

Healing Your Child's Heart





Our Mission:

Heart Care International is a non-profit organization that travels to under-developed countries offering a comprehensive spectrum of medical and surgical care for children and young adults suffering from Congenital Heart Disease.

Heart Care International's 100% volunteer medical team consists of an international panel of medical experts from 8 different pediatric disciplines including: Cardiology, Medical Intensivists, Surgery, Anesthesiology, ICU Nurses, Respiratory Therapists, Perfusionists and many more.

During your child's hospital stay, you will meet many local professionals, as well as foreigners, collaborating to coordinate the care of your child.



The Doctors Taking Care of My Child:

Pediatric Cardiologist: _____

Pediatric Intensivist: _____

Ped CV Surgeon: _____

Ped Anesthesiologist: _____

ICU Nurse: _____

Respiratory Therapist: _____

Perfusionist: _____



Important Information for My Child:

Full Name: _____

Diagnosis: _____

Operation/Surgery: _____

Surgical Date: _____

Blood Type: _____

Allergies: _____

Medicines: _____

Doses / Amounts: _____

Time_____



Causes/Reasons of Congenital Heart Disease:

The causes or reasons for the majority of children being born with Congenital Heart Disease (CHD) are not known for sure.

However, it is suspected that CHD may be caused by any of the following circumstances:

- **Infections:** Caused by a virus, especially Rubella.
- **Maternal Illness During Pregnancy:** Diabetes or Lupus.
- **Prenatal Medications:** Amphetamines or Lithium.
- **Toxins:** Prenatal exposure to alcohol, drugs, radiation.
- **Genetic Factors:**
 - Down Syndrome
 - Turner Syndrome
 - CHD can be passed from parent to child or grandparent to grandchild.



Signs/Symptoms of Congenital Heart Disease:

- **Dyspnea:** Difficult or labored breathing, especially during exercise. Slow breathing less than 20 breaths/minute.
- **Tachypnea:** Rapid or labored breathing greater than 60 breaths/minute while at rest. Stridor or noisy breathing. Choking.
- **Nasal flaring:** The enlargement of the opening of the nostrils during breathing. Often indicating that more effort is needed to breathe.
- **Tachycardia:** Heart rate or heart beats over 160/minute.
- **Cyanosis:** Blue or gray color around the mouth, lips and fingers during crying or feeding (breastfeeding), Anoxia attacks (Fainting).
- **Diaphoresis:** sweat profusely, cold and clammy skin.
- **Failure to Thrive:** Lack of weight gain and growth.
- **Chronic fatigue**
- **Wheezing**
- **Frequent Respiratory Infections**
- **Leg, abdomen or eye swelling**



To alleviate some of these symptoms, your child may take any of the 3 following positions:

- Knees tucked so touching the chest
- Squatting
- Early termination of the activity due to fatigue

Non-Invasive Tests Help Make the Diagnosis:

- Medical History
- Physical exam
- X-rays of the chest/thorax
- EKG/Echocardiogram.

Invasive tests:

- Blood Gas: An arterial blood test that measures oxygen in the blood
- PT/PTT: Coagulation test
- Complete Blood Count (CBC): Hemoglobin count and hematocrit
- Type and Cross Match: Determines the blood type of the child



Invasive tests (continued):

- **Electrolytes Test:** Determines the minerals in the blood and other body fluids that carry an electric charge. Common electrolytes include:
 - Calcium
 - Chloride
 - Magnesium
 - Phosphorus
 - Potassium
 - Sodium

Cardiac Catheterization:

Cardiac catheterization allows the cardiologist to:

- Draw blood samples from each chamber and each blood vessel
- Measure the pressure of each of the heart cavities
- Perform radiographs at the Coronary level
- Obtain samples of cardiac tissue for biopsy

The flexible tube (catheter) is inserted through a vein in the femoral vessels (groin) or brachial artery, located in the anterior elbow crease.



Cardiac Catheterization is the simplest and most effective diagnostic test to detect coronary and arterial anomalies and make decisions about surgical intervention. Once the definitive diagnosis is obtained a treatment recommendation can be made.

Treatment Options:

Since 1939, when the first congenital heart surgery was performed until today, there are three treatment options:

- **Medicines and Follow Up**
- **Correction by Catheterization:** Dilating narrow areas, closing vessels or abnormal vascular connections or creating or extending a hole for easy passage of blood (interventional catheterization).
- **Surgical Procedure:** Open or closed heart surgery

What should I do to take care of my child?

Crisis of hypoxia (lack of oxygen) with short, slow breaths with cyanosis (blue color) on the lips and fingers should be treated immediately.



If cyanosis (blue color) has not improved with oxygen and it takes longer than three hours or more to recuperate, the doctor should be notified immediately.

Children with birth defects are susceptible to infections or colds and should be treated immediately.

Avoid prolonged crying.

Evaluate the child's weight frequently.

Food should be in small frequent quantities in order to prevent excessive effort to eat.

