

# PEDIATRIC HEART TRANSPLANT GUIDE



Carolinus HealthCare System  
Levine Children's Hospital

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# WELCOME

Welcome to Levine Children’s Hospital. Thank you for choosing us to care for your child. Through our Pediatric Heart Transplant Program and the Ricky Hendrick Centers for Intensive Care, we offer full pre- and post-transplant inpatient and outpatient services. We can help you and your child get the medical and emotional support and services that you need during this time.

At Levine Children’s Hospital, our focus is on creating a welcoming, warm, comfortable and family-centered environment for your child to get better. In addition to our medical areas, we also have a:

- Parent lounge
- Family library
- Playroom
- Family consult room

If you have any questions or need anything during your journey with Levine Children’s Hospital, please contact us. We look forward to helping your child have a healthy future.

## About the Handbook for Patients and Families

This handbook is meant to help you learn more about heart transplants. It can help you explore the best options for your child. It also contains information about resources that can help you.

This handbook should not replace instruction given to you by your child’s healthcare team. It is not meant to be medical advice or a complete resource for all information on this subject. Your child’s doctor is the best source of information about what is right for your child’s treatment. If you have any questions about this handbook, please ask the Levine Children’s Hospital heart transplant team.

Words in *italics* can be found in the Glossary (page 48).

**In case of an urgent concern or emergency, call 911 or go to the nearest Emergency Department right away.**

# IMPORTANT PHONE NUMBERS

HEART TRANSPLANT TEAM	704-355-8092
ON-CALL HEART TRANSPLANT COORDINATOR	704-355-6649
BUSINESS OFFICE	704-355-0938
HEART TRANSPLANT SOCIAL WORKER	704-355-8092
CLINIC APPOINTMENTS	704-373-1813
FAMILY RESOURCE LIBRARY	704-381-2100
CHAPEL AND CHAPLAIN	704-381-2150
BLOOD DRAW/LAB	704-381-3125
CHILDREN'S EMERGENCY DEPARTMENT	704-355-6580
RADIOLOGY	704-381-3100
SURGERY CENTER	704-381-5200
DAY HOSPITAL	704-381-5100
PEDIATRIC INTENSIVE CARE UNIT (PICU)	704-381-6100
CARDIOVASCULAR INTENSIVE CARE UNIT (CVICU)	704-381-6200
NEONATAL INTENSIVE CARE UNIT (NICU)	704-381-7905
NEONATAL PROGRESSIVE CARE UNIT	704-381-7100
PEDIATRIC PROGRESSIVE CARDIOLOGY, NEUROLOGY, AND RENAL	704-381-8100

*\*All transplant questions should be addressed by the heart transplant team.*

# GENERAL INFORMATION SHEET

Child's Name \_\_\_\_\_

Medical Condition \_\_\_\_\_

## Your Child's Transplant Team

Please write down the name and phone number of each person you meet. Ask them how to spell their names and what they do.

### Transplant Surgeon

The doctor who performs the heart transplant surgery and is in charge of your child's care in the hospital following the transplant. The transplant surgeon, along with the **cardiologists** (heart doctors), follows your child's progress after discharge.

### Cardiologist

The doctor who often manages your child's care before and after a transplant. The cardiologist also performs routine heart biopsies and other tests and monitors your child's care after the transplant.

### Anesthesiologist

A medical doctor who monitors your child during surgery. Your child will be given a special medication (**anesthesia**) that allows him or her to be in a deep sleep so he or she cannot see, hear or feel anything, not even pain.

### Transplant Coordinator/Nurse Practitioner

A registered nurse who helps you and your family arrange your child's care and treatment before and after a transplant. The coordinator will: help take care of your child before, during and after a transplant; follow your child's progress in the hospital and during each outpatient visit after discharge; help answer your questions; and provide support to you and your family. A coordinator is available to you 24 hours a day for urgent problems.

### Intensive Care Unit (ICU) and Patient Floor Nurses

Registered nurses who care for your child while in the Intensive Care Unit (ICU) and on the patient floor. They will assist with monitoring your child's recovery and help plan for discharge from the hospital. These nurses are specially trained to care for transplant patients. They monitor your child's day-to-day progress and teach you how to care for your child's incision, give medicines and manage nutritional issues.

### Respiratory Care or Respiratory Therapists

Clinical staff who help your child with his or her breathing. They give breathing treatments and monitor how your child breathes.

### Registered Dietitians/Nutritionists

Clinical staff who will see your child before and after his or her transplant to evaluate diet and growth. Many children with heart disease are not able to maintain their weight. After the transplant, eating the right types of food is very important. A nutritionist can help with these issues.

### Transplant Pharmacist

A pharmacist who has special training with transplant medicines. This person arranges for your child's medicines, teaches you what you need to know about them and helps with research studies.

### Psychiatric Clinical Nurse Specialists/Child Psychiatrists

Medical professionals who assess your child and family's coping skills and patterns before transplant. They can also help with ongoing support and counseling after surgery.

### Child Life Specialists

Clinical staff who help you, your child and your family learn about why your child is in the hospital. They provide activities and services that allow your child to deal with the experience in ways that are healthy for his or her age. The child life specialist can: offer a hospital tour so your child can become familiar with the hospital; prepare your child before and after surgery; and answer questions your child might have about the surgery.

