

# The Heart Center

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# The Heart Center

## Welcome

All parents have hopes and dreams for their child's life. As a parent with a new baby or a child with a new diagnosis, you may find it hard to deal with all of the emotions you feel. It is normal to find yourself dealing with strong emotions from joy to excitement to helplessness or concern. We are here to give your child the best possible medical and nursing care, while providing emotional and spiritual support to your family. Our doctors, nurses, and support staff are able to give the best cardiac care to patients from around the world.

This binder will serve as a passport throughout your child's life. It contains helpful information about fetal maternal medicine, describes your journey through the Heart Center, helpful terminology, and patient information that will be important throughout their lives.

### Heart Center Overview

The Heart Center at Children's Health offers a program of specialized care for children with congenital and acquired heart disease with nearly 13,000 outpatient clinic encounters and over 900 inpatient visits each year. Ranked among the country's top cardiology and cardiothoracic surgery program, a multidisciplinary group of subspecialists work together to meet the full range of cardiac needs:

- Prenatal Consultation
- Non-invasive diagnostic imaging
- Interventional catheterization
- Electrophysiology (including catheter ablation and device therapy)
- Preventive cardiology
- Cardiothoracic surgery (including heart transplantation and congenital heart defect repair)

### Heart Center is staffed by world class physicians from the University of Texas Southwestern and employees of Children's Health:

- Cardiologists
- Interventional Cardiologists
- Cardiothoracic Surgeons
- Cardiac Radiologists
- Cardiac Anesthesiologists
- Cardiac Intensivists
- Registered Nurses specialized in Cardiac Care
- Advance Practice Nurses

# The Heart Center

## Support Services

### Care Coordinators

The Heart Center has Care Coordinators who have been assigned to patients to offer consistency in care management and help with your child's discharge needs. Care Coordinators make referrals for home care services and transitional care facilities, arrange home equipment and supplies, set up ambulance transports if needed, and coordinate insurance coverage for your child's discharge needs.

### Child Life

#### **Please have your bedside nurse consult your Child Life Specialist**

The child life specialist focuses on your child's developmental growth and helps your child maintain a sense of normalcy during what can be a very abnormal period. The child life specialist can educate you in ways to connect to and interact with your child even while he or she is undergoing intense medical treatment. They are also available to prepare and assist siblings with coping to the hospital setting. Child life specialists can assist with developing a plan with your child's school when a hospitalization or illness impacts their education.

### Language and Interpreter Services

For families who do not speak English, talking to nurses and doctors about their child's illness can be challenging – so we offer interpretation services free of charge. Children's Health staff members have access to interpreting services for talking with patients and their families, no matter the language. Staff Spanish interpreters are available 24 hours a day/7 days a week, every day of the year. For all languages, other options are available over-the-phone interpreting services.

The Heart Center has two dedicated Spanish interpreters available in the clinic and on the Cardiology Units.

### Pastoral Care

#### **Please call 214-456-2822 for your Chaplain**

Pastoral Care offers interfaith spiritual support and emotional care to patients and their families. Our chaplains are knowledgeable about spiritual and emotional development unique to children. The Pastoral Care team is dedicated to creating a compassionate environment that respects every individual's spirituality, as well as promoting health and wholeness of body, mind and spirit. Chaplains are available to provide prayers, blessings or other rituals at your request. Your personal spiritual leader (pastor, imam, priest, etc.) is also welcome to visit throughout your child's hospitalization. Our hospital chaplains are available twenty-four hours a day, seven days a week.

The Haggerty Chapel is open twenty-four hours a day and is located at Children's Health - Dallas on the lower level of Tower C, just off the main corridor that connects Towers B, C, and D. The chapel is a place for quiet thought, reflection and prayer. There are daily devotionals held Monday - Friday from 11:45 a.m. to noon in the chapel. On Sundays, there is a non-denominational worship service at 11 a.m. and a Catholic mass at 3:00 p.m. The Pastoral Care department also offers special services related to liturgical and spiritual calendars. We welcome your participation.

# The Heart Center

## Support Services

### **Psychologist**

**214-456-8011**

Pediatric psychologists help children and families cope when they are in the hospital. They can also help when children are feeling sad or having a hard time with being in the hospital. Pediatric psychologists also help families learn different ways to help their child when they go home from the hospital and go back to school. Pediatric psychologists can meet with each patient and family during outpatient and inpatient visits.

### **Social Work Services**

**Please call 214-456-2300 for your Social Worker**

Children's Health Heart Center has both outpatient and inpatient social workers to support you and your family through your pregnancy, hospitalizations, and follow-up care at Children's. These social workers, dedicated solely to our families seeking cardiac care, are specially trained and licensed to counsel families coping with illness, assess patient and family psychosocial needs, provide crisis and therapeutic counseling, prepare families for transition from hospital to home, and educate and link families to community resources. Our team of social workers focuses on the unique needs of every family at each visit to the hospital.

We routinely assist families with financial concerns. Many families come to Children's from out-of-town to obtain care for their children. Our social workers are knowledgeable about many area resources to make your stay in the Dallas area as smooth as possible. Lodging assistance is available and our social workers can facilitate referrals to the local Ronald McDonald House or assistance with hotel arrangements.

Our goal in social work is to help the family cope with the illness by addressing the anxiety and stress, financial concerns, or the day-to-day details that need attention during a child's illness.

# The Heart Center

## Fetal Maternal Medicine

The Fetal Heart Program at Children's Health is the only program in the country with disease-specific certification from the Joint Commission. The Children's Health team works closely with Maternal Fetal Medicine specialists at UT Southwestern and other programs statewide to coordinate care for mothers and babies. Customized delivery plans are created to ensure children with congenital heart disease receive the care they require from the moment they are born.

Typically, during your first visit prenatal visit, a fetal echocardiogram is performed. This is similar to an obstetric ultrasound but is focused on the heart. A Pediatric Cardiologist, specially trained in Fetal Echocardiography, reviews normal heart anatomy and discusses your baby's particular heart condition with you immediately following the fetal ECHO. We begin to create your customized birth plan at that time. Helping parents understand their baby's condition is a priority for our team. During the prenatal visit or follow up visits, the fetal coordinator will arrange for consults as needed or requested (Social Work, Financial Counselor, Child Life Specialist, Psychologist, Cardio-Thoracic Surgeon, and tour of the Heart Center.)

The Fetal Heart Program at Children's Health offers information, support and coordination to help children get the expert care they need starting from the moment they are born:

- **Advanced diagnosis:** fetal ECHO provides us the ability to visualize the heart conditions in fetuses as young as 18 weeks of age.
- **Experienced team:** All of the doctors in our program have advanced training in fetal heart care.
- **Patient education:** We pride ourselves in helping parents understand their baby's condition. We want you to feel comfortable taking an active role in decisions about your child's care.
- **Care coordination:** registered nurses help families transition their child's care to the Heart Center after birth with a special focus on finding the right cardiologist to meet their child's unique needs

**Support:** resources and support through the help of dedicated social workers

### *Additional Questions You May Be Having...*

#### **What is the birth plan?**

Working within the risks and limitations of child's condition; children's will assist in identifying the most appropriate hospital for the family to deliver their baby. We will do our best to support supporting delivery at a family's preferred community hospital.

#### **Will I need to deliver by C-section?**

In most cases mothers can give birth vaginally. Your OB will work with the Children's cardiac team to determine the safest mode of delivery for you and the baby.

#### **What happens after my baby is born?**

Both your MFM and the delivering hospital will receive a letter prior to birth outlining each baby's individual plan. Many times your baby will be taken to the NICU shortly after delivery where intravenous lines (IV) will be inserted and medications started (if necessary). Transport to Children's Health can be arranged if necessary.

# The Heart Center

## Fetal Maternal Medicine

### Can I interact with my baby prior to surgery?

You play an important role in your child's care; positive interactions are encouraged throughout the hospital stay

### Can I have my baby boy circumcised?

Due to risks of bleeding and infection, circumcision is not performed before or at the time of cardiac surgery.