Medication Some Children Must Take:

- Digoxin (Lanoxin)
 - Makes the cardiac muscle squeeze stronger.
 - Helps to slow the heart rate.
 - Used for the treatment of cardiac output and abnormal heart rhythms.
- Captopril (Capoten)
 - Expands the blood vessels and reduces blood pressure and allowing the heart to pump blood more easily.



Medication Some Children Must Take (continued):

- Enalapril (Antihypertensive)
 - Compresses the Blood Vessels, lowering blood pressure.
 - Helps the heart pump more efficiently.
 - Used in combination with other medications to treat heart failure.
- Spironolactone (Aldactone) Diuretic
 - Helps the body to retain potassium, an important mineral in the body.
 - Remove small amounts of water from the body.
- Furosemide (Diuretic) Lasix
 - Extracts excess water from the body
 - Used for the treatment/prevention of cardiac output, also after open heart surgery.
 - Removes potassium from the body.

Children should drink or eat food high in potassium such as orange or peach juice, bananas, milk, raisins, plums, grapefruit, potatoes, yogurt.

Do not stop giving/taking medications without first consulting your doctor.



What to Tell Your Child:

What you should tell your child about the surgery?
Here are some tips that will be useful. Remember it is very important to be clear and honest with your child. Tell them the truth!

- **Infants and Toddlers:** They feel more secure if they have a favorite blanket with a favorite pacifier or dummy. Children of this age, like to see their parents near them and they like to be held.
- **Children Aged 6-12 years old:** Children at this age like to ask questions, so be sure to support this activity. Be honest with your child about what is expected.
- **Teens:** Teens worry about what will happen in the hospital. Encourage them to ask questions and talk with our doctors and nurses. Agree to include them in the discussions and decisions with respect to their surgery.



Hospital Rules:

- Please wash your hands before touching your child.
- You may visit frequently after the operation.
- The nurse will inform you when you can visit.
- Please do not eat or drink liquids in the Intensive Care Unit.

Preparation For Your Child's Hospital Stay:

Keep your child as healthy as possible, inform the doctor if the child has had fever, cough or sore throat.

The day of the operation in the hospital:

- Your child will change to a hospital gown.
- Your child will have a pre-operative exam.
- You will need to sign some forms giving permission for the operation.
- The nurse will indicate the time of the operation.

Please follow the instructions of the nurse with respect to food and liquids in the 24 hours before the surgery, otherwise your child's operation may be canceled.

THIS IS VERY IMPORTANT.



Infection Control:

Preventing infections is one of the most important goals in the hospital. Although not all infections are preventable, many can be prevented by taking some precautions:

- **Practice good hand hygiene:** Hand hygiene refers to cleaning hands with soap and water or an alcohol-based hand sanitizer. In hallways and patient rooms throughout the hospital you will see Purell dispensers and bottles. Please use these products often. The healthcare team must use Purell or wash their hands before providing care to prevent the spread of infection. If you are not sure whether the person responsible for your child has washed their hands, please ask them to do so before viewing or performing a procedure. They would be happy to comply.
- **Follow the rules for visitors:** We want you to help prevent the spread of infection. If family or friends of your child have a cold, cough, fever, or rash, ask them not to visit until the symptoms are gone. Ask your child visitors to clean their hands with Purell before entering the room of your child.



Before Leaving the Hospital:

The following list will help you prepare to return home:

- Get the prescriptions and medications necessary for your child.
- Request explanation about each of the medicines that your child must take.
- Check the name, dosage and frequency of each medication.
- Ask the medical team to explain the treatment to be followed at home.
- Make sure you know the date/time for your follow-up appointment.
- Ask if there are any diet or food restrictions.
- Ask what activities your child is allowed to do.
- Ask when he or she can return to school.
- Ask when your child can start contact sports.
- Request a copy of the discharge summary that will include the following:
 - Diagnosis and procedure performed.
 - Instructions on medications, diet and activity.
 - Appointments for follow-up.



Caring for Your Child at Home:

- Keep your child's teeth and gums clean by brushing their teeth with fluoride toothpaste at least twice daily. The bacteria or germs can grow in the mouth and cause tooth decay and infection and this may affect his heart.
- If your child goes to the dentist to clean their teeth or have other dental work performed, talk to your doctor first because you might need antibiotics before visiting the dentist.
- Bathe your child every day with soap and water.
- Keep the wound clean and dry. But do not use ointments or creams on the wound or around the surgical areas (unless specifically instructed to do so by the medical team).



Medication List for Your Child:

You can use this table to update the list of prescription or over the counter drugs your child will be on before discharge.

Medication Name	Dose	Frequency/ Time of Day	Notes/Date Start/Stop



Signs of Emergency or Infection:

- Call your doctor immediately if your child:
 - Has a temperature/fever
 - Starts to feel worse
 - Has increased pain
 - Turns blue
 - Experiences swelling around the body
 - Has difficulty breathing
 - Has rapid breathing
 - Has prolonged periods of restlessness
- Call your doctor immediately if:
 - The wound has opened
 - There is redness around the wound
 - There is the presence of purulent discharge pus
 - The skin around the wound feels warm
 - The skin becomes swollen or inflamed
 - The skin is cold and mottled



Medical Definitions or Terms:

Acetaminophen Suppositories: Used to relieve mild to moderate pain, colds, sore throats, toothaches, backaches, and reactions to vaccines and to reduce fever.