### Social Workers

Healthcare professionals who help patients and families deal with all aspects of a heart transplant including the pre-transplant waiting time, the hospital stay, discharge and aftercare. They help provide guidance, counseling and coping skills for you and your family. Social workers help you get the services and resources you and your child need while in and out of the hospital.

### Physical Therapists

Clinical staff who are specially trained to help your child with exercises to make him or her stronger before and after transplant. Physical therapists can also teach you what you can do at home to help your child regain strength. Exercise is important to reduce complications after transplant surgery, improve endurance, and maintain a healthy lifestyle.

### Chaplains

Chaplains help meet your family's spiritual needs. A chaplain can work with your pastor or religious leader to provide needed spiritual support. Hospital chaplains also conduct interfaith services in the hospital chapel at Levine Children's Hospital.

### School Program Teachers

Hospital staff who are certified teachers. They help your child keep up with schoolwork so the transition between hospital, home and school will be easier. The schoolroom is located at Levine Children's Hospital.

### Transplant Financial Counselors

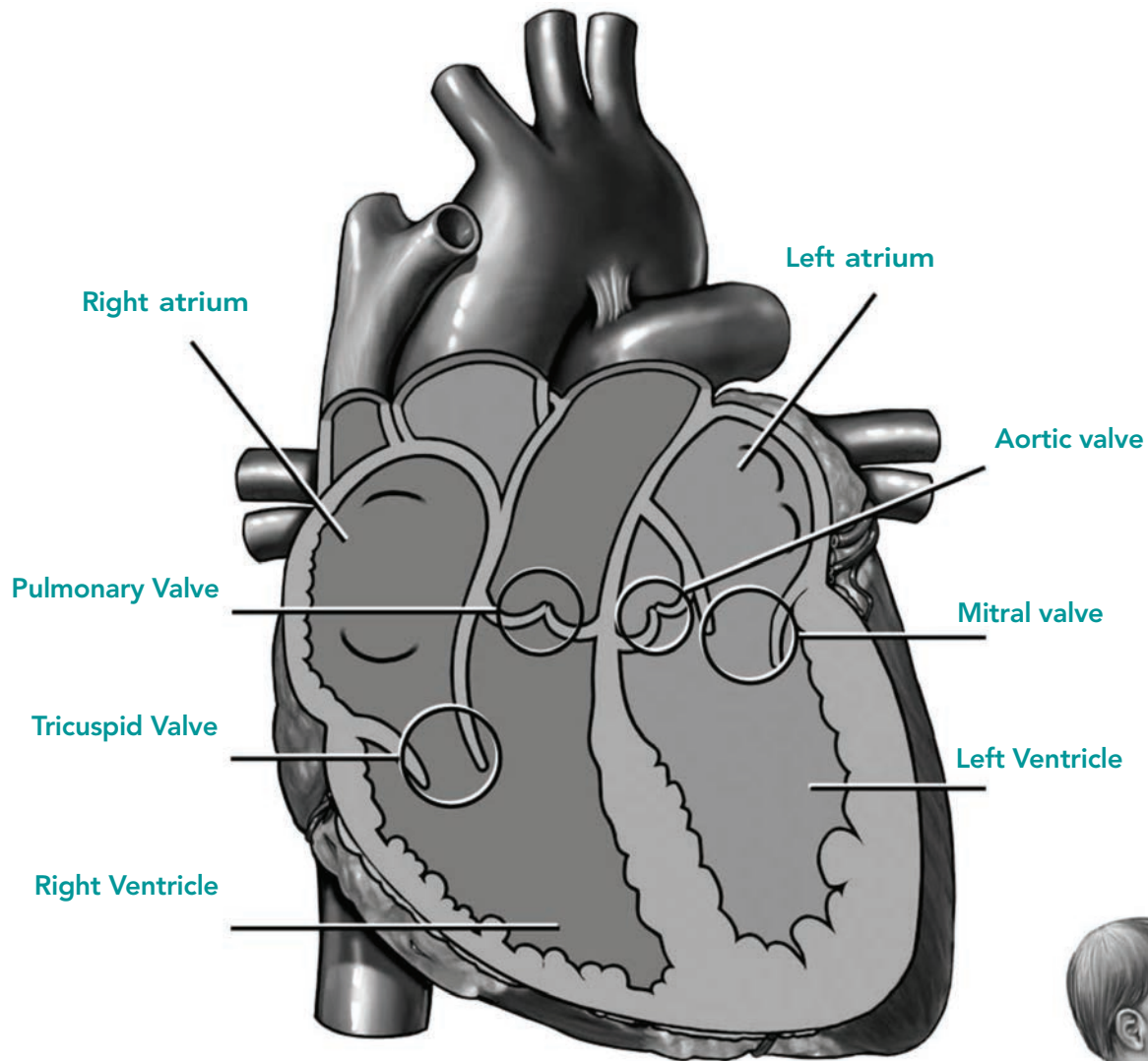
Financial counselors help you learn about your insurance plan and how to reduce your family's out-of-pocket expenses for your child's care. A financial counselor can help your family set up a long-term payment plan, if needed.

