately after birth an extra blood vessel known as the patent ductus arteriosus (PDA) will support the lung blood flow temporarily, but additional treatment is usually necessary.



Treatment for Pulmonary Atresia/VSD

Treatment for pulmonary atresia depends on its severity. Most babies born with pulmonary atresia need surgery to correct the problem soon after birth. The goal is to improve blood flow to the lungs, either by opening the narrowed pulmonary valve or bypassing it with an extra blood vessel called a “shunt” – this is a surgically placed tube that takes the place of the PDA. The surgeon will close the ventricular septal defect by using a patch when needed. Cardiac catheterization, a “heart cath,” is sometimes an option for newborns with pulmonary atresia/VSD. During this procedure the pulmonary valve is stretched open by using a balloon. In addition, sometimes a stent can be placed within the PDA to keep it open, so that a surgical shunt is not needed. Multiple heart procedures, a combination of both surgeries and catheterizations, are usually necessary throughout childhood for children pulmonary atresia/VSD.

Tetralogy of Fallot (TOF)

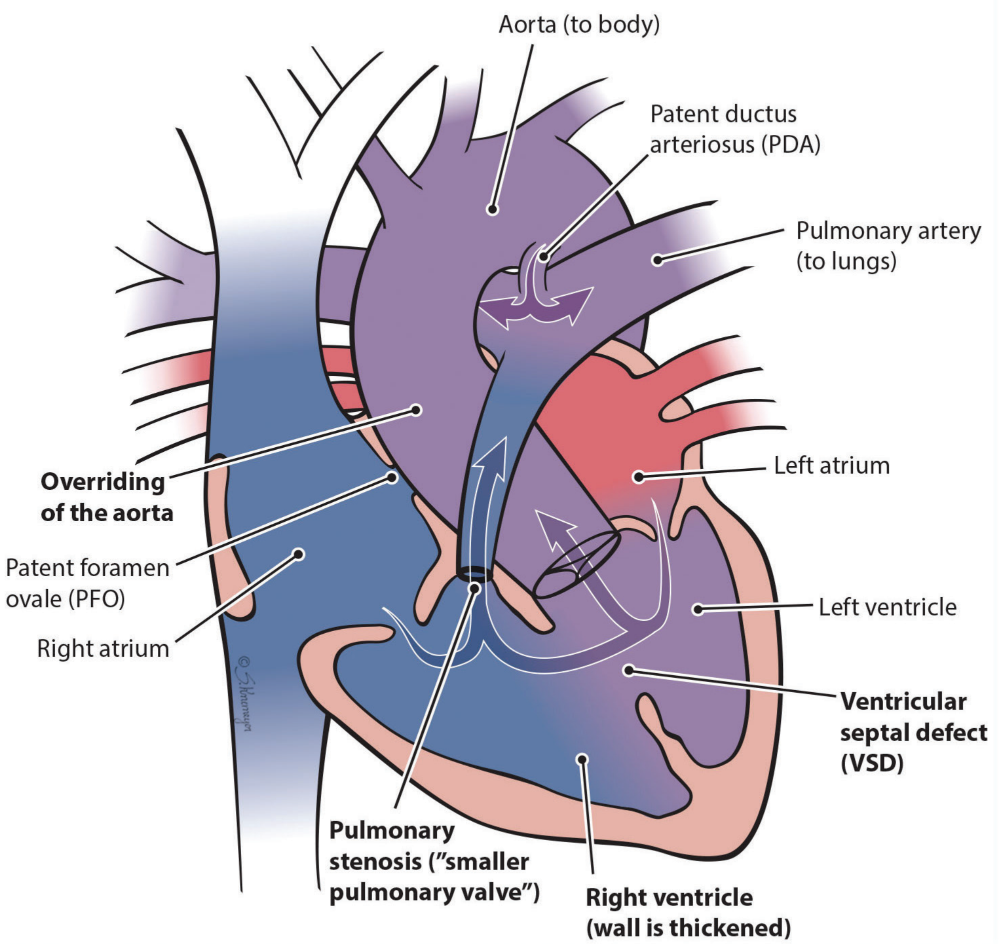
Tetralogy of Fallot (TOF) is a combination of four congenital heart problems that result in not enough blood flow to the lungs. In this condition, severity can range from mild to severe. These four heart problems are:

Ventricular septal defect (VSD): A hole between the two bottom pumping chambers of the heart (ventricles).

Overriding of the aorta: In the normal heart, the aorta comes off the left ventricle. In TOF, it sits over both the right and left ventricles and "straddles" the VSD.

Pulmonary stenosis: The pulmonary valve is more narrow than normal and does not open properly. This makes it harder for the right ventricle to pump blood to the lungs, and as a result baby may have low oxygen levels.

Right ventricular hypertrophy: Increased thickness of the walls of the right pumping chamber (ventricle) because the right heart has to work harder to pump blood to the lungs.