### Can I have my baby baptized before surgery?

Children's Health employs chaplains from all faiths and they are available to baptize your child at your request. If you have a particular individual whom you want to do the baptism, the hospital chaplain can assist with those arrangements.

### Can I donate blood for my child's surgery?

A blood transfusion may be necessary pre-operatively and post-operatively and blood products could be utilized during the operation.

Children's Health is partnered with Carter Blood Care for all blood products. All products are tested and screened for infectious disease. Blood less than 72 hours old is best utilized during the operating room; for this reason we do not offer direct donation.

### When and how do you communicate with my child's pediatrician following birth, procedures, and surgeries? When do I need to identify a pediatrician for my child and can you provide guidance in my search?

If you have identified a primary care physician (PCP) we will send them intermittent updates via secure electronic medical record communications. If your baby is enrolled in Safe at Home then they will receive an email and telephone call describing patient history and their role during the interstage. Case management can also help identify a PCP.

### Who will care for my baby between birth and his/her first procedure? After the procedure? Do you have a dedicated Cardiac Intensive Care Unit?

Your baby will be cared for by a cardiac attending physician, cardiac advanced practice providers, and cardiology/PICU fellows. As well, we have a Cardiac Intensive Care Unit dedicated to provide care for our cardiac patients.

## Packing List to Prepare for the Hospital

### Caregivers

- ♥ Change of clothes
- ♥ Flip flop/ slippers
- ♥ Sweatshirt  
*(it can get cold in the hospital)*
- ♥ Toiletry Items
- ♥ Camera
- ♥ Electronic charger  
*(phone, camera, computer)*
- ♥ Non-perishable snacks
- ♥ Book/magazines
- ♥ Blankets, towels, and pillows are available

### Patient

- ♥ Boppy pillow
- ♥ Blankets
- ♥ Baby legs warmers
- ♥ Side snap onesies
- ♥ Hats/beanies
- ♥ Baby socks/booties
- ♥ Baby nail clippers or mittens
- ♥ Lovie/wobby/or special toy that can comfort them
- ♥ A bag to keep in their room for infant items *(and dirty clothes/blankets)*
- ♥ Family pictures

### Siblings

- ♥ Books, coloring book, other fun activities
- ♥ Extra Clothes
- ♥ Sweatshirt
- ♥ Blanket

# The Heart Center

## Heart Center Progression

We recognize that you are the most important person in your child's life and this can be an overwhelming time. One of the best ways you can support your child is by taking an active role in their medical care! We encourage you to share information you have learned or observed about your child's care with the medical team. Over time, you will develop a working relationship with the doctors, nurses, and other members of the care team that are based on trust and respect.

Sometimes you might feel overwhelmed by your child's medical team. This may be especially true if your child has many specialists. It is important to remember that you will carry out treatment plans at home and you must understand everything your child care provider is telling you. You are invited and encouraged to participate in your child's treatment and care, and if there is something you do not understand, please ask questions. Remember, every question you ask is important!

- Ask for clarification from any care provider when you don't understand.
- Ask for more information when you don't understand a treatment or why it needs to be done.
- Ask about possible side effects.
- Keep asking questions until you are satisfied and you understand what you need to know.

### Cardiac Intensive Care Unit (CICU)

- 18 Bed Unit, 2 rooms have 2 beds
- Pediatric Cardiac Attending Physicians Advanced Practice Providers, and Fellows will be the caregivers in the CICU and will work closely with the pediatric cardiologist and cardiothoracic surgeon to develop the best plan of care
- Pediatric Cardiac Attending Physicians Advanced Practice Providers, and Fellows cover 24 hours a day, 7 days a week
- Nursing Ratio: 1 nurse to every 1 to 2 patient
- All rooms can be made into an operating room if needed
- Daily Family Centered Care Rounds at the bedside: We encourage you to participate in rounds to discuss your child's plan of care and treatment plan.

*Most patients remain in the CICU under close watch until:*

- Breathing tube is removed
- Begin tolerating feeds
- Demonstrate good weight gain

### Intermediate Care Unit (IMU)

- 12 Bed Unit
- Intermediate floor between CICU and C8 (cardiology floor)
- Pediatric Cardiac Intensivist and Advanced Practice Providers are caregivers in IMU
- Advanced Practice Providers cover 24 hours a day, 7 days a week
- Nursing Ratio: 1 nurse to every 2 patients
- Daily Family Centered Care Rounds at the bedside: We encourage you to participate in rounds to discuss your child's plan of care and treatment plan.
- Private Bathroom

*Most patients remain in the IMU under close watch until:*

- Family education begins
- Demonstrating weight gain
- Weaning off respiratory support. Patient able to progress to the cardiology floor on oxygen
- Begin care coordination prior to discharge
- Transition of Care Conference

# The Heart Center

## Heart Center Progression

### Cardiology Floor (C8)

- 22 Bed Unit
- Cardiologist is the Attending, with assistance of a Cardiology Fellow, Advanced Practice Providers, Residents, and Medical Students
- Residents and Medical Students will take a more active role in your child's daily plan of care.
- Daily Rounds are held within a conference room on the 8<sup>th</sup> floor. The medical team will examine the patient before rounds, the bedside nurse attends rounds, and your team will update you on the current plan of care.
- Telemetry Monitoring: heart rhythm monitoring is available by a trained individual 24/7 if needed
- Labs: Can be a finger stick, heel stick, or by phlebotomy.
- Chest X-Rays: Your child will possibly travel off the cardiology floor to radiology for their x-rays.
- Each room has a private bath
- Parent's can eat inside your child's room.

### *Remain on the cardiology floor until discharge:*

- Demonstrating good feeding and medication routine
- Caregiver can demonstrate understanding of your child's medical needs
- Caregiver completes a "Room In" process. This is usually a 24 to 48 hour time period, where the caregiver provides all the needed care to your child. Treatment team members are available to answer caregiver questions during this time, but the caregiver is encouraged to care for the patient independently.

### Cardiology Clinic

- Follow up with Cardiologist at scheduled intervals
- Vitals and Weight
- ECHO and EKG
- Lab work and Radiology