Ambient Air: The air we breathe every day (21% oxygen.)

Ambu bag and mask: Part of the equipment used if needed to manually ventilate with a rubber bag and a face mask it will fill the lungs with oxygen and air and helps the patient to breathe.

Antibiotics: Drugs that kill microorganisms (bacteria, fungi) or slow their growth. These drugs are used in the treatment and prevention of infections.

Apnea: An event that occurs when a child stops breathing for more than 20 seconds.

Arterial gas/gas tests: Arterial blood test that determines the amount of oxygen, carbon dioxide in the blood. Help in the evaluation of pulmonary and cardiac functions.



Arterial Line (AL): A catheter placed in an artery can monitor blood pressure and blood sampling. It also reduce the number of needle sticks for necessary blood sampling that your child may require.

Artery: These are blood vessels that carry oxygenated blood throughout the body.

Aspiration: Caused by aspirating foreign materials (usually food, liquids, vomit, or fluids from the mouth) into the lungs or airways leading to them.

Atria: The top of the heart is formed by the other two chambers of the heart, called the right and left atria. The left and right atria receive blood coming into the heart. A wall called the atrial septum that divides the atria are separated from the ventricles by atrial-ventricular valves. The tricuspid valve separates the right atrium from the right ventricle and the mitral valve separates the left atrium and the left ventricle.

Bladder or Foley Probe: A probe or catheter placed in your bladder to drain urine.

Bradycardia: When the heart rate is lower than normal.



Carbon Dioxide: The gas we release when we breathe out as a waste product.

Cardiac Monitor: This monitor displays waveforms and numeric values of heart rates and respirations child. If the frequencies are not within the normal range, an alarm sounds. False alarms are common and often occur when a child is moved or when an electrode falls.

Catheter: A tube used for inserting or removing body fluids.

Central Line: A special IV is inserted into a large vein and is used to administer medications, fluids or blood.

Chest Physiotherapy: Taps applied to the chest to help the child to drain secretions and mucus.

Chest tubes: tubes that are inserted through the skin into the space around the lungs to drain fluids, blood or air.

Coarctation of the Aorta: Stenosis or obstruction of the aorta so that blood can not get through to the lower part of the body and blood pressure above the obstruction are high.



CPAP: Continuous Positive Airway Pressure

Continuous flow of pressurized air or oxygen into the lungs through prongs placed in the child's nose to help his lungs inflate properly. With nasal CPAP, your child does all the breathing. A head support is used to hold the tube in place around the child's head and the nasal prongs will be placed in the nostrils of the child. The pressure and oxygen will be administered through these tubes.

Cyanosis: Bluish skin, lips, nails from lack of oxygen.

Desaturation: A term indicating that the oxygen level of the child is below normal.

Dextrose/Glucose: A type of sugar present in the blood. Different types of glucose control are performed, but the most common is done with a glucometer.

Diuretic: A type of drug used to increase the amount of urine excreted and will reduce excess fluid in the body.



Electrocardiogram (ECG): A test that measures the electrical activity of the heart, including the frequency and regularity of the beats, like the size and position of the chambers, any damage to the heart and the effects of drugs.

Echocardiogram (ECHO): This is a test that uses sound waves to create a moving picture of the heart. You can identify heart abnormalities and show how blood flows through the heart chambers and vessels entering and leaving the heart.

Edema: Also called "swelling" is due to the presence of excess fluid under the skin giving it a swollen appearance.

Electrode: A patch is placed over the child's chest to measure heart and respiratory rate.

Electrolytes: The measurement of sodium, potassium, chloride in the blood of children. The results may indicate the need to supplement them.

Endotracheal Tube (ETT): A soft plastic tube that is placed in the nose or mouth of the child, is inserted through the trachea and connected to a ventilator. When a child is intubated with an endotracheal tube he



cannot speak or make noises. Intubation is a process by which the tube is placed in the child, and extubation is the process of removing it.

Evaluation: Periodic review of your child conducted by a physician or nurse.

Glycerin Suppositories: Also known "as a silver bullet" glycerin suppositories help children have a bowel movement.

Hematocrit: A blood test that measures the percentage of the volume of whole blood that consists of red blood cells. This measurement depends on the number of red blood cells and their size.

Hemoglobin: The part of the red blood cells that contains iron, which carries oxygen from the lungs to body tissues.

Hypertension: Blood pressure is the force of blood against the artery walls. Each time the heart beats, it pumps blood into the arteries. It can be measured with a cuff placed on the arm or leg, or continuously monitor via a peripheral arterial line.



Hypoglycemia: Reduction of sugar/glucose in the blood.

Hypoplastic Left Heart Syndrome (HLHS):

Most of the structures on the left side of the heart (Left ventricle, Mitral Valve, Aorta, Aortic Valve) are small and underdeveloped. The functional ability of the left heart may be greatly affected and result in failure of the ventricle to pump enough blood to the rest of the body.