# WHAT IS THE HEART?

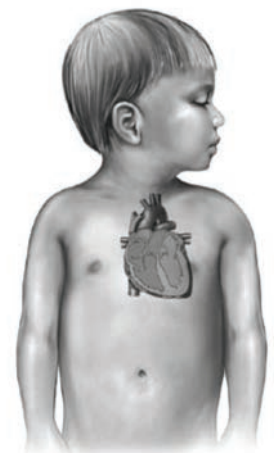
The heart is a muscular organ in the middle of the chest. A child's heart is about the size of his or her fist. The heart has four chambers:

- The two upper chambers are the *right atrium* and the *left atrium*.
- The two lower chambers are the *right ventricle* and the *left ventricle*.

The heart is separated lengthwise into the right and left sides by a wall called the *septum*. Four one-way *valves* control the flow of blood through the heart.



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# WHAT DOES THE HEART DO?

## STEP 1

Blood comes to the right side of the heart through two large veins, the *superior vena cava* and the *inferior vena cava*. This is blood that has been “used” by the body. It contains very little oxygen and also contains “waste” in the form of carbon dioxide.

## STEP 2

The blood then passes through the tricuspid valve to the *right ventricle*. From here, it is pumped out through the pulmonary valve and pulmonary artery to the lungs.

## STEP 3

In the lungs, the carbon dioxide is removed from the blood. It is exchanged for oxygen that has been breathed in through the nose and mouth.

## STEP 4

The oxygen-rich blood leaves the lungs and returns to the *left atrium* through the pulmonary veins. This process is called *pulmonary circulation*. The word “pulmonary” means of or relating to the lungs.

## STEP 5

Blood flows from the *left atrium* through the mitral valve into the *left ventricle*. The *left ventricle* is a thick, powerful muscle.

## STEP 6

The *left ventricle* pumps oxygen-rich blood through the aortic valve to the aorta and out through the body. This is the way your child’s body and all of its organs receive blood and oxygen.

The heart repeats this cycle of receiving and pumping blood to your child’s body many times a minute. This is called the heart rate or “pulse.”

Just as your child’s tissues need oxygen-rich blood for energy, his or her heart needs its own blood supply for energy. The *coronary arteries* are blood vessels that wrap around the heart and supply it with oxygenated blood.

# WHY YOUR CHILD MAY NEED A HEART TRANSPLANT

## What Happens When the Heart Fails?

When the heart fails, your child may have some of these symptoms:

- Feeling weak or tired
- Trouble breathing or shortness of breath
- Poor appetite
- Weight gain
- Swelling
- Sweating

## Common Causes of Heart Failure

MEDICAL NAME	WHAT THIS MEANS
<b>Congestive heart failure</b>	<p>Normally, the heart is very strong and can pump oxygen-rich blood to all parts of the body.</p> <p>When the heart becomes weak and cannot pump enough blood to the body, fluid can back up into the lungs, liver and legs.</p> <p>Some children are born with healthy hearts that become weak for reasons we do not always understand .</p>
<b>Cardiomyopathy</b>	<p>Sometimes the heart becomes weak in babies and sometimes much later in life. This problem is called <b>cardiomyopathy</b>, or a weak and enlarged heart muscle.</p> <p>There is no surgical treatment for <b>cardiomyopathy</b>. A transplant may be needed if medication do not improve the heart's function.</p> <p>Some children are born with heart disease that weakens their heart.</p>
<b>Congenital heart disease</b>	<p>There are many types of <b>congenital</b> (present at birth) heart disease. The transplant team will discuss your child's heart condition with you and will also discuss treatment options. Surgery may be able to repair the heart defect or reroute the blood flow so the heart can pump blood and oxygen to the body.</p> <p>A transplant may be needed if the heart muscle becomes weak in spite of medication and surgery.</p>



# STEPS FOR YOUR CHILD'S HEART TRANSPLANT

Your child's doctors will consider a heart transplant when neither medication nor other procedures can keep your child healthy.

## What are the Steps for Your Child's Heart Transplant?

The Levine Children's Hospital heart transplant team will discuss each step with you, your child and your family.

**STEP 1** Your child's doctor refers him or her to Levine Children's Hospital. Your child's doctor must state your child's need for a transplant.

**STEP 2** Our financial counselors obtain financial approval for your child's pre-transplant evaluation and for the transplant.

**STEP 3** Once we receive financial approval, we will call you to schedule a pre-transplant evaluation date. A pre-transplant evaluation is a series of tests. These tests help the heart transplant team decide if a transplant is the best option for your child. The transplant team will help you to understand your child's options.

**STEP 4** Your child will have a pre-transplant evaluation at Levine Children's Hospital. This is usually a one- or two-day process done either as an outpatient visit or while your child is in the hospital.

**STEP 5** Based on the evaluation, the heart transplant doctors and team will decide if a transplant is the best option for your child.

If a heart transplant is an option for your child, your child's name is placed on the **United Network for Organ Sharing (UNOS)** waiting list.

**STEP 6** Your child waits to be matched with a heart from the UNOS list.

**STEP 7** Your child has heart transplant surgery. He will stay in the hospital for about 10 to 14 days.

**STEP 8** Your child will receive follow-up care at Levine Children's Hospital.



# YOUR CHILD'S PRE-TRANSPLANT EVALUATION

## What is a Pre-Transplant Evaluation?

The pre-transplant evaluation is a series of tests that helps doctors decide if a heart transplant is the best option for your child.