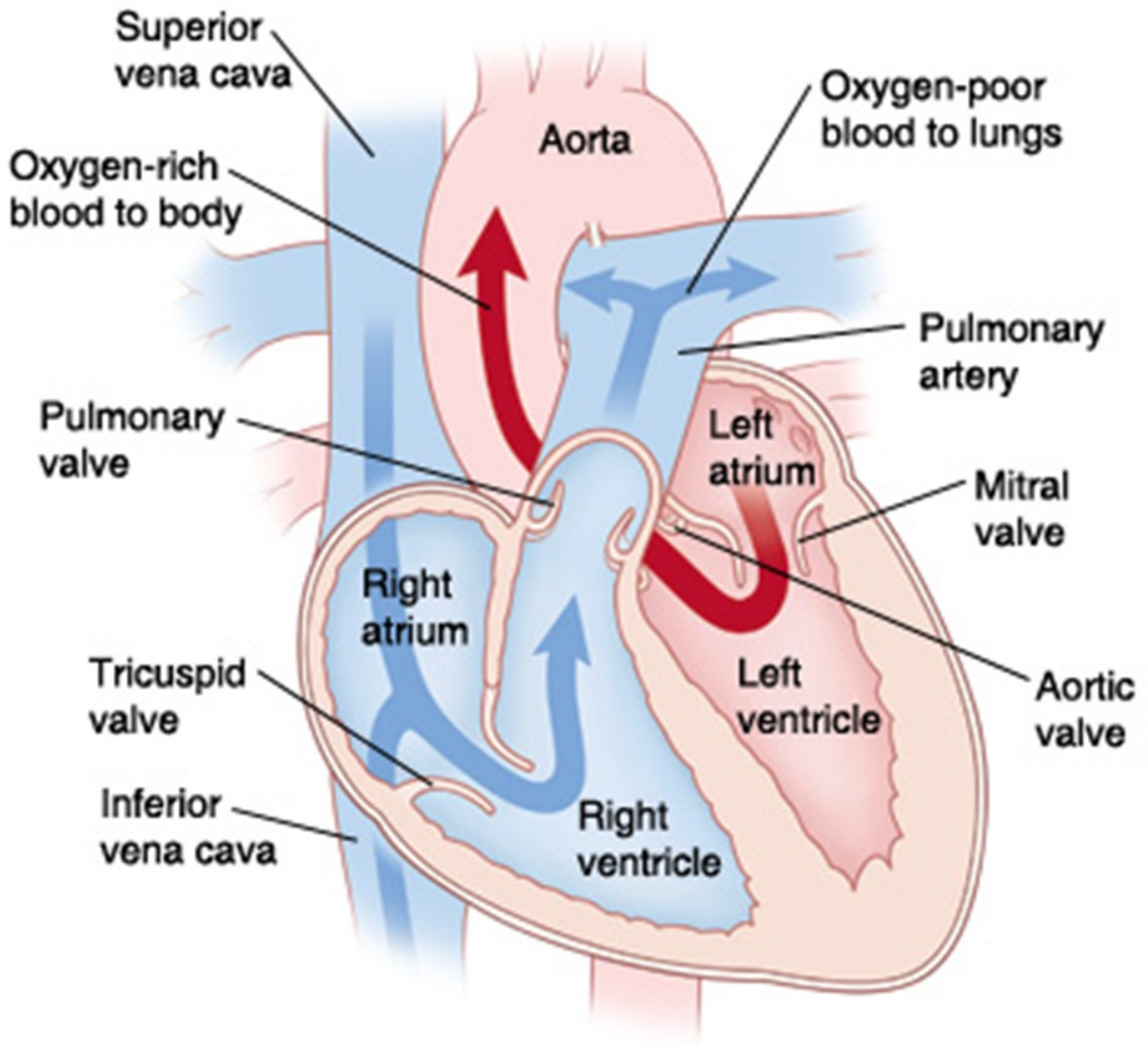
### Family Meetings/Care Conferences

Periodic family meetings with your health care team give you the opportunity to discuss your child's overall condition and progress in more details. Family meetings also give you the opportunity to meet with the many members of the health care team at one time. Some of our families will stay in the Heart Center for a short time and others may stay for several months. It's important to keep communication open to ensure we are supporting you and your family in the best way possible. If a family meeting is needed or requested; your social worker will make the arrangements. Please know that you do not have to wait for a family meeting to ask questions about your child's care.



# The Heart Center

## Normal Heart



# The Heart Center

## My Child's Information

**Name:** \_\_\_\_\_

**Birthday:** \_\_\_\_\_

**Heart Condition:**

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**Surgery Date:** \_\_\_\_\_

**Surgery Type:** \_\_\_\_\_

**Other procedures or surgeries:**

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**Other medical conditions:**

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**Normal Saturations (blood oxygen level):**

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**Allergies:**

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# The Heart Center

## My Child's Doctors

### Cardiologist

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Surgeon

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Pediatrician/Family Doctor

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Specialist: (Type)

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Specialist: (Type)

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

# The Heart Center

## Other Helpful Information

### Home Health Company

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Durable Medical Equipment (DME) Company

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Children's Case Manager

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Social Worker

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Nutritionist

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

# The Heart Center

## My Child's Medications List

Medication Allergies: \_\_\_\_\_

Pharmacy: \_\_\_\_\_ Phone: \_\_\_\_\_

<b>Medication:</b>
<b>Purpose:</b>
<b>Possible Side Effects:</b>
<b>Dosage:</b>
<b>Time(s) to Give:</b>

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# The Heart Center

## My Child's Medications List

<b>Medication:</b>
<b>Purpose:</b>
<b>Possible Side Effects:</b>
<b>Dosage:</b>
<b>Time(s) to Give:</b>

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<b>Time(s) to Give:</b>

<b>Medication:</b>
<b>Purpose:</b>
<b>Possible Side Effects:</b>
<b>Dosage:</b>
<b>Time(s) to Give:</b>

# The Heart Center

## Appointment Schedule

Date	Doctor	Reason

# The Heart Center

## Helpful Terms and Definitions

**Aorta** – The main artery to the body. The aorta originates from the base of the heart and arches over the heart like a cane handle passing down through the chest and abdomen near the spine. Normally the aorta receives blood from the left ventricle and moves it to smaller arteries which send blood to all parts of the body except the lungs.

**Artery** – Vessel that takes blood away from the heart to the lungs or body.

**Arterial blood** – Blood that carries oxygen from the lungs to the body.

**Arterial line** – Catheter placed directly in an artery that measures blood pressure continuously.

**Aspiration** – Entry of food or formula into the trachea or lungs from the mouth or throat.

**Atelectasis** – Inability of the lungs (all or parts) to fully expand. May be referred to as lung “collapse”

**Atresia** – Absence of a normal opening.

**Atrium** – Upper chambers of the heart. Normally there is a right and a left atrium.

**Blood pressure** – Force that flowing blood exerts on the artery walls.

- **Systolic blood pressure:** first number and correlates with the contraction of the heart that sends blood out to the body.
- **Diastolic blood pressure:** bottom number and correlates with relaxation of the heart as it fills with blood.
- **Noninvasive blood pressure:** measurement taken with a blood pressure cuff.

**Blue babies** – Many babies who have a type of cardiac defect termed cyanotic. These defects cause bluish discoloration or “cyanosis” of their skin, nail beds and mucous membranes. However in some babies, **blue is NOT always BAD.**

**Bradycardia** – slow heart rate for age of the child

**Cardiologist** –Physician who specializes in heart disease.

**Cardiopulmonary (Heart-Lung) Bypass Machine** - Used during open-heart surgery, this device performs the work of the heart and lungs by pumping and oxygenating the blood. This allows the heart to be motionless during the surgery.

**Cardiothoracic surgeon** – Physician who specializes in cardiac surgery.



# The Heart Center

## Helpful Terms and Definitions

**Cardiac catheterization** – Invasive procedure. The process of introducing a thin, flexible tube called a catheter into a vein or artery and guiding it to the heart chambers to measure pressures in the chambers, sample blood and take pictures (angiography). Your child will come to the hospital the morning of the procedure or be admitted the night before. Your child will receive sedation for the procedure and stay in the recovery room for a period of time. Most times your child will be sent home the day or 1 to 2 days after the procedure.

### **Interventional procedures that may be performed during a catheterization include:**

- **Angioplasty:** dilating or increasing size blood vessel
- **Atrial septal stent:** placement of a stent across the foramen ovale to keep the atrial septal open to allow blood to shunt freely across the septum.
- **Balloon atrial septostomy:** a balloon is used to open the atrial septum to allow the blood to flow freely across the septum.
- **Catheter devices:** a stent is a small wire mesh tube. It is most often made of stainless steel. It can be placed in a narrowed blood vessel.
- **Coil closure of collaterals:** a procedure or technique used during cardiac catheterization or surgery using a coil, a device placed in blood vessels to occlude blood flow
- **Hybrid procedure:** a catheterization and surgical procedure where bands are placed on the pulmonary arteries to decrease pulmonary blood flow and a stent is placed across the ductus arteriosus to provide "shunting of blood" from the aorta and pulmonary arteries.

**CBC** – Complete blood count.

**CBC and diff** – complete blood count including a differential or counts of the various types of blood cells.

**Celsius versus Fahrenheit** – Celsius is the temperature scale used in medicine instead of Fahrenheit. The conversions are:

Fahrenheit to Celsius: Subtract 32 and halve the resulting number  $[(temp - 32)/2]$ .

Celsius to Fahrenheit: Double the number and add 32  $(2x temp + 32)$ .

**Chest x-ray** - A chest x-ray is a noninvasive test. It provides pictures of structures in the chest such as the heart, lungs, ribs, and bones. Also provides information on the size and position of the heart. Used to check the position or placement of tubes such as breathing tubes, chest tubes, central lines, or nasogastric tubes.