Hypoxia: A decreased level of oxygen in the blood.

Infiltration: This term is used to refer to an intravenous (IV) route that is no longer in the vein and must be replaced. You may have swelling at or near the insertion site with swollen taut skin and pain.

Inflow and Outflow Fluid (I & O): A balance between fluid intakes and those that are lost or excreted.

Intubation: Placement of an endotracheal tube through the nose or mouth into the trachea to ventilate the patient and administer oxygen.

Mucus: A fluid secreted by the membranes of the nose, trachea and lungs.



Murmur: A sound made by blood passing through the heart in a different way than usual. It is detected by listening to the heartbeat in front of the chest or back with the help of the stethoscope.

Nasal Cannula: Soft small cannulas are placed in the child's nose to deliver oxygen

Nasogastric Tube/NG tube: A probe is inserted through the nose or mouth into the stomach to remove stomach contents or give medicine, liquids.

NPO: It stands for no food or drink by mouth.

Operating Room: is a room in the hospital where patients are operated. When operating or surgically intervening a person, a special doctor called a surgeon works in the body to fix something that does not work well.

Oxygen: A colorless, odorless gas, necessary for the body's cells. We breathe room air, which is 21% oxygen, if necessary, a child may receive up to 100% oxygen.



Oxygen Delivery: Also called "whiffs", given to children as an immediate and temporary desaturation response or a low level of oxygen.

Patent Ductus Arteriosus (PDA): A condition in which a blood vessel called the ductus arteriosus, fails to close normally in an infant soon after birth. (The word "patent" means open.) If it remains open it may interfere with normal blood flow and cause heart and lung failure. If necessary, the PDA can be treated with medication or surgery.

Peripheral Intra venous (PIV): A thin, short catheter inserted into a vein to administer fluids, medications. They can be placed on the scalp, hands, legs and feet. They can be rotated frequently due to infiltrations because of the small size of the vein used.

Pneumonia: Inflammation or infection of the lungs.

Pneumothorax: A condition in which air is trapped in the space between the inner and outer layers of the membrane that covers the lungs. The accumulation of air compresses the lungs and hinders its normal growth.



PO: An abbreviation meaning "by mouth"

Pulmonary Hypertension: An abnormally high blood pressure in the arteries of the lungs, which causes the right side of the heart work harder than normal.

Pulse Oximeter: A sensor that is placed in the hand, fingers or foot to monitor the concentration of oxygen in the baby's blood.

Red Blood Cells: Erythrocytes are responsible for transporting oxygen throughout the body.

Respirator or Ventilator: A machine to ventilate and deliver oxygen to the lungs to assist breathing while the child is intubated.

Respiratory Distress Syndrome (RDS): The air cavities of the lungs collapse (instead of opening and stretching like balloons), making it difficult to bring enough air into the lungs.

Sepsis: Refers to an infection that occurs in the blood. If there is any doubt about the possibility an infection, blood for blood culture and blood counts are



extracted, as well as urine, sputum samples. You can also start treatment with antibiotics while waiting for the culture results.

Suction: Elimination of mucus and fluids from the nose, mouth or an endotracheal tube.

Tachycardia: A faster than average heart rate.

Tachypnea: Faster than average respiratory rate.

Tetralogy of Fallot (TOF): A heart defect with four different abnormalities:

- 1) Ventricular septal defect /VSD: An abnormal opening that allows blood to flow from the right to the left ventricle without going through the lungs.
- 2) Pulmonary Stenosis is a narrowing of the pulmonary valve or just below , that partially blocks the flow of blood from the right side of the heart to the lungs.
- 3) Right ventricular hypertrophy: The layer of the right ventricular muscle, becomes thicker than normal because it pumps against a blocked outflow tract.



4) Overriding Aorta: The aorta is not in its normal position from the left ventricle, but rides or rests on the ventricular septal defect.

Transfusion: Treatment with blood or blood products is delivered intravenously. Usually for postoperative bleeding, anemia, requiring replacement of plasma, platelets, etc.

Transposition of The Great Arteries (TGA): A defect that has the arteries and aorta reversed. As a result:

- 1) The aorta arises from the right ventricle, so that most of the blood returning to the heart from the body is pumped back without going through the lungs.
- 2) The pulmonary artery arises from the left ventricle, so that most of the blood returning to the lungs returns to them. This causes an abnormal blood flow.

Tube Feeding: A method of feeding the children through a tube placed in the stomach via the nose or mouth. The probe is thin enough to remain in place even when not feeding without disturbing the child. As soon the child begins to eat by mouth, it will be removed.



Ultrasound: A procedure that uses sound waves to produce a picture of internal organs.

Veins: Blood vessels that carry deoxygenated blood (with no oxygen) back to the lungs for oxygenation.