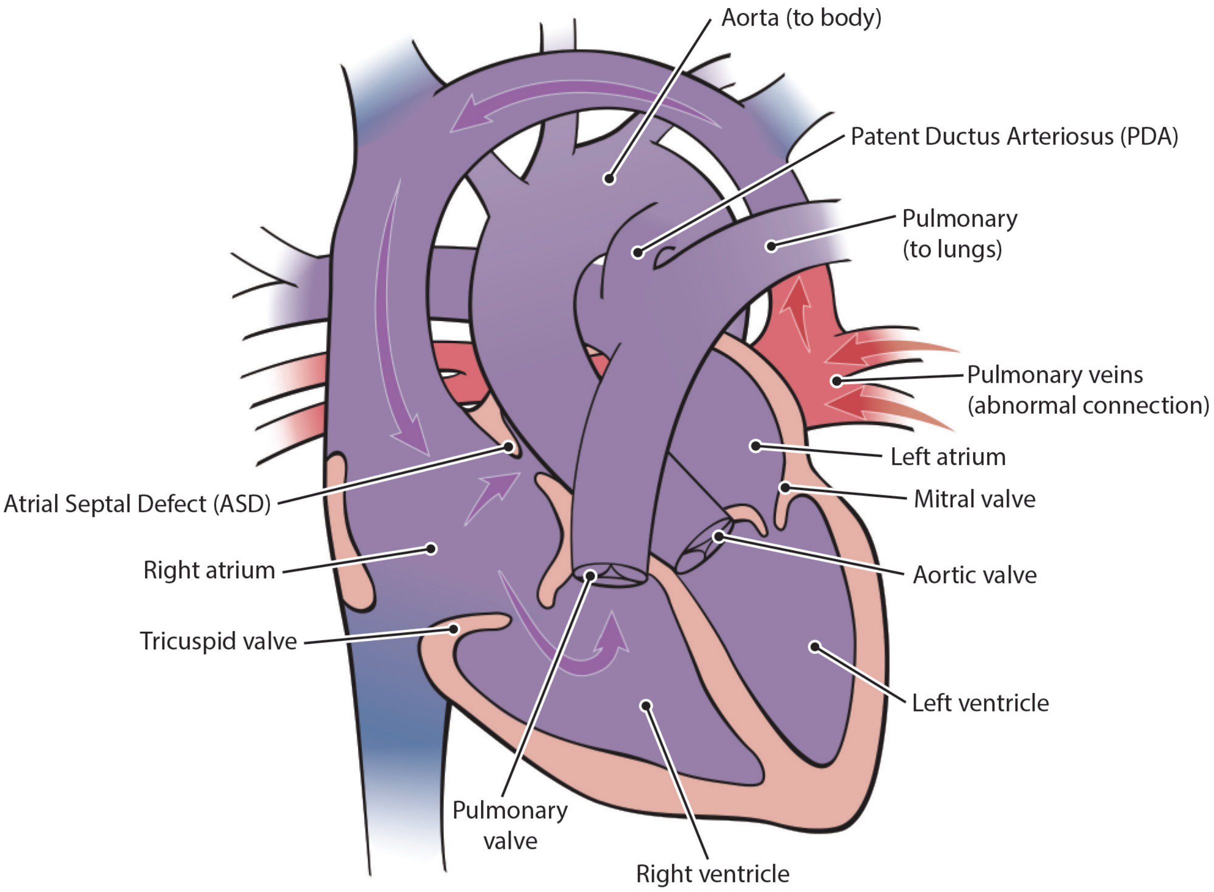


Treatment for Tetralogy of Fallot

All children born with Tetralogy of Fallot need to have surgery at some point. Most children will need surgery before they turn 1 year old, most commonly around 6 months of age. The goal for surgery is to improve blood flow to the lungs and the rest of the body. Some children will need a temporary shunt placed to provide stable pulmonary blood flow until a more permanent repair can be made at a later age. Surgical repair for TOF will fix the pulmonary stenosis by opening the pulmonary valve, and close the VSD using a patch. Another surgery later in life is sometimes necessary.

Total Anomalous Pulmonary Venous Return (TAPVR)

TAPVR is a heart condition where the blood vessels in the lungs, called the pulmonary veins, are not attached to the heart in the right place. These veins are important because they carry blood with oxygen to the heart. Normally, these veins are connected to the upper left chamber of the heart, called the atrium. In TAPVR, they are connected to different vein that returns to the heart. This causes the body to not get enough oxygen. To survive after birth, babies with TAPVR usually have a hole between the right atrium and left atrium. This is called an atrial septal defect. This lets blood with some oxygen (purple in picture) get to the left side of the heart. This blood is then pumped out to the rest of the body.

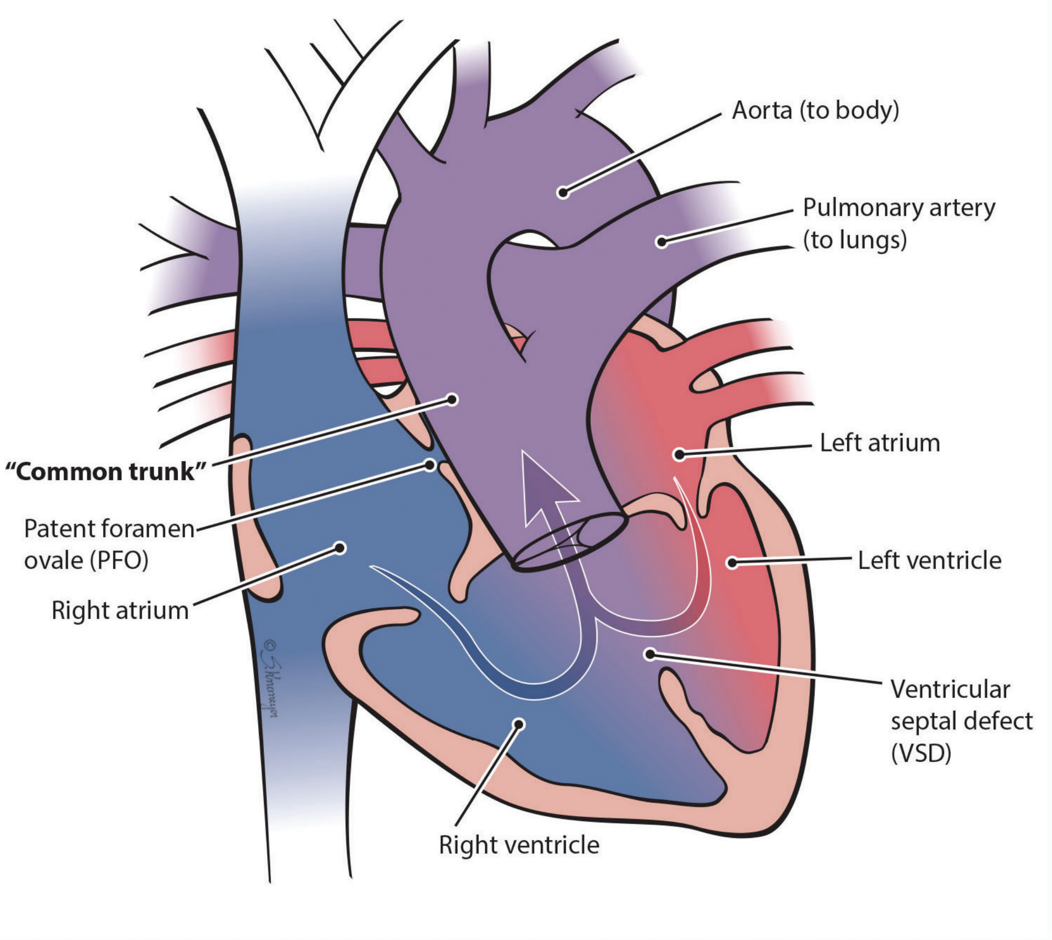


Treatment of TAPVR

All children born with TAPVR will need open heart surgery. The goal is to connect the pulmonary veins to the left atrium and close the atrial septal defect. This lets blood flow through the heart and lungs the right way. Depending on how sick your baby is after birth, the surgery may be done a few days after they are born. However, they may have to wait a few months until they are stable enough to handle surgery.