**Chyle** – A milky fluid consisting of lymph and emulsified fats; formed from foods in the small intestine, absorbed by the lacteals and passed into the blood through the thoracic duct.

**Chylothorax** – Leakage of chyle into the pleural space (around the lung). Treatment begins with draining the fluid and eliminating fats from the diet. Nutrition will be consulted on the best formula or foods your child can eat should they develop a chylothorax.

**CT scan** - A CT scan is a study that shows cross-sectional pictures of the body. The CT scan shows in great detail the internal structures and any abnormalities. Some CT scans need contrast given in an IV or by mouth.

**Congenital defect** – Any type of defect present at birth.

# The Heart Center

## Helpful Terms and Definitions

**Congestive heart failure** - A condition in which the heart is unable to pump the amount of needed blood to the body.

**Ductus arteriosus** – A connection outside the heart of the fetus that is between the pulmonary artery and aorta. It normally closes after birth.

**Echocardiogram (ECHO)** - Noninvasive test. This test uses ultrasound to provide a picture from the sounds waves that are reflected from an organ or tissue. A transducer is placed over the chest. High frequency sound waves bounce off the heart structures. They are transmitted back through the transducer to produce images of the heart structure and heart function.

**Electrocardiogram (ECG)** - This is a noninvasive test. Small special pieces of tape, called Electrodes, are placed on the arms, legs, and chest. These detect the electrical changes of the heart and are able to record them by a graphic tracing.

**Edema** – Large amounts of fluid in the tissues of the body; swelling

**Electrolytes, BUN/Creatinine** – Blood tests that measure electrolytes (such as sodium, potassium, and chloride), blood urea nitrogen (BUN), and creatinine levels and reflect how well the kidneys are working.

**Extracorporeal Membrane Oxygenation (ECMO):** A special procedure that uses an artificial heart-lung machine, similar to the cardiopulmonary bypass equipment used during open-heart surgery. ECMO also performs the work of the heart and lungs.

**GERD** – Stands for “gastrointestinal esophageal reflux disease.”

**gtt**– Latin meaning “guttae” or drops. Used in medicine as an abbreviation for a dosage form known as drips.

**HGB/HCT** – Hemoglobin and hematocrit (a.k.a. “crit”). These molecules carry oxygen to the body.

**Holter monitor** - Noninvasive test. This is a portable ECG recorder that is worn by the patient for a specified period of time, usually 24 or 48 hours. This test evaluates how fast or slow the heart beats while the patient is involved in various activities as well as sleeping. These activities are linked with the ECG tracing.

**Hypertrophy** – Enlargement of a tissue or organ due to increase in the size of its cells.

**Kilogram** – Unit of measure to provide weights of a person. 1 kilogram = 2.2 pounds.

**Mitral valve** – The heart valve between the left atrium and left ventricle. It has two cusps or flaps.

**Magnetic Resonance Imaging (MRI)** - A noninvasive test. An MRI is a test using magnetic waves to provide a three dimensional view of the body without the use of radiation. This test is similar to a CT scan and may also require contrast. Newborns and small infants may need to be intubated for this study because it can take some time and movement of any type may affect the results. A MRI cannot be done in patients with pacemakers, mechanical prosthetic valves, or other medically implanted devices.

**Murmur** – Noise made by blood flow which may or may not be normal.

# The Heart Center

## Helpful Terms and Definitions

### Common Medications

#### **ACE inhibitors/ vasodilators**

ACE stands for Angiotensin Converting Enzyme inhibitors. These medications work to stop the constriction of blood vessels and decrease the resistance to blood flow. It is easier for the blood to flow through the body's organs. It also works to decrease blood pressure. Examples of ACE inhibitors are enalapril and captopril.

Possible side effects of ACE inhibitors include:

- Dry persistent cough
- Weakness or swelling
- Low blood pressure and dizziness
- 

**Antiarrhythmic** – Medications to treat irregular heartbeats:

- **Amiodarone** – Medication to suppress abnormal electrical conduction in the heart. It is important to have thyroid testing, liver functions tests, and an eye exam while taking this medication.
- **Beta-blockers** - Medication to treat arrhythmias. They increase the non-excitability or refractory period of the AV node.
- **Calcium channel blockers** – Medications that decrease the calcium entry into cells. This slows the heart.
- **Digoxin** – Medication that causes the heart to slow and pump blood more effectively. It increases the force of each contraction of the heart. This medication may also be used to treat rapid heart rate. Take digoxin at the same time each day. There can be a risk of toxicity. If you miss a dose or child throws up the Digoxin, it should not be re-dosed.
- **Isuprel** – Drug used as a cardiac stimulant to treat an abnormally slow heart beat and increase the strength of the heart's pumping.

#### **Anticoagulants (examples: aspirin, plavix, coumadin, lovenox, or heparin)**

This group of medicines is used to reduce the formation of clots in the blood stream. Anticoagulants are used to:

- Reduce the risk of clot formation in artificial grafts (an example is a BT shunt)
- Decrease the risk of clot formation secondary to blood moving slowly through the body due to the heart not pumping properly.
- It is important when taking anticoagulation to schedule regular blood tests. The goal is to make sure your child's blood is within the target range, examples are Coumadin and Lovenox.
- It is important to take anticoagulation medicine at the same time each day.

**Beta-blocker** - Medication used to treat arrhythmias. They increase the nonexcitability or refractory period of the AV node. Examples of beta-blockers are propranolol and atenolol.

**Diuretic** – This group of medicines works to stimulate the kidneys. Diuretics remove excess water and salt from the body to increase urine output. The different diuretics work on different parts of the kidney. It is important to call your cardiologist if you have diarrhea or vomiting while taking diuretics. **With diarrhea and vomiting there is an increased risk of dehydration.** A commonly used diuretic is Lasix (furosemide).

**Heparin** – An anticoagulant medication given by injection or in an IV.

*Many medicines have interactions. Consult your cardiologist or PCP with extra questions. Patients also need to stop or hold medicines prior to dental or surgical procedures.*

# The Heart Center

## Helpful Terms and Definitions

**NGT** – Naso-gastric tube.

**NDT** – Naso-duodenal tube.

**P.O.** – To take something by mouth.

**Prostaglandins** – Hormone-like substances made from fatty acids which are found throughout the body tissues and thought to have important roles in tissue metabolism and blood flow. This can be given in an intravenous drip solution to keep the ductus arteriosus open newborns with congenital heart defects.

**Regurgitation** – Abnormal backward flow of blood through a valve in the heart.

**Shunt** – Passage between two blood vessels or between the two sides of the heart. Placed during surgery, it creates a passage between blood vessels to divert blood from one part of the body to another.

**Tachycardia** – Fast heart rate for the age of the child.

**Tachypnea** fast respiratory rate/breathing

**Tricuspid valve** – Heart valve between the right atrium and right ventricle, has three cusps or flaps.

**Valve** – An opening covered by membranous flaps between two chambers of the heart or between a chamber of the heart and blood vessel. Normally when a valve is closed, blood cannot pass through.

**Vocal Cords** – Vocal cords are structures in the larynx which are designed to vibrate and make sound when air passes through. Occasionally, damage to one or both vocal cords can occur during cardiac surgeries. Symptoms of vocal cord damage includes a hoarse or weak cry, inability to eat or suck their bottle without coughing or choking, and possible pneumonia from aspirating fluid or food into the lungs. Vocal cord injury is diagnosed by a physician who specializes in ear, nose, and throat disorders. Using an endoscope (a special camera), this physician can directly view the vocal cords to determine movement and position.

- **FEES** — stands for **fiberoptic endoscopic evaluation of swallowing**. This test may also be recommended if there is vocal cord damage. It is used to evaluate stages of swallowing and if your baby can eat by mouth. It can be done at the bedside.
- **VFSS** – stands for **video fluoroscopic swallow study**. This test may also be used to evaluate swallow dysfunction in your baby. It is done in Radiology and requires the baby to be able to suck and swallow approximately 10 ml's of a radiopaque liquid (usually barium) mixed with formula. As the baby sucks, images are recorded and analyzed to determine if the baby can safely swallow their formula without risk of aspiration.