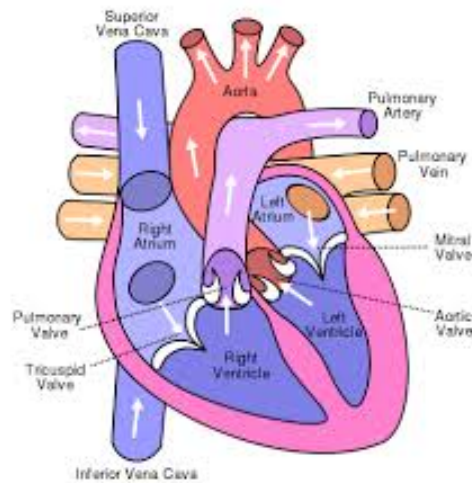
Ventilation with Ambu bag: A method used to help the child breathe. Placing a small mask over the nose and mouth of the child or the bag is placed directly to the endotracheal tube. It is manually pump (bagged) to deliver air and oxygen.

Vital Signs: The combination of temperature, heart rate, respiratory rate and blood pressure that are recorded on the child.

White blood cells: leukocyte blood cells are cells in the body responsible for fighting infections.

X-ray: An image is taken to check the organs, bones, or tubes placed within the body and to assess any evidence of infection or fracture.

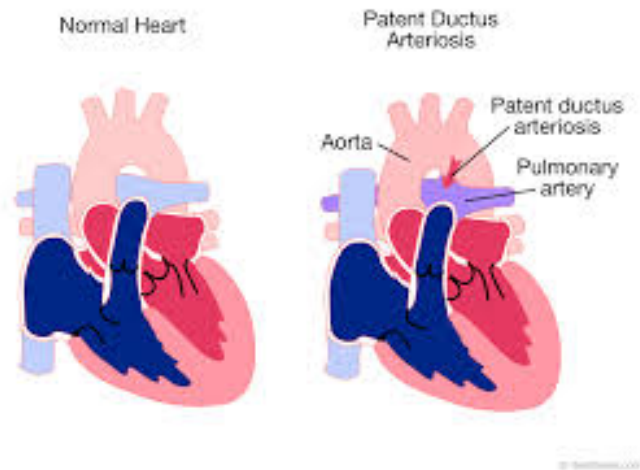
Normal Heart



Congenital Heart Disease

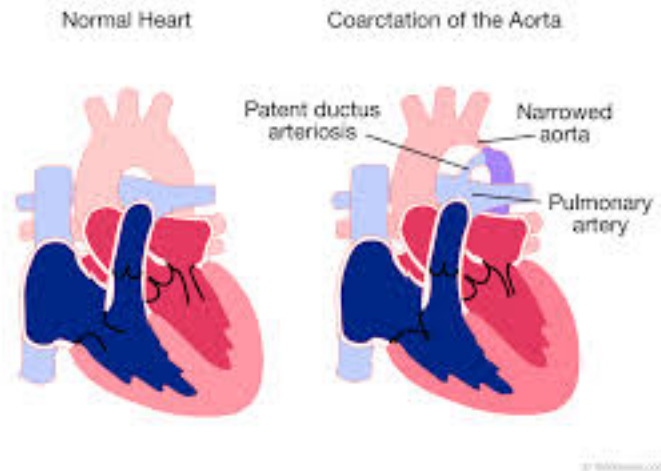
It is a defect in the structure of the heart or major blood vessels. This heart defect occurs during fetal development and causes abnormal heart function.

Patent Ductus Arteriosus (PDA):



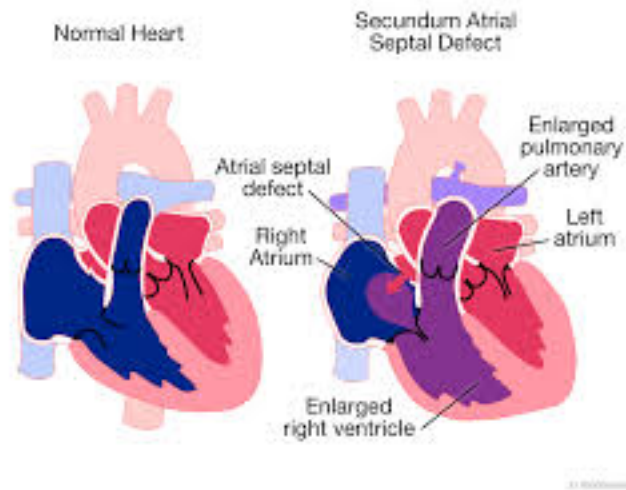
This is a communication between the aorta and pulmonary artery thru a vessel during the fetal period (in utero) must be open, but at the time of birth when the lungs begin to function, it must close. As there is a communication, oxygenated blood passes from the aorta (high pressure) to pulmonary artery (low pressure) to the lungs, where is not needed as they are already oxygenated. All this causes the lungs and left side of the heart to be overloaded and it causes it to fail, presenting a picture of Heart Failure and Pulmonary Hypertension. Treatment may be with medication for newborns. If not corrected, it is necessary to close surgically or by cardiac catheterization.