Truncus Arteriosus

When a normal heart develops, there are two large blood vessels (great arteries) that take the blood to the body (aorta) and the lungs (pulmonary artery). Sometimes only one blood vessel forms instead of two. This is called a "common trunk," or truncus arteriosus. With this defect, there is also a hole between the ventricles called ventricular septal defect (VSD). Blood "mixes" inside the heart through the VSD hole before getting pumped though one big blood vessel to both the lungs and the body. Because blood leaving the heart is "mixing," baby may have lower oxygen levels and trouble breathing.



Treatment for Truncus Arteriosus

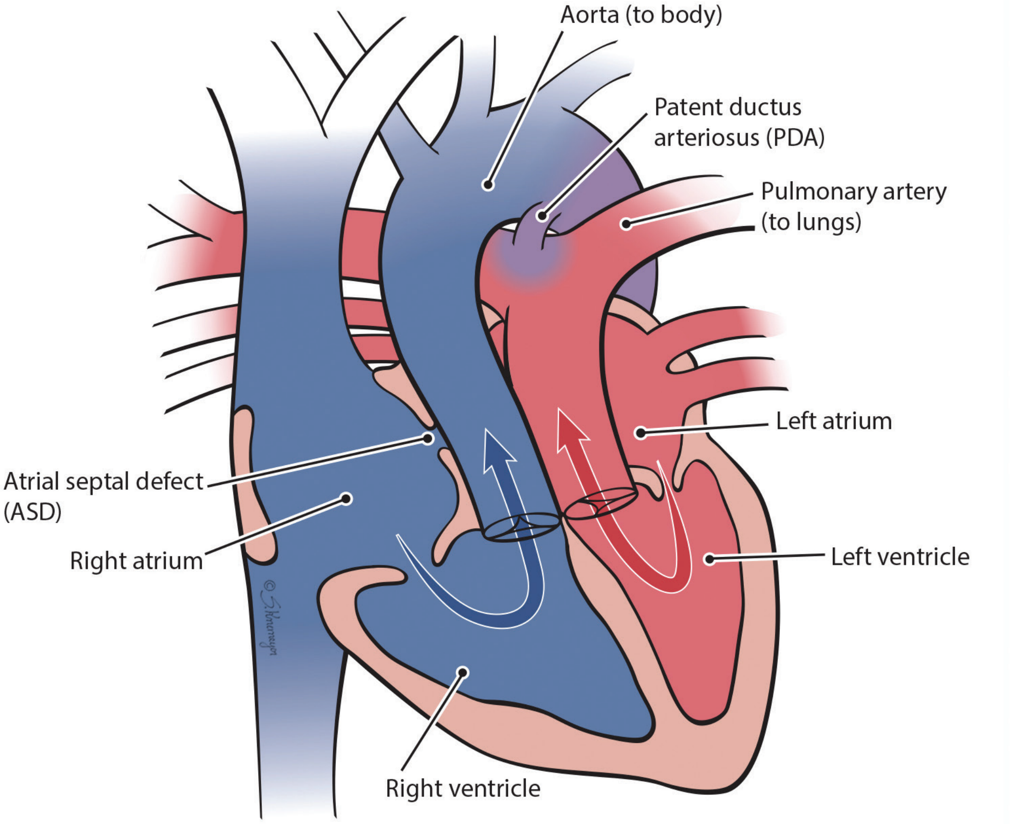
All children born with truncus arteriosus will need to have surgical repair to close the hole, and separate the "common trunk" into two separate blood vessels for the body and the lungs. The surgeon uses the following steps to repair the defect:

- Close the ventricular septal defect by using a patch.
- Detach the pulmonary arteries from the truncus arteriosus (common artery) and connect them to the right ventricle. This new connection requires a tube, either a homograft or a conduit. A homograft is a human tissue valve. A conduit is a small tube containing a valve. Because this tube does not grow with the child, it usually needs replacement at some point in childhood.

Transposition of the Great Arteries (TGA)

In a normal heart, oxygen-poor ("blue") blood from the body returns to the right heart and is pumped through the pulmonary artery to the lungs to get more oxygen. Then, oxygen-rich ("red") blood returns to the left heart and is pumped out to the body through the aorta. In transposition of the great arteries, the two major arteries leaving the heart (pulmonary artery and aorta) are switched and get blood from the wrong chamber. This means that the aorta is connected to the right ventricle, and the pulmonary artery is attached to the left ventricle. Most babies born with transposition of the great arteries have lower oxygen levels at birth and may have problems breathing.

In TGA, immediately after birth the "blue" blood and "red" blood need to mix to make sure enough oxygen gets to the body. Mixing happens two ways – within the top chamber hole (ASD) or through an extra blood vessel called the patent ductus arteriosus (PDA). If there is enough mixing, babies with TGA can be very stable after birth. However, babies with TGA who do not have enough mixing can have very low oxygen levels and require emergency treatment.



Treatment for TGA

All children born with TGA will need to have surgery to switch the blood vessels. Surgery is typically done in the first week of life once the baby is stable after birth. Immediately, they may need help with breathing, extra oxygen, or a medicine called prostaglandin E (PGE). This medicine keeps the blood flowing through the PDA. A balloon atrial septostomy (BAS) can be done shortly after birth by cardiac catheterization if needed. This uses a balloon on a catheter to enlarge the atrial septal defect (ASD), which increases mixing and makes it easier for oxygen-rich blood to reach the rest of the body.

The surgery for TGA repair is called an arterial switch. The goal is to restore the normal blood flow through the heart and out to the lungs and the body. The surgeon will move the aorta and pulmonary artery back to their normal places. The coronary arteries also need to be moved and reattached to the aorta.