- The heart transplant coordinator will schedule your child's evaluation. This will be done at Levine Children's Hospital either as an outpatient visit or while your child is in the hospital.
- The coordinator will schedule tests and meetings with the heart transplant team during your visit. They will work closely with you during the entire process.
- Please plan to stay for the entire one or two days of evaluation.

## How Can Your Family Prepare for the Evaluation?

To help ensure that the pre-transplant evaluation goes as smoothly as possible:

- Bring a copy of your insurance benefits and insurance identification (I.D.) card. Also bring your deductible and co-payment amounts. [See Page 43: Finances and Insurance]
- Your child must have a pediatrician. Bring the doctor's name and phone number to the evaluation.
- Arrive on time. If you and your child are late, we may need to reschedule the visit.
- Please leave other young children and siblings at home. Your focus needs to be learning about the transplant. We do want your family to take part in follow-up clinic visits.
- Call your pediatrician to make sure that your child's immunization (shot) records are up-to-date. Please bring a copy of the immunization record with you.
- Bring any of your child's medical records that you may have.
- Write a list of questions to ask the team. Share your concerns and fears with them.

## What Happens During Your Child's Evaluation?

During the evaluation, your child will undergo many tests and procedures that may include:

1. A routine medical exam. This includes your child's height and weight, blood pressure, review of the medical history, including family history and any surgery your child had in the past. Bring the following items with you:
  - A written record of your child's medical history—have it ready before you come to the evaluation to share with the doctors
  - Your child's medication and a medication list
  - A list of questions you have about your child's transplant or evaluation
2. Blood tests that check your child's:
  - Blood type – this test checks your child's blood type to see if it is A, B, AB or O
  - Tissue type markers for organ matching
  - Blood counts, such as red and white blood cell counts
  - Blood chemistry to check **electrolytes** and other organ function
  - Blood for viruses
3. Urine tests to make sure your child's kidneys are working well.
4. **Pulmonary function tests** (breathing tests), if your child is old enough, to check the function of the lungs.
5. An **echocardiogram** (ECHO) to look at the heart's structure and see how well the heart is pumping.
6. A **cardiac catheterization** (cardiac cath) to measure the pressures inside your child's heart.
  - This is another way to look at the heart's structure and see how well it is working.
  - The cath may also include a **biopsy** of your child's heart to gather more information about your child's heart disease.

# WAITING FOR A TRANSPLANT

## The Waiting List

If you, your child and the transplant team decide that a heart transplant is the best option, the next step is to place your child on the waiting list for a donor heart.

UNOS (United Network for Organ Sharing) is the national agency that oversees organ transplant. This agency works with our local procurement agency, Lifeshare of the Carolinas, to recover organs. UNOS also maintains the national computerized list of people waiting for heart transplants.

Once your child's evaluation is done and a decision has been made to move forward, the heart transplant coordinator will place your child on the waiting list through the UNOS secure website.

Your child will be listed as a Status 1A, Status 1B or a Status 2 on the heart transplant waiting list.

- Status 1A patients are the most critical. They are in a hospital intensive care unit (ICU) with breathing support or on one high-dose or multiple low dose *intravenous* medication to help their hearts work better. Children younger than 6 months old with certain heart conditions are also Status 1A.
- Children younger than 6 months old who do not meet the criteria for a Status 1A will be listed as a Status 1B.
- Status 1B patients need low doses of *intravenous inotropic drugs* (heart medication that temporarily improve heart function) or they will have growth failure due to their heart disease.
- Status 2 patients are on the active list for heart transplant, but do not meet the standards for Status 1A or 1B.
- Status 7 patients who have been 1A, 1B, or 2 who are temporarily inactivated. Patients can be temporarily inactivated from the transplant list for several reasons, for example they can be too well or too sick for transplant.

## How Does the UNOS Donor Matching Process Work?

*US heart allocation policy is based on medical urgency, waiting time, blood group compatibility and geography.*

1. A heart is donated from a person who has just died.
2. The donor's medical information is put into the UNOS database.
3. UNOS notifies Levine Children's Hospital that a heart is available.
  - A donor heart will be offered to regional Status 1A and 1B candidates. The heart goes to the patient in the highest priority group who has waited the longest.
  - If there are no matching candidates, the donor heart will be offered to Status 2 candidates. The heart will go to the patient who has waited the longest on the transplant list.
4. The transplant surgeon and team review whether to accept or decline the organ. This is based on whether the heart is a good match for your child.
5. The transplant coordinator calls you when a heart that is a good match for your child is available.
6. To understand how patients are matched on the national waiting list:
  - Think of the list as a "pool" of patients.
  - When an organ is available, UNOS searches the entire "pool" for a match.Other factors include:
  - Location of the heart and the child.
  - Amount of time the child has been on the waiting list.
  - Size of the child.
  - Blood type: your child can receive a heart from a person with the same or with a compatible blood type. The four blood types are O, A, B and AB.