Coarctation of Aorta:



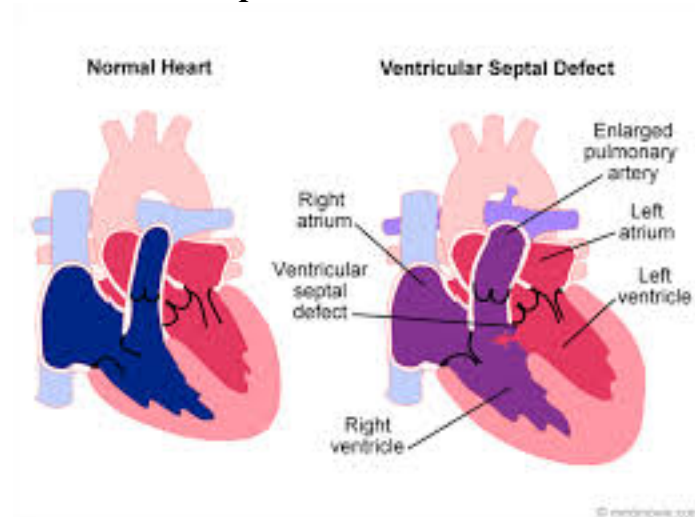
This is a narrowing of the aorta, the largest artery that we have, the left side of the heart carries oxygenated blood throughout the body. If the narrowing is severe, the heart has to work with more energy and may cause hypertension in the upper body (the narrowing is located at the end of the vessels that carry oxygenated blood to the head and arms) and heart failure, whereas the abdominal organs and lower extremities receive less blood. Highlights include: high blood pressure in the upper body. The lower limbs are usually colder than the upper, muscle cramps can occur during heavy exercise. The child may experience dizziness, headache, epistaxis (nosebleed) caused by the hypertension. The surgical treatment is removing the portion that is narrow and re-attaching it or replacing the narrow part by grafting.

Atrial Septal Defect/ASD:



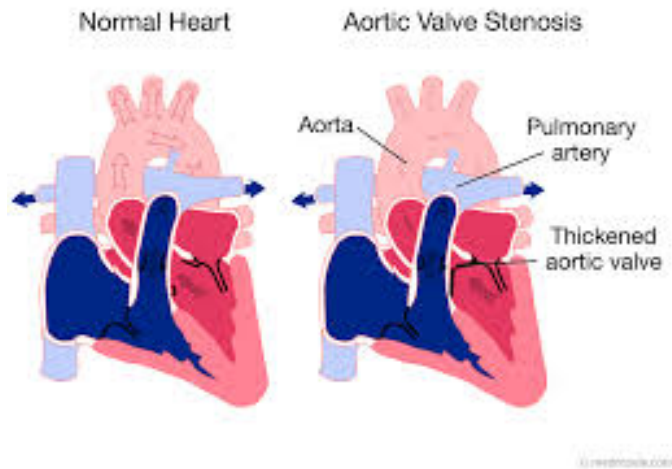
This is a communication between the two upper chambers (the two atriums) of the heart allowing oxygenated blood from the Left Atrium to mix with deoxygenated blood from the Right Atrium. In fetal life there is communication between the two atriums (PDA) that should close at birth or soon after. ASD's are corrected by surgery or cardiac catheterization.

Ventricular Septal Defect/VSD:



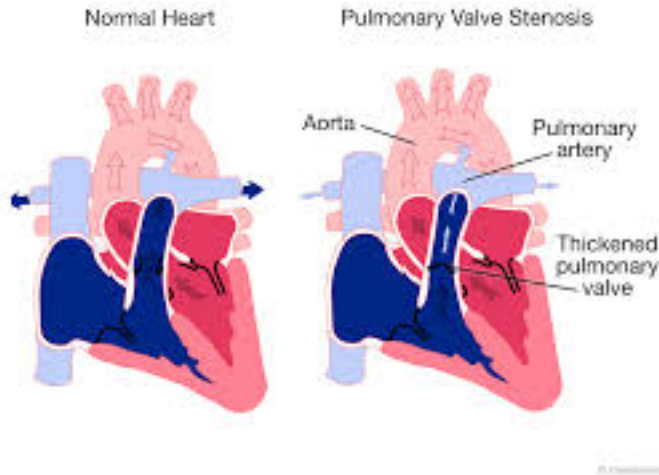
This is an opening in the wall between the two lower chambers of the heart (the two ventricles). The pressure in the left ventricle causes the oxygenated blood to pass through the defect into the right ventricle {allowing it to mixed with deoxygenated blood} allowing the lungs to be oxygenated, when they were already carrying oxygenated blood. A consequence of this, the heart and lungs become overloaded, causing cardiac insufficiency (difficulty breathing, fatigue, not gaining weight, and eventually Pulmonary Hypertension). Some of these defects close spontaneously in the first weeks or months of life. If not, they can cause significant symptoms, treatment is surgical or if a candidate for a device it can be done thru a cardiac catheterization.