**Vein** – Series of vessels of the vascular system which carries blood from various parts of the body back to the heart.

**Ventricle** – One of the two main pumping chambers of the heart. The left ventricle pumps oxygenated blood through the aorta to the body. The right ventricle pumps blood through the pulmonary artery to the lungs.

# The Heart Center

## Growth and Nutrition

### Formula & Breast Milk Safety Guidelines

	Room Temperature	Refrigerator	Home Freezer	Deep Freezer
<b>Discard formula and breast milk remaining in bottle 1 hour after start of feed</b>				
Prepared Formula	4 hours	24 hours	Do not freeze	Do not freeze
Fresh Breast Milk	4 hours	96 hours	3 months	12 months
Fresh Breast Milk + Additives	4 hours	24 hours	Do not freeze	Do not freeze
Breast milk thawed in warm water	4 hours	Do not return to refrigerator	Never re-freeze	Never re-freeze
Breast milk thawed in the refrigerator	4 hours	48 hours from removal of	Never re-freeze	Never re-freeze
Breast milk thawed at room temperature	Do Not Use	Do Not Use	Do Not Use	Do Not Use

Thaw frozen breast milk under cool or warm running water or in the refrigerator  
Place frozen breast milk in a sealed bag prior to thawing under water

Sterile bottled water or sterile nursery water is preferred. Do not use well water. If baby is less than 3 months old, boil tap water or unsterile bottled water for 1 minute. Let cool before adding.

#### Proper Steps to Safe Preparation

1. Clean hands thoroughly with warm water and soap, for at least 15 seconds; or use alcohol based hand gel.
2. Clean countertop of preparation area
3. Measure liquids and powders separately.
4. Combine into a clean container and mix well.
5. Cover and store in an air tight container.
6. Refrigerate until ready to use.

#### Tube Feeding

Formula or Breast milk hang time must not exceed 4 hours

Feeding bags are to be emptied and rinsed out between feeds or every 4 hours with continuous feeds

Give tube feeds at room temperature; avoid giving cold formula straight from the refrigerator.

# The Heart Center

## Growth and Nutrition

### Additional Information

- Providing breast milk improves the immune system, protects against illness and promotes brain development. The American Academy of Pediatrics recommends infants receive breast milk for at least 6 months, but preferable through the first year.
- Moms wanting to breastfeed are encouraged to start pumping the day of delivery and should pump every 3 hours, 8 times per day, to establish an adequate milk supply. An electric pump is necessary when mom and baby are separated. Check with insurance or WIC for assistance with an electric breast pump for home.
- A hospital-grade electric breast pump will be provided for hospital use while visiting the infant; there is also a breast milk lab to store breast milk during admission.
- Breast milk is encouraged but formula or donor breast milk can also meet all of the infant's nutritional needs.
- Most infants will require extra nutrition to support growth and weight gain. This is met by fortifying breast milk or concentrating the formula. Parents will be given a special recipe to prepare the formula or breast milk.
- Direct breastfeeding is generally postponed until after surgery once the infant is stable and growing well. Please talk to your care team about when you can begin breastfeeding.
- Participate in skin-to-skin contact as often as possible to benefit mom with lactation production and baby. Other caregivers are also encouraged to do skin-to-skin contact with baby. Skin-to-skin contact helps with growth and development.
- Many times infants with heart disease have trouble eating and they may require a tube that goes into their tummy or into their nose. This tube will help feed them. Depending on the patient, the tube will either be removed before discharge or the child will go home with the tube to help them grow. Feeding tubes are very common and can be short-term.
- Speech Therapists are available to help infants learn how to eat at the hospital and while they are at home.
- Your baby may need a vitamin D supplement if taking breast milk since it naturally contains very little. The AAP recommends infants receive a minimum of 400 units vitamin D per day for optimal bone health.

# The Heart Center

## Growth and Nutrition

### Tips for feeding your baby

- It is important to hold infants while they are eating; infants benefit from comfort and human contact while receiving essential nutrition (this also applies when they have a feeding tube).
- When eating from a bottle, angle it enough to avoid air from entering the nipple which can cause increased gas and discomfort. Never prop the bottle. This can cause choking or cavities.
- An infant may have specific feeding instructions provided by a speech therapist, it is important to follow these recommendations for the safety of the infant.
- Spit-up is normal for most babies. Infants with heart defects can have even more spit-up. It is important to learn the difference between a spit-up and true vomiting
- Infants with feeding tubes can still be burped.
- Never give infant water in place of formula or breast milk.
- Infant cereal is introduced between 4 to 6 months depending on their developmental milestones. Introduction of solids might be delayed until after surgery since they do not provide as many calories as formula. Infant cereal should always be given from a spoon; do not add cereal to the bottle unless instructed by a clinician. Wait at least 3 days before introducing each new food in case of allergies.

# The Heart Center

## Growth and Nutrition

### Lactation Resources for Pumping

#### Children's Lactation Support Services

How can we help?

- Using an Electric Breast Pump
- Assessing Flange Fit
- Milk Supply Concerns
- Medications and Breastfeeding,
- Engorgement
- Plugged Ducts and Mastitis
- Treatment for Sore or Cracked Nipples
- Breastfeeding positions and latch
- Using a nipple shield
- Non-nutritive suck

**Please ask your bedside nurse or social worker for additional information**

#### Lactation Care Center – WIC Dallas

**214.670.7222**

2600 Stemmons Freeway, Suite 188

Dallas, Texas 75207

Services are provided by Internationally Board Certified Lactation Consultants (IBCLC), free of charge, in a calm and friendly environment to mothers who are eligible for the WIC Program.

When you have a question or concern about breastfeeding, The Lactation Care Center-Dallas is here to help and support breastfeeding mothers. We can help with:

- Latch on problems
- Premature Babies
- Low Milk Supply
- Special Needs Babies
- And more...

Not on WIC? Call 1-800-WIC FOR U (1-800-942-3678) or 214-670-7200



# The Heart Center

## Cognitive and Developmental

There have been some big changes in the Heart Center at Children's Medical Center and we are excited to tell you about our new **Developmental Clinic**. Your baby's growth and development are very important to us, therefore we now offer a program to screen and monitor your baby's development. This allows us to make sure your baby gets all of the support they need to be successful as they continue to grow.

Many children's hospitals across the country are creating developmental clinics. Close developmental follow up is recommended by the American Heart Association. Children who have had a significant heart surgery should have developmental screening every 6 months through age 3. Most children begin screening between 6 and 12 months of age. This screening will take place during one of your outpatient Cardiology Clinic visits and will let you and your doctor know if your child needs developmental testing.

If your child does need developmental testing, our Heart Center Psychologist, Dr. Corinne Anton, will meet with you and your child for a developmental appointment. Each appointment will take place at the Heart Center in Children's Medical Center – Dallas. The developmental appointment lasts about 2 - 3 hours and involves playful activities, similar to games you and your child play at home. After the testing you will meet with Dr. Anton to talk about your child's development. Dr. Anton will provide you with recommendations on games to play at home with your child to help with their development. You will be able to ask any questions you may have.