Vascular Ring

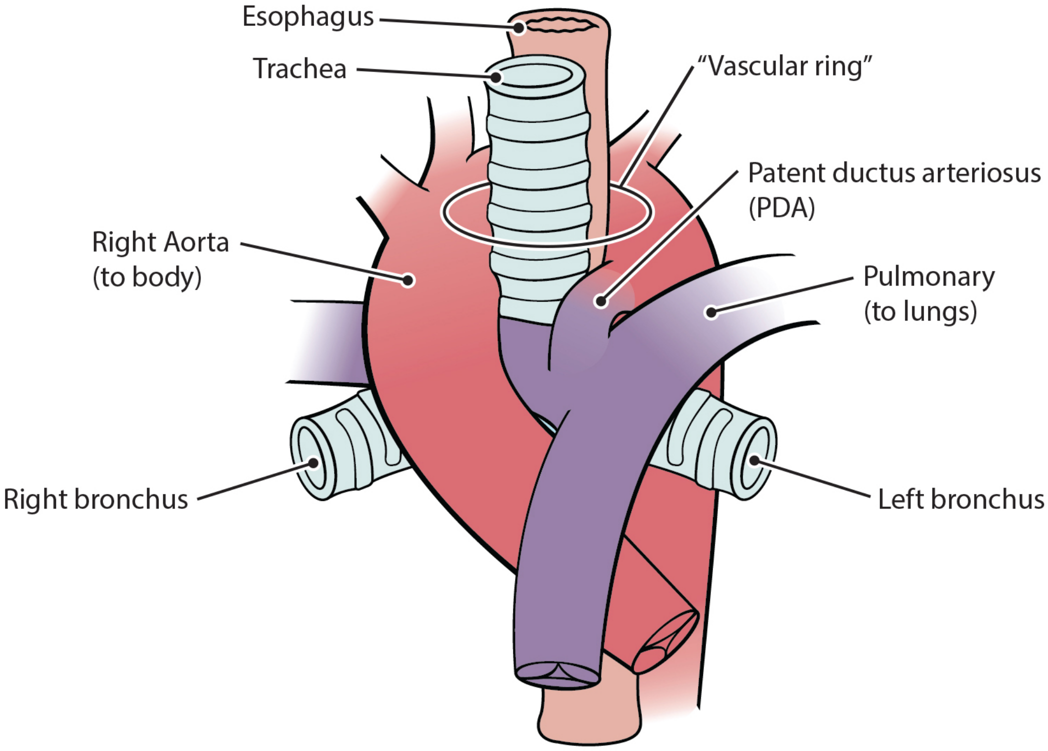
A vascular ring is when the aorta wraps around the trachea and esophagus. This can make it hard to breath and eat. The three most common vascular rings are:

- Double aortic arch
- Right aortic arch
- Abnormal right subclavian artery

Symptoms of Vascular Rings

Symptoms may happen early or later in life depending on the type of ring. There may never be any symptoms at all. Babies born with a vascular ring can have:

- Noisy breathing
- A cough that won't go away
- Acid reflux
- Problems eating or swallowing.



Treatment of a Vascular Ring

Surgery is usually needed if your child is having symptoms. The type of surgery done depends on the type ring and how bad it is. The goal is to reduce the pressure of the ring by cutting part of it or removing a piece of the aorta or artery.

What to Expect

Treatment During Pregnancy

If a test finds that you are carrying a baby with a heart defect, you will continue to get care from your pregnancy doctor (obstetrician). Your obstetrician may refer you to a maternal fetal medicine (MFM) specialist. You may be referred to the Ohio Fetal Medicine Collaborative (OFMC), which will help you connect with a team of experts at the Fetal Medicine Clinic at Nationwide Children's Hospital.

At Nationwide Children's you will meet with a multidisciplinary team including cardiologists (doctor s who specializes in baby's hearts), neonatologists (doctors who specialize in treating newborns), cardiothoracic surgeons (doctors who perform surgery) and nurses to learn more about your baby's care after he or she is born. Nurse coordinators will help answer your questions and concerns, guide you through your pregnancy and prepare you for what to expect. During your clinic visits the medical team will discuss the diagnosis, treatment, recovery and long-term prognosis of your baby. The nurse coordinator will take you on a tour of the Cardiac Intensive Care Unit to help prepare you for the hospital stay.

Your doctor will watch your pregnancy closely. You will deliver your baby at a hospital that is ready to care for babies like yours. You should discuss your plans for labor and delivery with your obstetrician. Contact your doctor right away if you have any concerns.

Care After Your Baby is Born

At the delivery hospital, a doctor who specializes in working with sick infants (neonatologist) will manage the care of your baby. This doctor will watch your baby's breathing and heart rate and look for other problems. Babies born with heart defects may need care in the Neonatal Intensive Care Unit (NICU) at the delivery hospital. An intravenous line (IV) may be started in your baby's belly button (umbilicus), arm, leg or scalp. The IV gives fluids, medicines and antibiotics to prevent dehydration and infection.

Some heart conditions won't need to be fixed right away. In fact, when possible, waiting to give your baby the chance to get bigger and older will make recovery much easier. For these cases, your baby can safely stay close to you at the delivery hospital, and then will see the heart doctor (cardiologist) as an outpatient, or once you are home. The medical team may order tests like an echocardiogram or genetic studies, based on your baby's condition.

Some heart conditions cause problems right away. Your baby may need help with breathing, extra oxygen or may need to be started on a medicine called prostaglandin E (PGE, or "prostins"). This medicine keeps the blood flowing through the patent ductus arteriosus (PDA). Keeping the PDA open lets blood flow to your child's lungs or body, helping to keep him/her stable until surgery.

Your baby may need to be transferred to Nationwide Children's Hospital Cardiothoracic Intensive Care Unit (CTICU) shortly after birth. Nationwide Children's Mobile Intensive Care team will take your baby from the birth hospital to Nationwide Children's. The team is very experienced at transporting newborns with heart defects. Every effort is made to let you see your baby before leaving the birth hospital.

At Nationwide Children's Hospital, you will meet with a team of many different specialists.