## About the Donor

Families often want to know the age of the donor and how the donor died. Information about the donor is not able to be shared. Likewise, information about you and your family will not be given to the donor's family without your consent. You may write a letter to the donor's family. If you write a letter, a transplant coordinator will send it to Lifeshare of the Carolinas. They will then forward it to the donor family.

# IMPORTANT QUESTIONS

You should be able to answer the questions below after meeting with the heart transplant team. Please ask the team to explain anything you do not understand.

## Questions to Ask the Transplant Team

What are the reasons for a transplant?

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What are the risks and alternatives (other kinds of treatment) of a transplant?

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How long is the transplant process from beginning to end?

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Questions that haven't been answered yet:

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Notes:

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# PREPARING FOR YOUR CHILD'S TRANSPLANT

## While You Wait

Here are some simple steps you and your family can take while your child waits for a transplant:

### Stay in touch and be ready at all times.

- Make sure the transplant coordinator can reach you at all times. Provide school, work, family and vacation phone numbers. This ensures that the transplant team can contact you right away.
- Tell us if your phone number or address changes. If we can't make contact, the heart will be given to another patient waiting for a transplant.
- Contact the transplant financial counselor if your family has a change in work status or insurance coverage.

### Have a plan to get to the hospital the day of the transplant. The transplant coordinator will tell you when your child must arrive at Levine Children's Hospital.

- Make sure your vehicle is working well and is ready for your trip at any time.
- Have a plan for family or friends to take care of other children and siblings during the transplant.

### Make sure your child is ready.

- Make sure the transplant team is aware of any changes in your child's health.
- Report all infections. The transplant may be canceled if your child is sick.
- If your child becomes ill, get treatment right away. This helps ensure he or she will be ready for the transplant when a donor heart is ready.

### Help your child get in good physical shape for the transplant.

- Have your child eat healthy foods as allowed by his or her diet guidelines. Keep him or her as active as possible.
- Spend time with your child. Talk with him or her about the transplant. Let him or her express feelings, fears or concerns. Let him or her ask questions and be truthful with your answers. The transplant team will be happy to help you if concerns or questions arise.
- Keep your child in school and involved in activities, if possible. Try to keep your child's routines normal and balanced.

## When the Call Comes

The transplant coordinator will call you when UNOS finds a donor heart. When the call comes, your child must get to Levine Children's Hospital as quickly and safely as possible.

- When you receive the call, plan to leave your house within 30 minutes. Your child should stop eating and drinking so his or her stomach will be empty. Make sure your child takes all medication as prescribed to prevent problems. It is OK to swallow small sips of water with his or her medication.

Bring the following with you to the hospital:

- A list of your child's medication
- All of your child's medication in original bottles
- A list of drug allergies
- Your child's health information
- Your health insurance card



## Transportation

You need to get to the hospital as quickly and safely as possible, sometimes in less than three hours. If you live far from Charlotte, you and your family should be ready to fly here for the transplant if needed.

The surgeon will decide whether you should drive or fly to the hospital on the day of the transplant. The transplant coordinator and social worker will help you set up air transportation with an air ambulance company that is available 24 hours a day.

If your insurance company does not cover the flight, you must pay for it. Please talk to your insurance carrier about how to make these arrangements.



# THE TRANSPLANT SURGERY

## Your Child's Heart Transplant

**STEP 1** When a donor heart is ready, the transplant coordinator will call you at home to let you know about a potential organ donor. If no one is home, you will be paged or called on your cell phone. Be sure to call us back as quickly as you can.

- You will be asked if your child has had any recent illnesses or currently has fever, diarrhea or vomiting. We will tell you when you and your child need to be at the hospital. You and your child must be able to leave your house within 30 minutes of our call, so make sure your vehicle is working well at all times.

*Note: Do not give your child anything to eat or drink after we call your child in for the transplant.*

**STEP 2** The transplant coordinator will tell you where to report. You will go either to admissions or to the Emergency Department to check-in.

**STEP 3** Your child will be admitted and staff will direct you to your child's room. He or she will then be prepared for surgery.

**STEP 4** The heart transplant team will do a medical review of your child in the next few hours that might include:

- A complete history and physical exam
- A review of your child's current medication – please have a complete list of all medicines your child is taking
- A review of any health problems that your child has had lately such as a sore throat, cold, ear infection, rashes, cold sores or contact with people who have infections
- A chest X-ray
- Blood work (blood tests)

*Note: If your child is sick or if an emergency occurs, your child's surgery may be canceled.*

**STEP 5** The **anesthesiologist** will come to your child's room to discuss his or her allergies and types of **anesthesia**. An **anesthesiologist** is a medical doctor who monitors your child during surgery. **Anesthesia** is medicine that allows your child to be in a deep sleep so he cannot see, hear or feel anything, not even pain.

**STEP 6** The transplant surgeon will come and talk to you about your child's surgery. You will be asked to sign a consent for surgery after the transplant surgeon has explained the operation and its possible risks.

**STEP 7** The transplant surgery will take place.

- The surgery may take from four to six hours. If your child has had previous heart surgeries, the operation may take longer.
- During surgery, there is a room for you and your family to wait.
- The transplant coordinator, an operating room (OR) nurse or a child life specialist will give you updates about your child.
- The surgeon will talk to you after your child's surgery.
- If you need to leave the hospital, please tell your coordinator. Be sure to leave a number where you can be reached.