### During your Developmental Appointment

- You will receive detailed information about your child's development and what we can do to help
- You will receive detailed recommendations and referrals, as well as a plan to help your child succeed as they grow
- Information about your child's development will be shared with their medical team and other treatment professionals, including their pediatrician or primary care provider
- Various therapeutic services to assist in development, including, but not limited to the following:
  - Speech/language/feeding therapy: helping your child learn how to feed and speak to the best of their ability
  - Physical therapy: helping your child decrease pain and increase physical activity by building strength and range of motion
  - Occupational therapy: helping your child learn how to be as independent as possible for their age
  - Social-emotional/cognitive therapy: helping your child to build thinking, emotional, and social skills
- You will receive regular follow-up screening to check your child's progress and meet their changing needs
- As your child enters school-age, we will work with your child's school to establish a plan to help them receive support and assistance in the school environment as needed
- Social workers, child life specialists, nutritionists/dieticians, and other care team providers will be available to assist with any non-medical needs

Corinne Anton, PhD  
Pediatric Psychologist  
214.456.8011

Cardiology Clinic  
Heart Center - Dallas  
214.456.2333

# The Heart Center

## **Developmental Care Tips: How Caregivers Can Stay Involved and Support Development**

Developmental care allows caregivers to engage in activities that promote the maximum potential of development for sick infants admitted in the hospital. Developmental care activities can help your child cope with routine nursing procedures and invasive treatments through neurosensory integration activities, such as those listed below. Caregivers are also encouraged to partner with their child's medical and developmental care team.

### **Family Involvement**

- ♥ Attend morning rounds. Learn your child's needs through rounds.
- ♥ Participate at bedside and in procedures.
- ♥ Contact support services when needed
- ♥ Talk to your nurse about holding and ways to interact with your child.
- ♥ A Heart Center caregiver gathering is available to meet, interact, and engage with other caregivers in a supportive atmosphere.
  - Every Wednesday from 2:00 – 3:00pm in the C8 multipurpose room.

### **Positioning and Handling**

- ♥ Different positioning can be helpful when medically appropriate.
- ♥ Ask your nurse about different ways to participate in holding your child.
  - Examples include:
    - Holding your child on their back
    - Holding your child on each side
    - Holding your child on their tummy
- ♥ Promote hand to mouth and hand to face contact, especially if your child is an infant.

### **Environment**

- ♥ Babies like to explore new and different objects.
  - Feel free to bring objects and toys from home.
  - Transfer smell of your family to your child using a small cloth doll, blanket, or lovie (mom can express breast milk on a cloth for her child to smell)
- ♥ When a baby is tired or needs a break, they tell you by yawning, crying, arching their back, or turning away from you.
- ♥ Babies love to hear voices! Use soft voices when your baby is awake.
  - Read books or sing
  - Show your baby pictures.
- ♥ The sense of smell is also important for the development of your child.
  - Be aware of strong smelling hygiene products
- ♥ Help us with your child's baths each day.

# The Heart Center

## **Developmental Care Tips: How Caregivers Can Stay Involved and Support Development**

### **Feeding Strategies**

- ♥ Speech and feeding therapy, as well as lactation consultation is available in Heart Center.
  - Let us know your preferred source of nutrition (breast milk or formula).
  - We have established a donor breast milk program.
  - Talk to your child's provider to determine if donor breast milk is an option.
- ♥ Your child may benefit from oral stimulation.
  - Examples:
    - Observe your child's response to their pacifier.
    - Consider fresh breast milk or formula pacifier dips for procedures
- ♥ Ask bedside nurse about oral care.
  - Oral care can happen once daily, but preferably every 2-3hrs after feeding.

### **Holding and Kangaroo Care (KC)**

- ♥ Kangaroo Care is a method of holding babies skin to skin – speak with your bedside nurse about when to start Kangaroo Care.
- ♥ Start with kangaroo care once a day, ask your bedside nurse to help.
- ♥ Baby will wear only a diaper, hat, and socks.
- ♥ Caregiver will be wrapped with a blanket while holding baby.
- ♥ Positioning:
  - Place the baby between the caregiver's breast/chest, upright, chest to chest.
  - Keep the head midline.
  - Hips flexed and in "frog" position, arms flexed.
- ♥ If your child is older but would still enjoy being held, please ask your bedside nurse how to best help you.

### **Schedule**

- ♥ Help your child establish a schedule.
  - Example: Sleep schedule
    - Opening blinds during the day.
    - Lower lights during nap times.
    - Lower lights in the evening.
    - Limit television and noise during rest times.
- ♥ We want to develop a routine or schedule with your child as you would at home.
- ♥ Examples of what a schedule will include; nursing cares, therapies your child is receiving, play times, quiet times.
- ♥ We will re-evaluate the schedule as needed, at a minimum of every two weeks.

Child life specialists, your bedside nurse, and your medical care team are all available to help promote developmental care while your child is hospitalized. The above information are suggestions. Feel free to ask your care team if you have additional questions or suggestions for your child's developmental care.

# The Heart Center

## Support and Resources

### Lodging

If you are not from the Dallas area, your social worker can help with finding lodging. Lodging options in the area include:

#### **Ronald McDonald House** **214-631-7354**

The Ronald McDonald House is a short-term lodging facility for families of out-of-town patients. The house has limited space available and accepts families based on space available. There is a cost of \$15 per night for a family of five. Please see your social worker for additional information.

#### **Open Arms Apartment**

Provides short term housing for families from out of town who need extended medical treatment in Dallas. Referral must be made by your social worker.

#### **Ark House**

Provides short term housing for families from out of town who need extended medical treatment in Dallas. A deposit is required and low cost rent. Referral must be made by your social worker.

#### **Nearby Hotels**

Some hotels offer discounted rates to families with a child at Children's. Please ask your social worker for a list of these hotels.

## Helpful Resources for Children with Congenital Heart Disease

#### **Congenital Heart Information Network (C.H.I.N.)**

**215-627-4034**

**[www.tchin.org](http://www.tchin.org)**

C.H.I.N. is an international nonprofit organization that provides reliable information, support services, and resources to families of children with congenital and acquired heart disease, adults with congenital heart defects, and the professionals that work with them.

#### **Family Advisory Board at Children's Dallas**

The Safe At Home Program started a parental advisory board in the spring of 2013. The purpose of this council is to enhance the program by partnering with families who serve as advisors, provide valuable insight and recommendation for improvement, as we strive to improve to develop a world-class safe at home program. Family names are submitted and rotated every two-three years. Currently the group meets every three months but may meet more if additional projects identified. Please speak with your social worker if you are interested in joining the advisory board.

#### **HopeKids**

**[www.hopekids.org](http://www.hopekids.org)**

HopeKids provides ongoing events, activities and a powerful, unique support community for families who have a child with a life-threatening medical condition. We surround these remarkable children and their families with the message that hope can be a powerful medicine.

# The Heart Center

## Support and Resources

### **Linked by Heart**

**[www.linked-by-heart.org/index.html](http://www.linked-by-heart.org/index.html)**

Linked by Heart is a collaborative effort between Sisters by Heart and additional HLHS mothers known as "Regional Coordinators." The Regional Coordinators are moms from across the nation who've walked in your shoes and want to help you locate other families in your same situation via Regional Facebook Groups and a searchable database for networking.

### **Mended Little Hearts**

**[www.mendedhearts.org](http://www.mendedhearts.org)**

**[www.facebook.com/pages/Mended-Little-Hearts-of-Dallas](https://www.facebook.com/pages/Mended-Little-Hearts-of-Dallas)**

Mended Little Hearts, a support program for parents with children with heart defects and heart disease, is dedicated to inspiring hope in those who care for the littlest heart patients. They offer resources and a caring support network, connecting families in crisis with other parents who have survived the shock of learning a child has a heart problem. Other services offered include: social events, accredited hospital visiting monthly, group meetings, and outreach packets.

### **NPC-QIC**

**<https://jcchdqi.org/parents>**

National Pediatric Cardiology Quality Improvement Collaborative focuses primarily on interstage morbidity and mortality.

### **Sisters by Heart**

**[www.sistersbyheart.org](http://www.sistersbyheart.org)**

An organization created by moms with children who have HLHS that strives to help new moms with newly-diagnosed babies. They provide care packages to make your stay in hospital a little easier. As well, provide information and links to many resources to help better your understanding of HLHS

## Financial Assistance

### **Catholic Charities of Dallas**

**214-826-8330**

**[ccdallas.org](http://ccdallas.org)**

### **East Texas Angel's Network**

**[www.easttexasangelnetwork.com](http://www.easttexasangelnetwork.com)**

A non-profit that wishes to help every child we can. We know that the parents bear the burden of children with special needs. Sometimes a billion dollars can't help, but we can give them a few moments. Application for financial assistance can be found on their website.