This team includes:

- **Cardiologists:** doctors who specialize in working with the heart
- **Cardiothoracic surgeons:** doctors who specialize in surgery on the heart and lungs
- **Neonatologists:** doctors who specialize in treating newborns
- **Interventional cardiologist and catheterization team:** a team of healthcare professionals that specialize in heart procedures
- **Sonographer:** a person trained to use ultrasound technology to view the baby's heart
- Additional specialized support, like **social work, nutrition, therapy, psychology, chaplain**
- A specialized team of **nurses** and **nurse practitioners**

Pre-Operative Care and Testing (For Babies Who Require Neonatal Surgery)

When your baby gets to the CTICU at Nationwide Children's Hospital, he/she will have many tests. These tests include an echocardiogram and EKG. This gives the cardiologists and surgeons the best information about your baby's heart. Once these tests are done, the health care team will talk about the plan for your baby at the Heart Center Case Management Conference. The doctors will review all of the information to make the best choices about surgical procedures and timing.

Depending on your baby's heart problem and the timing of surgery your baby may need an IV called a **peripherally inserted central catheter (PICC)**. A PICC is an IV that can be kept in for a longer period of time. It is used to give medicines and a form of IV feeding called total parenteral nutrition (TPN) and draw blood for lab work.

Because the internal organs and the brain are developing at the same time as the heart, it is important to check your baby for any other health problems. A head ultrasound (HUS) will be done in the first days after birth to look for any concerns, such as bleeding or an abnormality in the brain. An ultrasound of the kidneys (renal ultrasound) will also be done to be sure the kidneys are healthy.

Conserving Blood

The Heart Center at Nationwide Children's Hospital has special techniques and processes to save (conserve) as much blood as possible during surgery and decrease the need for a blood transfusion. These techniques include:

- Saving your child's blood from surgery to use after surgery
- Using a shorter cardiopulmonary bypass circuit
- Using the smallest amount of blood needed for lab tests
- Increasing time between lab tests
- Discontinuing lab tests when possible

Surgery

The decision about surgery is based on your baby's heart problem. Some heart problems have to be fixed within the first several days to weeks after birth. Other problems can wait until the child is older. Sometimes the repair takes more than one operation. **Learn more by visiting NationwideChildrens.org/Congenital-Heart-Defect-Corrective-Surgeries.**

Care After Surgery

After surgery, your baby will be cared for in the hospital's Cardiothoracic Intensive Care Unit (CTICU). Your baby might be on a breathing machine after surgery. There will be many tubes, wires and equipment that help to closely watch your baby and give care after surgery. Many doctors, nurse practitioners, nurses and respiratory therapists will make changes to your baby's medicines and breathing machine often. This will happen the most in the first 24 to 48 hours after surgery.

Other treatments your baby will probably get after surgery are:

- Antibiotics to prevent infection
- Fluids and nutrition given through an IV or PICC line
- Heart medicines by IV or by mouth
- Chest drainage tube
- Oxygen
- Pain medicines
- A tube placed through the nose into the stomach (nasogastric [NG] tube) to keep the stomach empty
- Blood transfusions, when needed

Feeding

Growth and nutrition are an important part of your baby's care. Your child's medical team will discuss feeding goals specific to your baby. They will also help you understand the safest way to feed your baby, including when to start feeds.

Some babies nurse and drink milk right away while others need to start with a small amount of milk with very slow increases. Some babies may need early nutrition through an intravenous (IV) line. It is rare for babies to wait until after surgery to start feeding.

Feedings may be by breast/chest, bottle, IV or tube. We encourage and support parents who are interested in breast/chestfeeding or using human milk. We also offer lactation and donor human milk to support your baby's early nutrition.

Feeding can be very hard for babies with congenital heart defects. Some problems they may have include:

- Tired while feeding
- Trouble gaining weight (Your baby may need extra calories in milk or formula to grow. The dietitian will teach you how to add calories to your baby's formula or human milk and change the feeding plan as needed.)
- Stomach pain during meals (medicines and special formulas may help with this)
- Problems with sucking and swallowing

For all these reasons, a temporary feeding tube may be put into your baby's nose down into the stomach. It is used for feedings to help make sure your baby is getting good nutrition. Occupational, speech and lactation therapists can help with oral and feeding skills. When your baby is ready, they will switch from tube feeds to eating and drinking by mouth. The medical team will help make a plan that supports your baby's wellness, growth and nutrition in the hospital and at home.

Why is Human Milk Important for My Baby with Congenital Heart Disease?

Human milk is best for babies because it has infection-fighting factors for the immune system. Necrotizing enterocolitis (NEC) is a serious infection in the intestines that babies can get. If a baby has NEC, surgery may be needed to remove the part of their intestine that is infected. Premature newborns and newborns with congenital heart disease are at an increased risk of getting NEC. Some babies can die. Studies show that babies who are fed human milk are less likely to have NEC than babies who are not fed human milk.

How Will Human Milk Be Given to My Baby with Congenital Heart Disease?

Some newborns with congenital heart disease can have your expressed (pumped) milk from a bottle. Some can even feed directly from the breast/chest. However, some may have to wait to feed or may need a feeding tube through the nose to get nutrition. When your baby is ready to feed by mouth, they will get your pumped milk. Your health care provider or doctor will let you know when your baby can have your milk.

If you can't provide milk for your baby, they may be able to have donor human milk for a short period of time. Let your nurse know if you are interested in this option.

Donor Human milk

When parents can't give their own milk, they can feed their baby pasteurized donor milk. This milk contains growth hormones, developmental enzymes and infection-fighting factors found in a parent's own milk.

How is the Milk Donated?

The Mother's Milk Bank of Ohio follows the guidelines of the Human Milk Banking Association of North America. It gets free human milk donations from healthy, lactating parents. Before donating, parents are screened for HIV, HTLV, hepatitis B, hepatitis C, syphilis and other health issues. The donated milk is pasteurized and frozen. You need a prescription to get this milk. If you choose to use pasteurized donor milk, you must sign a consent form.

When do I Use Pasteurized Human Milk?