**STEP 8** Right after your child's surgery, he will go to the Ricky Hendrick Centers for Intensive Care Cardiac Intensive Care Unit on the 6<sup>th</sup> floor of Levine Children's Hospital.

**STEP 9** After a few days, your child will be taken to Progressive Care on the 8<sup>th</sup> floor of Levine Children's Hospital.



# AFTER THE TRANSPLANT

## In the Hospital

### 6<sup>th</sup> floor – The Ricky Hendrick Centers for Intensive Care Cardiovascular Intensive Care Unit (CVICU)

After surgery, your child will go to the CVICU on the 6<sup>th</sup> floor of LCH.

- Your child will be sleepy from the *anesthesia* (a medicine that puts your child to sleep during surgery).
- I.V.s (small, plastic tubes that provide fluids and medicine through his or her veins) and drainage tubes will be connected to your child. A *ventilator* will also be attached to your child. The *ventilator* will breathe for your child until he or she wakes up from *anesthesia*.
- Your child will not be able to talk while on the *ventilator*.
- Once your child wakes up and can breathe on his or her own, the breathing tube will be removed and your child will be able to speak.
- Your child may stay in the CVICU for two to three days.
- The heart transplant team and the CVICU staff will take care of your child after surgery.

### 8<sup>th</sup> floor – Progressive Care

After a few days, your child will be taken to the 8<sup>th</sup> floor of Levine Children's Hospital.

- The nurses and staff will help your child recover and prepare him or her to go home.
- Your child can usually go home seven to 14 days after surgery.
- The transplant coordinator and nursing staff will teach you how to care for your child at home.

### Guidelines for Visiting the CVICU and Progressive Care

- Wash your hands each time you enter and leave your child's room.
- Tell your child's nurse if any visitors are sick. The nurse will give them protective clothing to help keep your child healthy and prevent infections.
- Due to limited space, only two visitors at a time are allowed in the CVICU.
- While on the 8<sup>th</sup> floor, please stay in your child's room when doctors do daily rounds. Rounds are times when doctors, nurses and the transplant team talk about the care of your child. Your child's nurse will tell you when the doctor will make rounds.
- It is best to stay with your child at all times. A family member or friend who is at least age 18 is allowed if the parent cannot stay.
- One parent can stay in the room with your child overnight. Your social worker can help you arrange rooms for other family members.
- Child visitors less than age 12 must be with an adult at all times.

### Taking Care of You and Your Family

The heart transplant team knows you have a great need to be near your child during the hospital stay. We also know that it is easy to become tired from worry or lack of restful sleep.

This means you should take regular breaks, eat well and get plenty of rest. You will be better able to make decisions for your child. Please let us know if there is anything that we can do to help you.

### Getting Ready to Go Home

Taking your child home with a new heart can be very stressful. The transplant coordinator and team will help prepare you for discharge. They will give you information to help care for your child at home.

# COMPLICATIONS AFTER TRANSPLANT

Most children who receive a heart transplant have one or more complications after their surgery. Most of these complications are minor, and there is no need for alarm. Your child's transplant team can help you understand the early warning signs, discuss your child's care and teach you about further treatment when needed.

**Rejection** and infection are two of the most common complications seen in children after a heart transplant.

## Rejection

**Rejection** happens as a natural response of the **immune system**. The **immune system** is the body's defense against foreign, or unknown, matter such as viruses, germs and some types of cancers. This natural defense system also treats a transplanted organ as foreign and tries to reject the new heart.

- **Rejection** is common after a transplant.
- It is most often treated with a medicine given through an I.V. and does not usually require hospitalization.

To check for **rejection**, either a **cardiac biopsy** or an **echocardiogram** (ECHO) is done.

- The ECHO looks at the function of the heart. A decrease in function may be caused by **rejection**.
- The **cardiac biopsy** is done in the cardiac cath lab. This is currently the best way to check for **rejection**. During the biopsy, a sample of the heart tissue is taken and checked under a microscope.

Rejection Warning Signs:

- Fever greater than 99°F
- Tiredness
- Shortness of breath
- Overnight weight gain of more than two pounds (less in infants and toddlers)
- Loss of appetite, nausea or vomiting
- Change in pulse rate or heart rhythm

Many times children have none of these warning signs during times of **rejection**. If your child has any of these signs, call the transplant coordinator **right away**.

## Immunosuppressants

To prevent your child's body from rejecting the new heart, he or she is given medication called **immunosuppressants**. These medication lower his or her body's ability to defend against foreign matter. When given on time and as prescribed, they help to reduce the risk of severe **rejection** that damages the heart muscle. Your child will take these medication for the rest of his or her life.

Some of the medication commonly used to prevent **rejection** are:

- Cyclosporine (Sandimmune®, Neoral®, Gengraf®)
- Tacrolimus (Prograf®)
- Azathioprine (Imuran®)
- Mycophenolate mofetil (CellCept®)
- Sirolimus (Rapamune®)
- Prednisone

## Heart Biopsy

After the transplant, heart biopsies are done on a regular basis to check for heart **rejection**, but the frequency can vary depending on the child's age and risk for rejection.

Note: Babies usually have fewer biopsies and more **echocardiograms**. Your doctor will explain your baby's follow-up schedule to you.