### **Ragan's HOPE**

**[www.raganshope.org](http://www.raganshope.org)**

Ragan's HOPE is committed to helping parents of children with serious ongoing medical conditions or injuries endure the initial impact and embrace the future, in the name of Christ.

### **Medicaid Transportation Program**

**877-633-8747**

Through the Medicaid program, families who are staying with their child in the hospital may be eligible for limited financial assistance for travel and/or meals. Please contact your social worker for information.

# The Heart Center

## Support and Resources

### Insurance and Supplemental Programs

- Programs are provided through the state and assistance is based on the income of your household and the financial need of the family.
- Please contact your Heart Center Social Worker for additional information
- Children's Financial Counseling Office (214-456-8640) assists in applying for Medicaid, CHIP, and CSHCN.

There are a variety of healthcare coverage options for children, such as the following:

#### **Medicaid (Managed Care Medicaid)**

**1-877-543-7669**

**[www.chipmedicaid.org](http://www.chipmedicaid.org)**

#### **CHIP (the Children's Health Insurance Plan)**

**1-877-543-7669**

**[www.chipmedicaid.org](http://www.chipmedicaid.org)**

#### **CSHCN (Children with Special Healthcare Needs)**

**1-800-252-8023**

**[www.dshs.state.tx.us/cshcn](http://www.dshs.state.tx.us/cshcn)**

#### **Insurance Marketplace through the Affordable Care Act**

**1-800-318-2596**

**[www.healthcare.gov](http://www.healthcare.gov)** (To get help from application, go to <https://localhelp.healthcare.gov>).

#### **ECI (Early Childhood Intervention)**

**1-800-628-5115**

ECI provides home therapy for children who have disabilities or developmental delays. Services are designed for children ages 0-3. Referrals can be made by a child life specialist or pediatrician's office. Once a referral has been made, ECI will contact your family to begin services as soon as possible. If you do not hear from the ECI office, please contact them yourself. The ECI therapist will work with the family to plan appropriate activities that will best serve the child. It is essential that your child receive ECI services to ensure that any delays are captured right away and an intervention can be implemented.

#### **Medicaid Buy In Program**

**1-877-541-7905**

**[www.hhsc.state.tx.us/help/healthcare/MBIC.shtml](http://www.hhsc.state.tx.us/help/healthcare/MBIC.shtml)**

Medicaid Buy-In for Children can help pay medical bills for children with disabilities. This program helps families who need health insurance, but make too much money to get traditional Medicaid. Families "buy in" to Medicaid by making a monthly payment (premium). To be in this program a child must be age 18 or younger; meet the same rules for disability that are used to get Supplemental Security Income (SSI), live in Texas, be a U.S. citizen or legal resident, and not be married.

# The Heart Center

## Support and Resources

### **HIPP (Health Insurance Premium Payment Reimbursement Program)**

**1-800-440-0493**

**[www.gethipptexas.org](http://www.gethipptexas.org)**

A Medicaid program that helps families pay for private health insurance. It's for families who have a parent or a spouse with private health insurance AND a child or a spouse with Medicaid. Medicaid will pay the family's private health insurance if the total cost of that insurance is less than the total cost of care with Medicaid. The total cost of the private health insurance includes the premium, coinsurance, and deductibles. If approved, Medicaid may pay the private health insurance costs for the entire family and not just for the family members who get Medicaid. The family will get services through the private health insurance plan.

### **SNAP (Supplemental Nutrition Assistance Program)**

**[www.yourtexasbenefits.com](http://www.yourtexasbenefits.com)**

Previously known as "Food Stamps." The program assists with food through the form of a Lone Star Card.

### **SSI (Supplemental Security Income)**

**1-800-772-1213**

**[www.ssa.gov](http://www.ssa.gov)**

SSI provides monthly assistance for children with disabilities. Eligibility is dependent on income and the number of individuals in your family, as well as the severity of your child's disability. If your child qualifies for SSI, he/she is also eligible for Medicaid benefits.

### **Institutional SSI (Supplemental Security Income)**

If your child has been in the hospital for more than 30 days, he/she could be approved depending on length of stay and diagnosis for SSI and Medicaid. You must apply for Institutional SSI prior to discharge to be eligible. Children's Financial Counseling Office can assist with the initial application.

### **TANF (Temporary Assistance for Needy Families)**

**[www.yourtexasbenefits.com](http://www.yourtexasbenefits.com)**

Temporary Assistance for Needy Families (TANF) provides financial help for children and their parents or relatives who are living with them. Monthly cash payments help pay for food, clothing, housing, utilities and other basic needs for up to 5 years. The amount of the TANF payment depends on family size and household income.

### **WIC (Women, Infants and Children)**

**1-800-942-3678**

Program provides nutrition counseling, food, and referrals to health and social service.

WIC serves pregnant women, breastfeeding mothers, women who have had baby in the past 6 months, and children under the age of 5.

# The Heart Center

## Support and Resources

### Community Care for Children with Special Health Care Needs

The Texas Department of Aging and Disability Services provide community based services so that children with disabilities can remain in their own homes and communities. Some of these services are based on the family's income and others are based on the child's income and assets. Services for which your child may be eligible include:

#### **In-home and Family Support**

**1-877- 438-5658**

**[www.dads.state.tx.us](http://www.dads.state.tx.us)**

Provides a direct grant benefit to allow families to purchase services that enable their child to live in the community- Individual must be at least age 4, must have a physical or mental disability that limits independent function, fee for services are based on a sliding scale, and there is a waiting list. Funding is provided for a variety of services and supports, such as lease of special equipment, home modifications, attendant care, and costs of specialized child care.

#### **Primary Home Care**

A non-technical medically related personal care service that is available to eligible children whose health problems cause them to be functionally limited in performing activities of daily living. Individual must be eligible for Medicaid. This program offers attendant type services such as assistance with bathing, dressing, feeding, meal preparation, toileting and helping with self-administered medication.

#### **Home and Community-Based Services (HCS)**

**[www.dads.state.tx.us/contact/la.cfm](http://www.dads.state.tx.us/contact/la.cfm)**

HCS provides services to individuals with intellectual and developmental disabilities. Individuals must have an IQ below 70 or a related condition that results in deficits in adaptive behavior with a full scale IQ of 75 or below. As well, HCS provides community-based services to people who live with their families, live in their own homes, who live in a foster/ companion care setting or in a residence with no more than 4 people. Program has lengthy waiting list.

#### **Community Living Assistance and Support Services (CLASS)**

**1-877-438-5658**

**[www.dads.state.tx.us/contact/DADSServicesByCounty.html](http://www.dads.state.tx.us/contact/DADSServicesByCounty.html)**

CLASS provides services to individuals in their own home or their family's home. CLASS is for individuals who have a qualifying disability, other than an intellectual disability, which originated before age 22 and which affects their ability to function in daily life. Program has lengthy waiting list.

#### **Medically Dependent Children's Program (MDCP)**

**<http://www.dads.state.tx.us>**

The program provides services to support families caring for children and young adults who are medically dependent and to encourage de-institutionalization of children in nursing facilities. Provides service such as respite care, home modifications adaptive aids, and support to enable children to participate in childcare.

#### **Deaf Blind with Multiple Disabilities (DBMD)**

**1-877-438-5658**

**[www.dads.state.tx.us/contact/DADSServicesByCounty.html](http://www.dads.state.tx.us/contact/DADSServicesByCounty.html)**

DBMD provides services for individuals who are 18 years or older and who have legal blindness; a chronic, severe hearing impairment; or a condition that leads to deaf-blindness and a third disability that results in impairment to independent functioning.