- Biological parent's milk not available
- Extra nutrition after surgery
- Baby can't handle formula
- Premature babies

Mother's Milk Bank of Ohio **(614) 544-5906**
Nationwide Children's Hospital Lactation Consultants **(614) 722-5228**

Discharge Planning

Depending on your baby's heart condition, hospital stay after birth may be as short as a couple of days, or may be as long as weeks to months. The type of heart disease, surgery, prematurity, genetic syndrome or other problems contribute to this. For every baby, discharge home happens when baby is able to:

- Breathe comfortably and with safe oxygen levels
- Gain weight on a home-going feeding plan
- Regulate their own temperature in a regular baby crib
- Family is comfortable with care

The hospital staff will talk with you about your baby's goals for discharge and will make sure you and your baby are ready for home. As needed, therapists, lactation consultants and social workers will help with resources and give ideas for continued care. You will need to choose a pediatrician for your baby before going home. The medical team will help to make your first pediatrician appointment, as well as appointments for cardiology clinic (and any other clinics). Your baby may need heart tests (echocardiogram or EKG) before going home, or these may be scheduled for after your baby is home.

Discharge Education

- You will need to do CPR training in the Columbus Blue Jackets Family Resource Center before you leave.
- Your medical team will teach you how to give well-baby care, feed your child and about the medicines that your baby is taking.
- You will learn signs and symptoms to watch for at home, as well as when to call and when to bring your child directly to the hospital.

Tests Before Going Home

- **Hearing screen:** All babies have a state-mandated hearing screen before being sent home for the first time.
- **Newborn screening:** This test is sometimes called a PKU test. It is drawn at 24 hours of life. It looks at your baby's blood for many serious but rare medical conditions. If left untreated, these conditions can lead to slow growth, developmental disabilities and possible death. Finding these conditions early and giving the right care may prevent serious problems in the future.
- **Hepatitis B vaccine:** We encourage all parents to have their baby get the Hepatitis B shot (vaccine) before going home for the first time and continue to get all immunizations at the recommended times.
- **Car seat test:** This test makes sure your baby's heart rate, breathing and oxygen levels are stable while in the car seat. Your baby will need to sit in the car seat with a monitor on for a set amount of time before going home.
- **Cardiac tests:** Your baby may have a discharge chest X-ray, echocardiogram and EKG before being sent home.

Special Considerations if Your Baby is Transferred to the NCH CTICU

Your baby will go to the step-down unit (H4A) when they are ready to leave the cardiac intensive care unit (CTICU, H4B). This happens when your baby is off breathing machines and can tolerate heart medicines and feedings. While on the step down unit, your baby will learn to eat, may slowly come off of oxygen support and will continue to recover. During the last 24 hours of the hospital stay you may be required to complete "rooming in." This helps parents get comfortable with all the care their baby will need once they are at home. Parents will give all the care for their baby on their own while still in the hospital. Parents will have had all the training needed before starting the rooming in period. Parents are asked to make all the bottles, give all medicines, complete all well-baby care and use any equipment the baby will need at home. Your baby may also have a discharge chest x-ray, echocardiogram and EKG before going home. Your child's pediatrician will receive information about your child's hospital stay.

Looking Ahead

Pediatrician

You will want to find a primary pediatrician for your baby to have routine checkups to measure growth, development and nutrition. Usually, these appointments are every two months for well-baby checks and immunizations. Your pediatrician will work with the heart team to care for your baby.

Pediatric Cardiologist

A physician who specializes in abnormalities of the heart. Your cardiologist will follow up with your baby's heart needs even after your baby is discharged from the hospital.

Neurodevelopmental Follow-Up

Your baby may qualify for close follow-up of his/her development as your baby grows. With your pediatrician, Nationwide Children's Hospital Follow-Up programs ensure your baby receives the therapies and support he/she needs as they grow.

Immunizations

All children should get the recommended vaccines (immunizations) at the scheduled times. We encourage all family members and caregivers to have all vaccines updated, including flu shots. These will help protect your baby from life-threatening illnesses.

Activities/Sports

We encourage all of our heart kids to stay active. We will help you make decisions about safe physical activities for your child.

Smoking

Smoke in any form is very bad for all children, particularly heart patients. We recommend your baby not be around someone who is smoking (secondhand smoke).

Lifelong Considerations

Parenting Tips

Parents often ask how they should treat their child who has a congenital heart condition. Go out and experience life just like any other healthy child would. There may be some limitations, but the heart team at Nationwide Children's Hospital will help support and guide you throughout the journey.

Future Pregnancies

Most of the time, congenital heart defects do not happen again with future pregnancies. However, it is recommended that you meet with a geneticist, maternal fetal medicine doctor (high risk) or obstetrician before getting pregnant again. They can help you find out if you are at high risk of having another child with a heart defect. They can also recommend options and testing.

Dealing with Stress

It is normal to feel stressed and overwhelmed during this journey. However, there are lots of people who can help. While your baby is in the hospital, you will meet the team that will help support you during this stressful time.

Other Support

See "Other Support Resources Recommended By Parents."

Additional Common Testing

B-type natriuretic peptide (BNP): BNP is a substance that comes from the lower chambers of the heart. It helps the doctor know more about how the heart is functioning.

Arterial blood gas (ABG)/venous blood gas (VBG)/ capillary blood gas (CBG): A blood sample is taken from an artery, vein or the capillary bed to measure the amount of oxygen and carbon dioxide in the blood. The acidity (or pH) of the blood is also measured.

Complete blood count (CBC): This test measures the size, number and age of different cells in the blood. Red blood cells are important because they carry oxygen through the bloodstream to the organs and cells of the body. If you don't have enough red blood cells, you have anemia. White blood cells are infection fighting cells; looking at these cells gives clues about inflammation or infection. Platelets help the blood clot (stop bleeding).

Electrolytes (chemistry): This test measures minerals in the bloods, such as sodium, potassium, calcium and magnesium. Minerals are very important for the proper function of organs. The heart medicines called diuretics, also called "water pills," can cause problems with electrolyte levels. Potassium and calcium levels are very important for healthy heart function.

Lactate: A lactate level is part of a blood gas. It helps find acid levels caused by shock or heart failure. A normal lactate is less than two.

Chest X-ray (CXR): Chest Radiographs, or X-rays, look at the heart and lungs. Changes in the normal structure of the heart, lungs, lung vessels and bones can be because of disease or other conditions.

Echocardiogram (echo): An echocardiogram is a special ultrasound used by a pediatric heart doctor (cardiologist) to look closely at your baby's heart and surrounding blood vessels.

Electrocardiogram (EKG, ECG): A quick, painless test that records the electrical activity of the heart. Small stickers called electrodes are put on different parts of the body. This test uses a machine to diagnose abnormal rhythms (arrhythmias) of the heart. It also checks to see if the heart is getting enough blood and if any parts of the heart are thicker than they should be. Doctors study the shape and size of the waves, the time between waves and the rate and regularity.