Biopsies are done in the cardiac cath lab by the cardiologist.

- STEP 1** The day before your child's biopsy, a nurse will call you at home with your appointment time. The biopsies start between 7 a.m. and 9 a.m. Plan to be at the hospital early.
- During this call, the nurse will tell you when to stop giving your child food and fluids. Your child's stomach needs to be empty to safely receive sedation for the biopsy. Sedation is medication that helps your child relax and sleep during the biopsy.
  - If your child takes blood pressure medicines, give them to him or her before his or her biopsy. He or she may take them with a small amount of water.
  - **Do not give cyclosporine or tacrolimus before the biopsy.**
- STEP 2** On the day of your appointment, go to Admissions on the first floor of the hospital. Tell them that your child is having a heart biopsy.
- STEP 3** After checking in, Admissions will send you to the cardiac cath lab. A nurse will prepare your child for the biopsy.
- STEP 4** Depending on your child's age, biopsies are done either through a large vein on the right side of the neck or through a large vein in the upper leg.
- Your child will be given medication before the biopsy to make him or her sleepy.
  - We can also use a special numbing cream on his or her skin one hour before the biopsy to make the needle stick less painful.
- STEP 5** After your child's cardiologist inserts a catheter in his or her vein, blood samples will be drawn and three to four small pieces of heart tissue will be taken.
- STEP 6** The heart tissue is checked by a pathologist (a doctor specially trained to examine tissue) under a microscope to decide if there are any signs of **rejection**.
- STEP 7** After the biopsy, your child will return to the "holding area."
- STEP 8** A nurse will take your child's **vital signs** (blood pressure and pulse) for about one hour if the biopsy was done through his or her neck. The nurse will check them for about three hours if the biopsy was done through his or her leg. During this time, a coordinator will do a physical exam and check on your child's progress.
- STEP 9** Your child is usually finished with the biopsy at lunchtime and may go home.
- STEP 10** Biopsy results are usually ready by early evening on the day of the biopsy or by 5 p.m. the next day. A coordinator will call you after a doctor has looked at the results of both the blood work and the biopsy.
- STEP 11** The coordinator will talk with you about:
- The biopsy results
  - Any medication changes
  - When your child's next biopsy is scheduled
  - When your child will need to have lab work done

Biopsies are graded by using the following scale:

0	1R	2R	3R
No rejection	Mild rejection	Moderate rejection	Severe rejection

## Infection

Your child may be more likely to get an infection when taking *immunosuppressants*. The risk of infection from germs and viruses is greatest in the first three to six months after the transplant. Some ways to help prevent infection include:

- Washing your hands – wash them often and teach your child to wash his or her hands after:
  - Going to the bathroom
  - Giving and taking medication
  - Handling uncooked food
  - Touching garbage or anything that might have germs
  - Blowing his or her nose, coughing or sneezing
  - Teach your child to wash his or her hands before:
    - Eating and drinking
    - Giving and taking medication
  - Wiping his or her nose
  - Caring for someone who is sick
  - Leaving a public place
  - Playing with a pet
- Avoiding people with colds, measles, mumps, chicken pox or the flu. Use common sense.
- Cleaning your child's cuts and scrapes with soap and water and cover with a clean, dry bandage.

## Infection Warning Signs:

- Fever greater than 99°F
- Chills, sore throat, ear pain
- Nausea, vomiting, diarrhea
- Headache, sinus drainage
- Productive cough (cough with *sputum*)
- Wound redness, swelling or pus
- Pain or burning with urination
- Rash

If your child has any of these signs, call the transplant coordinator **right away**.

## Transplant Coronary Disease

In some cases after the transplant, the *coronary arteries* (arteries that supply blood to the heart) can narrow over time. This is called *transplant coronary artery disease*.

- It may begin as a result of *rejection* by the body's *immune system*. This type of *rejection* cannot be found by a heart biopsy.
- A *cardiac cath* is done at the first-year mark post-transplant and at yearly intervals after that. If the pathways are too narrow, blood cannot flow freely to the heart muscle. This can lead to heart problems and heart failure. If this happens, your child may need another transplant. Sometimes, a heart biopsy may be done in conjunction with the cardiac catheterization.
- In lieu of a cardiac catheterization, a stress test may be performed per physician discretion.

## High Blood Pressure

Many children will be given medication after the transplant to control *hypertension* or high blood pressure.

- Prednisone, cyclosporine and tacrolimus (medication used to limit *rejection*) may increase blood pressure.
- Blood pressure is read as a top and bottom number. Normal blood pressures range from 80/50 to 130/80 depending on your child's age, sex and height.
- After the transplant, you will be asked to take your child's blood pressure often and keep a record in a daily diary that we give you.



## Clinic Visits

On the day your child goes home, the coordinator will set up his or her next appointment for an office visit and a heart biopsy or lab work. Follow-up clinic visits are vital to your child's care when he or she is well and ill. Even when your child is well, infection and *rejection* can occur. There are not always signs or complaints to show a problem. Every child is different. Talk to your child's doctor so you can learn about the treatment plan and any problems that may arise.

An office visit includes seeing the coordinator, who will do a physical exam and review all of your child's medication.