# The Heart Center

## Support and Resources

### Child Care Assistance Programs

**Child Care Group: Dallas County**  
**214- 630-5949**  
[www.childcaregroup.org](http://www.childcaregroup.org)

**Texas Workforce Commission:**  
**800) 234-9306**  
[www.dfwjobs.com](http://www.dfwjobs.com)

For other Counties: Collin, Denton, Ellis, Erath, Hood, Hunt, Johnson, Kaufman, Navarro, Palo Pinto, Parker, Rockwall, Somervell and Wise

### Medically Fragile Child Care

**Bryan's House**  
**214-559-3946**  
[www.bryanshouse.org](http://www.bryanshouse.org)  
3610 Pipestone Road, Dallas, Texas 75212  
**214-941-0892**  
802 S. Beckley Avenue, Dallas, Texas 75203

**Children's Choice Learning Centers, Inc.**  
**972- 881-1900**  
[www.childrenschoice.com](http://www.childrenschoice.com)  
Locations in Dallas, Arlington, Irving, Lewisville, Richardson

**Pediatrics Plus**  
**214.687.9374**  
[www.pediatricsplus.com](http://www.pediatricsplus.com)  
Located in Frisco, Texas. Developmental preschool that provides a natural classroom environment for children integrated with typical peers, but with the added benefit of skilled teachers, therapists, behavior specialists, and/or registered nurses available to work within and alongside the classroom structure.

# The Heart Center

## Support and Resources

### Helpful Websites

#### **CaringBridge**

**[www.caringbridge.org](http://www.caringbridge.org)**

CaringBridge websites offer a personal and private space to communicate and show support, saving time and emotional energy when health matters most. Learn more about creating your own website that gives recognition to Graham's Foundation.

#### **Grief Works**

**[www.grief-works.org](http://www.grief-works.org)**

GriefWorks helps children ages 5–18 and their families grieve the loss of a loved one in a way that brings them closer to answers they are seeking, rather than leaving them stuck in their grief journey and closer to others, rather than becoming relationally isolated. They foster a place of healing and peace, rather than sliding into depression, anger, or other emotional traps that can occur when grief is not dealt with

#### **Jewish Family & Children's Service Fragile Beginnings**

**[www.jfcsboston.org](http://www.jfcsboston.org)**

Fragile Beginnings is a network of initiatives committed to improving the lives of parents of premature infants through direct support services, educational materials, and connections to community resources and to each other. We are guided by the principle that the families of preemies strongly benefit from parenting support beginning in the hospital, during their transition home, and throughout their preemie's developmental years.

#### **March of Dimes**

**[www.marchofdimes.com](http://www.marchofdimes.com)**

Our mission is to improve the health of babies by preventing birth defects, premature birth, and infant mortality. They carry out this mission through research, community services, education and advocacy to save babies' lives. March of Dimes researchers, volunteers, educators, outreach workers and advocates work together to give all babies a fighting chance against the threats to their health: prematurity, birth defects and low birth weight.

#### **Navigate Life Texas**

**[www.navigatelifetexas.org](http://www.navigatelifetexas.org)**

An online resource for families and parents to find the resources and services they need to support children with disabilities or health-care needs.

#### **Parent to Parent**

**[www.txp2p.org](http://www.txp2p.org)**

TxP2P empowers families to be strong advocates through parent-to-parent support, resource referral, and education. The heart of TxP2P is the parent-to-parent peer support model—parents volunteering to provide support and information to other parents. The parent-to-parent model has been developed by and for parents to address the powerful emotions, new responsibilities, stress and isolation that parents and families face in caring for a child with special health care needs..

#### **The Texas Low Income Home Energy Assistance Program**

**[www.tdhca.state.tx.us/ea/index.htm](http://www.tdhca.state.tx.us/ea/index.htm)**

Can help you pay winter heating bills and medically necessary summer cooling bills.

# The Heart Center

## Support and Resources

### Information on Post-Partum Depression

Dear New Mom,

"Sometimes, reaching out and taking someone's hand is the beginning of a journey. At other times, it is allowing another to take yours." ~Vera Nazarian

One of the most misunderstood parts of motherhood is the emotional roller-coaster you are on right after giving birth. It can feel like everyone expects you to be settling in and staring happily at your bundle of joy. Having a baby is both fantastic and exhausting. Pregnancy and childbirth is an enormous physical and hormonal undertaking and you may have a difficult time adjusting to life afterward. There are many changes that happen after childbirth and that can make finding stability and a routine difficult. You may also experience sleep deprivation and worry about your child being hospitalized in the Heart Center. You may not feel like yourself for a while and we want you to know are not alone. Negative emotions can happen during a time that is "supposed to be" wonderful. This can be confusing to you and those around you. Many women think there must be something wrong with them, assuming they "should" feel happy. Often feelings of guilt, shame, and the need to put on a happy face prevent women from reaching out to tell anyone how they really feel. Good emotional health during pregnancy and your baby's infancy is very important. It is brave to reach out. It is smart to reach out if you feel negative emotions like these:

- Episodes of crying
- More sensitive than usual
- Irritability (or even rage), triggered by really minor stuff
- Constant fear of something bad happening to your baby
- Lack of emotion toward your baby

Recognizing your need for support, counseling, and/or medication is a reflection of your strength. You do not have to go through this alone. We are here to listen to your story, cheer you on, and empower you.

If you have concerns about post-partum depression or would like to complete a post-partum depression screening, please contact your Heart Center Social Worker or a member of your treatment team.

### Post-Partum Websites and Support Groups

#### **Dallas Association for Parent Education**

**972-699-0420**

**[www.dallasparents.org](http://www.dallasparents.org)**

777 S. Central Expressway, Suite 1-T, Richardson, Texas 75080

#### **Mental Health Association of Greater Dallas (Depression Support Group)**

**214-871-2420**

**[www.mhadallas.org](http://www.mhadallas.org)**

624 N. Good-Latimer, Ste. 200, Dallas, Texas 75204

#### **Post-Partum Support International**

**English: 1-800-944-4773 (4PPD)**

**Spanish: 1-800-944-4773, Option 1**

**<http://www.postpartum.net>**

# The Heart Center

## Transitioning to Adulthood

It can be difficult to imagine your tiny newborn growing into an adult, but it will happen before you know it! We encourage our families to begin to develop a plan for their child's adult health care before they turn 18. We recommend that our families develop a plan for their child's adult health care before your child turns 18 years old. In order to make sure that there is not a lapse in your child's medical care, you will need to determine what kind of health insurance coverage he/she will have as an adult.

- CHIP and/or Medicaid coverage ends when your child turns 19 years old, unless your child is severely disabled and continues to receive SSI and Medicaid as an adult.
- Children's with Special Health Care Needs (CSHCN) ends when a child turns 21 years old.

You are not alone in this process and your child's Pediatric Cardiologist will help your child transition to an adult health care provider. It's also very important that you learn about different adult primary care providers and specialists (such as Cardiologist, Gastroenterologist, or Pulmonologist).

- **Specialized adult care:** As an adult with congenital heart disease, you have unique needs that may not be well understood. We are able to help you get the specialized care you need. If you have problems getting specialized care, we can help with that too!
- **Team approach:** We want you to work with a team of specialists in pediatric and adult cardiology. They will work together to develop a treatment plan to fit your individual needs. You may receive treatment at Children's, Parkland, UTSW Clements Hospital, or Baylor based on what is best for your condition.
- **Expert surgeons:** You can relax knowing that if you need surgery at Children's Health, we are ready to care for you.
- **Experience:** We have a high degree of experience caring for adults. In fact, nearly 15 percent of the 1,000 cardiac catheterization procedures we perform every year are on adult patients.
- **Care that meets your needs:** Not every adult with a congenital heart defect needs care at Children's. If you are at low risk for complications we help transition you to an adult care practice. We will work with your cardiologist to discuss your needs and let you know what to expect. You can always come back to Children's if your condition changes.
- **We care for all your needs.** The Adult Congenital Heart Defect Team includes social workers, financial counselors and Advanced Practice providers who can help plan for non-medical needs, such as transportation and financial assistance.

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## Notes

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