Abdominal X-ray (AXR): Abdominal X-rays are pictures that look at the stomach and intestines. The X-ray lets the doctor see how well food moves through the intestines, or if there is something wrong with the intestines, like necrotizing enterocolitis (NEC).

Upper gastrointestinal series (UGI): An UGI is a special series of X-rays to look at the organs in the upper part of your child's digestive system. These organs include the esophagus, stomach and the first section of the small intestine (duodenum). For this test, your child will drink a metallic liquid that coats the inside of the organs called barium. This helps the organs show up on X-ray.

Gastric emptying/milk/achalasia scan: This test will show if your child's stomach contents empty into his or her small intestine the right way. Delayed gastric emptying can cause reflux and feeding problems.

Video swallow study (VSS): A video swallow study checks to see that milk is safely moving from the mouth into the esophagus and stomach and not spilling into the lungs. These video pictures will be taken in Radiology.

Glossary of Common Terms Used in Pediatric Cardiology

ABG (arterial blood gas): a test that tells how much oxygen is in the blood and how well the child is breathing. It also measures the acidity of blood (pH).

Angiocardiography: a special X-ray of the heart. A fluid that shows up on x-ray is injected into a vessel or chamber of the heart to make a detailed picture.

Anoxia: lack of oxygen being delivered to important organs.

Anticoagulant: a medicine that slows the clotting of the blood. Also commonly called a blood thinner.

Aorta: the main artery that supplies the blood and oxygen to the body. It usually comes off the left ventricle (main pumping chamber).

Aortic valve: the valve between the aorta and the left ventricle. The aortic valve usually has three leaflets.

Arrhythmia: an abnormal pattern of the beating of the heart; this may be too fast or too slow.

Atrial septum: the muscle wall between the left atrium and right atrium.

Atrium: one of the two upper collecting chambers of the heart. The right atrium collects unoxygenated blood (blue blood) from the body. The left atrium collects oxygenated blood (red blood) from the lungs.

Blood pressure: the pressure of the blood in the arteries. Systolic blood pressure is the top number when the heart is contracted. Diastolic blood pressure is the bottom number when the heart is relaxed.

Bradycardia: abnormally slow heart rate.

Cardiac output: the amount of blood pumped by the heart in one minute.

Cardiopulmonary bypass: a machine that functions as the heart and lungs during open-heart surgery. The machine takes blood from the child, oxygenates it and then pumps the oxygenated blood back to the child's body. This can also be called heart lung bypass or ECMO (extracorporeal membraneous oxygenation).

Catheter: a small tube used to collect fluid, measure blood pressure or give medicine into a blood vessel or other body chamber.

Catheterization: a test in which a catheter is put into the heart to take pictures (angiography) and measure pressure and oxygen.

Congestive heart failure: a condition where the heart cannot pump well enough, and there is backup of blood and congestion in the veins and lungs.

Cyanosis: when the lips and nail beds turn blue. This is caused by a loss of oxygen in the blood.

CT scan: an X-ray test that uses a computer to make cross-sectional (tomographic) pictures of the chest, heart, great vessels or other organs.

Dextrocardia: a congenital condition where the heart is located on the right side of the chest instead of the left side where it normally sits.

ECMO (Extracorporeal Membrane Oxygenation): it is a type of life support that uses a machine to pump blood rich in oxygen to support the heart or lungs, or both.

Echocardiogram (echo): special ultrasound test using sound waves (ultrasound) to make pictures of the heart and how it moves. An "echo" gives important information about the structure, function and health of the heart and if there are any abnormal rhythms (arrhythmias).

Electrocardiogram (EKG, ECG): a quick, painless test that records the electrical activity of the heart. This test uses a machine to diagnose abnormal rhythms (arrhythmias) of the heart. It also checks to see if the heart is getting enough blood and if any parts of the heart are thicker than they should be. Small stickers called electrodes are put on different parts of the body. Doctors study the shape and size of the waves, the time between waves and the rate and regularity of the heartbeat. This tells the doctor a lot about the heart and its rhythm.

Gastrostomy Tube (G-Tube): a thin, flexible feeding tube that goes through the skin and into the stomach. Liquids, like milk and medicines, go right into your child's stomach through this tube. The G-tube can be easily removed once it no longer needed.

Heart rate: how fast the heart is pumping. This is usually reported in beats per minute.

Hemodynamics: the study of the flow of blood and the pressures in the heart and blood vessels. This is usually measured during a cardiac catheterization.

Heterotaxy: involves the heart and other organs. There are different kinds of heterotaxy syndromes, all of which have heart defects. Also, organs like the stomach, intestines, liver, and spleen may be on the wrong side of the chest and abdomen.

Hypertension: high blood pressure.

Hypoxia: less than normal amount of oxygen in the blood.

Ischemia: too little oxygen in the blood carried to a certain part of the body.

Leads: the small wires connected to stickers that are put on the child's chest to look at the heart on the Electrocardiogram (EKG, ECG) or for bedside monitoring.

Left ventricle: the main pumping chamber of the heart for the body.

Mitral valve: the mitral valve is two flaps of skin leaflets between the left atrium and left ventricle. The valve keeps the blood moving forward in one direction.

MRI of Heart: a test that uses powerful magnets to look inside the body and take pictures of the heart muscle and problems it may have. Coronary magnetic resonance angiography (CMRA) combines standard magnetic resonance (MR) imaging with an injection of a chemical dye (contrast medium). This lets doctors look at and measure blood flow to the heart muscle.

Murmur: the sound of turbulent blood flow through the heart and heart valves that is heard on auscultation with a stethoscope. Murmurs may be normal or abnormal.

Nasal Cannula: a small tube with two prongs that delivers oxygen and air flow into the nostrils.

Nasal CPAP (continuous positive airway pressure): a machine that provides high flow air or oxygen through a nose mask to help keep the lungs inflated.

Nasogastric tube (NG Tube): tube that passes through the nose into the stomach. NG tubes are used for feeding infants and children who are not able to take in enough calories by mouth. Tube feedings are also given to older children who cannot eat by mouth.