Aortic Stenosis (AS):



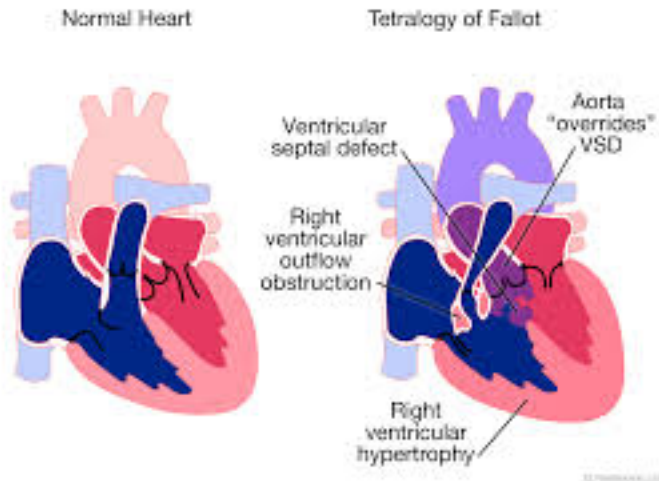
This is a narrowing of the aortic valve or the first portion of the aorta coming out of the left ventricle. The Left Ventricle pumps blood around the body through the aorta. As there is a narrowing of the output, the left ventricle has to have greater force to get more blood to reach the body and there comes a time when the Left ventricle deteriorates and fails causing pulmonary vascular congestion. If the stenosis is severe, it can cause a very serious clinical condition in young children. Children often suffer from exercise intolerance, tire easily, poor feeding, syncope or fainting spells and chest pain at rest or during exercise. The treatment in most cases is surgical. In very young children they can temporarily dilate the stenosis during an angioplasty in a cardiac catheterization.

Pulmonary Stenosis (PS):



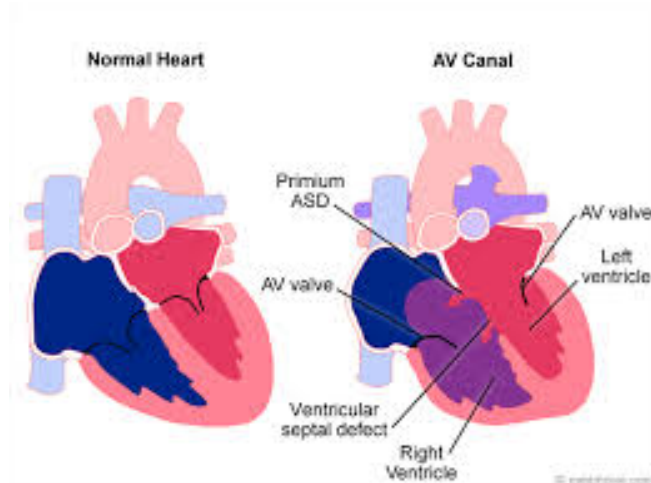
This is a narrowing of the Pulmonary Valve or the Pulmonary Artery (it goes from the right side of the heart to the lungs). The right ventricle must work harder to pump blood thru the obstruction to send blood to the lungs and oxygenate. There comes a time when the right ventricle deteriorates and starts failing. Depending on the narrowing, the symptoms may vary from minimal to a serious clinical picture. The treatment can be surgical or by dilation via a cardiac catheterization.

The Tetralogy of Fallot (TET):



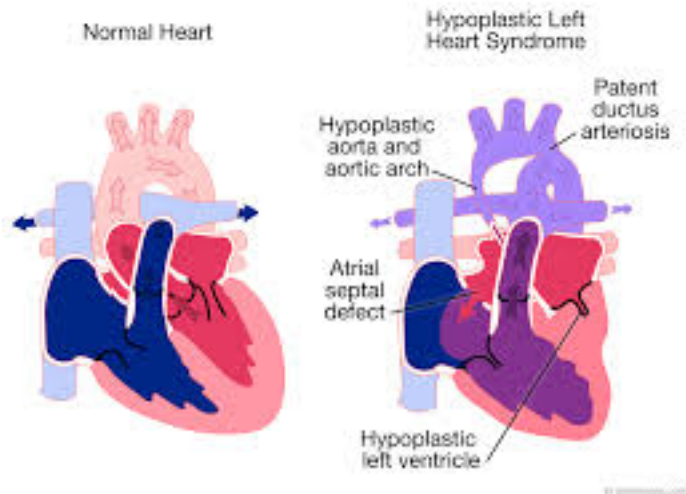
This includes 4 defects: •Ventricular Septal Defect • Pulmonary Stenosis • Aortic dextroposition { The aorta arises from the right ventricle instead of the left} • Right ventricular hypertrophy. The blood that should go to the lungs for oxygen, can barely go by related to the PE or tightness in this area which makes the blood go to the body without having received the necessary oxygen from the lungs, which gives the characteristic blue-gray color of these children {cyanosis}. The increased effort causes hypertrophy of the right ventricle. The aorta receives blood directly from the two ventricles due to the overriding {dextroposition}. The severity of symptoms depends on the degree of pulmonary stenosis {if severe it can result in the death of the child}. In infants have severe episodes of cyanosis and hypoxia especially during crying or after feeding. Cyanosis, delayed growth and development occurs in these children. Immediate treatment is the squatting position to relieve hypoxia} {lack of oxygen.} The treatment is surgical. Currently there are surgical techniques to repair this delicate combination of defects, allowing the majority of children affected by it to have a normal life.

Atrioventricular Canal (AVC):



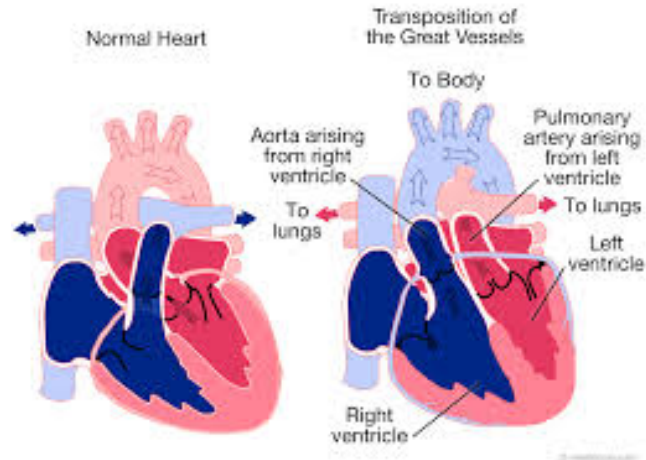
This is an opening that connects the left and right side of the heart. The defect is due to incomplete closing of the walls and valves. The heart must work harder than usual. The pressure and flow of blood sent to the lungs are higher than normal, and they become increasingly congested. The children tire easily, have poor weight gain and stunted growth. Quite often they suffer from respiratory infections, pneumonia, breathe fast and have a pale, pasty appearance are very sweaty as a result of the efforts to breathe and eat. The surgery must be done before they develop pulmonary hypertension, which would affect the lungs with irreversible damage.

Hypoplastic Left Heart Syndrome (HLH):



This is an abnormality in the structure of the heart. This is a group of related defects that together, means that the left ventricle is smaller than usual. Normally, oxygen-poor blood is pumped from the right ventricle of the heart to the lungs where it is oxygenated and returned to the left ventricle. Then, the left ventricle pumps oxygenated blood to the rest of the body. All babies are born with two connections between the two ventricles of the heart; but after a few days, these connections are closed. In children with HLHS, the left ventricle did not grow to normal size and cannot pump enough blood to the body. The normal connections present at birth help direct the flow of blood to the body; but when these connections are closed, the supply of oxygenated blood decreases. So, after a few days of age, babies with HLHS present symptoms of this condition.

Transposition of the Great Arteries or Vessels (TGA):



This is a heart condition present at birth. The TGA occurs when the two main arteries that carry blood from the heart, the pulmonary artery and aorta are switched or "transposed". Generally, the blood returning to the heart from the body goes from the right ventricle to the lungs through the pulmonary artery. There it is oxygenated and returns to the left side of the heart. Then, the oxygenated blood is pumped from the left ventricle into the body via the aorta. In the TGA, blood returning from the body bypasses the lungs and returns directly to the body, this occurs because the main connections are reversed. The pulmonary artery, which normally carries oxygen-poor blood from the right ventricle of the heart to the lungs, now comes the left ventricle and carries oxygenated blood returning from the lungs back to them. The aorta, which normally carries blood from the left ventricle of the heart to the body, now comes out of the right ventricle and then carries



oxygen-poor blood back to the body. The outcome of this transposition of the two arteries is that blood is pumped by the heart to the body has less oxygen. Since the main arteries are switched, two independent blood flows rather than one is connected. Thus, the oxygenated blood from the lungs never gets to the body. This means that the TGA is a cyanotic heart defect (lack of oxygen) which produces a bluish color to the skin and difficulty breathing. Symptoms appear at birth or shortly thereafter. The severity of symptoms depends on whether there is a way you can mix the two independent circuits of blood flow to allow a certain amount of oxygenated blood to go to the body.

The combination may occur from other defects or anomalies, such as a hole between two chambers of the heart (ventricular septal defect) or a deviation that is usually present at birth. (PDA) Symptoms may also depend on the presence of other birth defects. TGA symptoms include:

- Bluish skin
- Shortness of breath
- Difficulty feeding

Your child may need surgery shortly after birth. Most hospitals offer a type of surgery called "arterial switch", with which you can fix the problem and no further interventions are required.

**References:**

www.heartcareintl.org

www.americanheart.org

www.childrensnyp.org

www.childrenscolumbus.com/patient_family/heartcenter

www.aibarra.org

www.cardiopatiascongenitas.net

www.cdc.gov

Please be advised: The information contained herein is strictly informative and does not substitute the medical diagnosis. Your doctor is the professional indicated to guide you about your child's care.

This booklet is dedicated in memory of all the children that have suffered from CHD, their parents, siblings and other family members. And to all of the nurses and doctors that have had the privilege and honor to care for them.

Betsy M. Tirado-Ortiz, RN
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