Necrotizing enterocolitis (NEC): NEC is the most common gastrointestinal (GI) medical/surgical emergency occurring in neonates. NEC is a serious illness in newborns that happens when tissue in the intestine gets swollen and irritated (inflamed). This inflammation can damage or kill the tissue in your baby's intestine. NEC occurs more often in babies with congenital heart defects than the normal newborn population.

NPO: NPO is a Latin abbreviation for Nil per os, which means "nothing by mouth."
It is an order to not give any oral food and fluids by mouth into the stomach/intestines.

Open heart surgery: surgery done on the heart while the blood flow is re-routed through the heart-lung machine.

Oxygen: a gas in the air we breathe. Sometimes extra is needed due to an illness or a heart defect. Every cell in our bodies requires oxygen to do its job. Diseases of the heart and lungs can affect the level of oxygen in the blood and delivered to the body.

Palliative cardiac surgery, palliation: heart surgery to relieve symptoms and improve quality of life for heart defects that can't be fixed.

PO: Latin phrase "by mouth" or "by way of the mouth." It is an order that means to give feeds or medicines orally.

PICC (Peripherally Inserted Central Catheter): A plastic tube that is inserted into a large vein to give intravenous (IV) therapy. The catheter is used when IV therapy will be needed long term.

Pulmonary valve: the valve between the right ventricle and the pulmonary artery.

Right ventricle: pumping chamber of the heart to the lungs.

Saturation: also known as "sats." It is a measurement of the oxygen level in the body using a pulse oximeter.

Stent: a wire mesh tube to prop open an artery.

Septum: a dividing wall in the heart.

Shunt: an abnormal passage of blood between two blood vessels or between the two sides of the heart. A shunt may occur naturally or may be made with surgery.

Stenosis: a heart valve or blood vessel that is too small or smaller than normal.

Tachycardia: abnormally fast heart rate.

Tricuspid Valve: the tricuspid valve is between the right atrium and right ventricle.

Ventricle: one of the two lower chambers of the heart. The right ventricle pumps blood to the pulmonary artery and into the lungs. The left ventricle then pumps this oxygenated blood to the aorta to supply oxygen rich blood to the body.

Ventilator: a machine that breathes for a patient or helps with breathing.

Other Support Resources Recommended by Parents

Little Hearts, Inc.
littlehearts.org
Little Hearts, Inc. is a national organization with a mission to give support, education, resources, networking opportunities, and hope to families affected by congenital heart defects. Members are families from around the country who have or are expecting a child with a congenital heart defect. Through the support services, Little Hearts hopes to promote public awareness for this No. 1 birth defect.

National Pediatric Cardiology Quality Improvement Collaborative
npcqic.org/resources/parents-and-families
Improving care and outcomes for babies with HLHS.

Icing Smiles
icingsmiles.org
Icing Smiles is a nonprofit organization that gives custom celebration cakes and other treats to families dealing with the critical illness of a child. We know that the simple things, like a birthday cake, are luxuries to a family battling illness. Our goal is to make a custom cake for the ill child, or their sibling, that gives a temporary escape from worry, and creates a positive memory during a hard time.

Congenital Heart Network of Central Ohio, part of the national: Pediatric Congenital Heart Association (PCHA)
pcha.oh@conqueringchd.org
PCHA is aimed at improving the lives of those with congenital heart disease and their families through direct support and education.

Sisters By Heart
sistersbyheart.org
We are a volunteer organization that works to help moms with newly-diagnosed babies. We provide care packages to make your stay in the hospital a little easier. We also give resources to help you better understand HLHS. All our volunteers are moms with children who have HLHS and know what you are going through. We are here to help!

The Children's Heart Foundation
childrensheartfoundation.org
The Children's Heart Foundation is a not-for-profit organization that funds the most promising research to advance the diagnosis, treatment, and prevention of congenital heart defects.

Saving Little Hearts
savinglittlehearts.com
Saving Little Hearts helps children with congenital heart defects and their families by giving emotional assistance and educational information through the giving of care packages.

Connecting Families
Connecting Families program links individuals who have already experienced diagnosis and management with those who are facing it for the first time. These one-to-one relationships inspire hope and offer the chance to ask personal questions and receive support from someone who has "been there." The Parent-to-Parent volunteers are family members who have completed specialized training. They talk to families via telephone and/or email about the experience of congenital heart disease, guide them through the hospital system, and discuss available resources. For more information on Heart to Heart Connecting Families call (614) 722-6284.

Suggested Hospital Items to Pack for Cardiac Families

Parents

- ☐ Breast pump and kit
- ☐ Lansinoh or similar nipple cream for pumping moms
- ☐ Camera
- ☐ Chargers (phone, laptop, iPad…)
- ☐ Headphones
- ☐ Ear plugs/eye mask
- ☐ Journal to write your thoughts, questions
- ☐ File folder for important documents and handouts
- ☐ Reading material (books, magazines, crossword puzzles)
- ☐ Scrapbook kit
- ☐ Changes of clothes and pajamas
- ☐ Flip flops/ slippers
- ☐ Sports bras/ Nursing bras
- ☐ Toiletries
- ☐ Dry shampoo
- ☐ Sanitary pads
- ☐ Tylenol/ ibuprofen
- ☐ Chapstick
- ☐ Hand lotion
- ☐ Insulated cup
- ☐ Cash for coffee, vending machines, food
- ☐ Snacks/gum/mints
- ☐ Cord blood collecting kit if you plan to preserve cord blood

Heart Baby

- ☐ Boppy pillow with extra covers
- ☐ Pictures to hang on their crib
- ☐ Hats/beanies
- ☐ Baby mittens
- ☐ Snap outfits
- ☐ Baby nail clippers
- ☐ Lovey/special toys for comfort
- ☐ Swaddlers/blankets (hospital will provide standard issue)
- ☐ Bag for dirty clothes and blankets
- ☐ Book/poster board/autograph frame for nurses, docs & visitors to sign

Siblings

- ☐ Books
- ☐ Coloring supplies
- ☐ Snacks/drinks that don't need refrigerated
- ☐ A special gift (new teddy bear/doll)
- ☐ Sweatshirt/blanket if they get cold while visiting

Source: Devised from Sisters by Heart

Notes

Notes

NATIONWIDE
CHILDREN'S®

When your child needs a hospital, everything matters.