- The coordinator will ask you questions about your child's **vital signs**, energy level, appetite, breathing, swelling of feet or face, swollen gums and activities.
- This is a great time for you to ask any questions you have.

After the coordinator sees your child, the cardiologist will examine your child.

- **Do not give your child his or her morning cyclosporine or tacrolimus until after the biopsy or lab work.**
- Bring all of your child's medication and medicine bottles with you to the hospital so that you can give them to your child after the biopsy or lab work.
- The transplant team will also use them to check your child's current dose and see if it needs to be changed.



## Routine Lab Work

Checking lab results is one way the transplant team can make sure your child is on the right amount of medicine. A blood test measures blood levels of cyclosporine or tacrolimus, so the transplant team can decide on the right amount of medicine for your child.

- These levels are only correct 10 to 14 hours from the last dose of medicine (eight hours in babies). This is why your child cannot take these two medication before lab work or a biopsy.

The transplant team will check lab work on your child with every biopsy and clinic visit.

- If your child's scheduled clinic visits are more than two months apart, please have your child's labs checked at either Levine Children's Hospital or at a lab near your hometown every two months.
- You or your local lab will be provided with a list of lab tests to be checked as well as a fax number for your local lab to fax the test results to our office.
- One tube of blood has to be sent overnight to LCH to be checked. This is so that we can check the cyclosporine or tacrolimus level the same way each time.
- Always call our office on the day that your child has labs so that we know to expect the specimen.
- Two or three days after the labs are drawn from your child, a coordinator will call you with any medication changes. The coordinator will also let you know when to have the labs checked again.

## Ongoing Exams

Every other year, around the anniversary of your child's transplant, a complete exam will be done. This is an all-day event, so make sure that you plan for it. Your child will have a:

- Heart biopsy
- Full *cardiac cath* to check the *coronary arteries*
- ECHO to check heart function
- Chest X-ray
- Lab work

# CARING FOR YOUR CHILD

## Caring for Your Child at Home

Taking your child home with a new heart is very exciting. However, it can also be very stressful because of all the medication and new information you must learn.

### Vital Signs

Many children have high blood pressure after a transplant. *Anti-rejection* medicine may increase blood pressure. It is vital to give your child his or her blood pressure medication as ordered by the transplant doctor.

- When you get home, you may be asked to keep a daily record of your child's **vital signs**. Check his or her blood pressure, heart rate and temperature every morning and evening.
- You will be given guidelines for normal readings based on your child's age, sex, height and condition.
- Call the transplant coordinator any time the reading is not normal for your child. If there is a problem, the coordinator may ask for your child's recent **vital signs**. Bring the **vital signs** record with you when you visit the Pediatric Transplant Clinic.

### Daily Weights

If your child is able to sit or stand on a regular bathroom scale, weigh him or her every morning.

- Please try to do this at the same time every day. Weigh your child in the morning after he or she uses the bathroom, wearing the same amount of clothing each time.
- Write the weight in your diary each day.
- If your child has gained more than a pound overnight or more than 2 to 3 pounds over a few days, call the transplant office. Your child may be retaining fluid.

### Follow-up Medical Care

Your child will need medical care for the transplanted heart for the rest of his or her life. All transplant care is given at Levine Children's Hospital or at another pediatric transplant center.

- The heart transplant team can provide all of your child's transplant care.
- If your child becomes very ill, contact the heart transplant team so we can determine the best place for your child to receive treatment. In case of an emergency, call 911 or go to the nearest emergency department.
- Your child can receive routine care such as immunizations and ear infections treatment at your child's local pediatrician's office.
- If your child is admitted to another hospital, please contact the heart transplant office as soon as possible. We may need to coordinate care with that doctor and hospital.
- If your family moves to another state, a transplant coordinator will help you locate another pediatric heart transplant center. We can also help with transferring your child's medical record.

### Immunizations (Vaccines)

- When possible, your child should receive all needed vaccines before the transplant.
- Talk with your child's doctor about the vaccines your child needs. In general, your child should receive these vaccines before a transplant:
  - Diphtheria, pertussis and tetanus (DPT)
  - Polio
  - Measles, mumps and rubella (MMR)
  - Inactivated influenza
  - Haemophilus flu Type B (Hib)
  - Chicken pox
  - Hepatitis A
  - Hepatitis B
  - Pneumococcus
  - Meningococcal disease (meningitis or septicemia)

- After the transplant, your child cannot receive any vaccines for three months. Your child also cannot receive any live vaccines at any time because his or her **immune system** is weak; Your child could get the disease the vaccine is trying to prevent. Live vaccines include the measles, mumps and rubella (MMR), smallpox and chicken pox.
- Babies, children and family members who live in the transplanted child's home should receive the inactivated polio vaccine (IPV).
- You, your child and family members older than six months should receive a flu shot each year.
- If your child is exposed to chicken pox or shingles, call the transplant coordinator right away. Your child might need **intravenous** medicine to slow down the virus. If your child has not had chicken pox, or a chicken pox vaccine, and is exposed, he may need a varicella zoster immune globulin (VZIG) shot within 72 hours of exposure.

## Pediatrician

- After the transplant, make an appointment with your local pediatrician or family doctor. This gives your local doctor a chance to check your child and update his or her chart with new medication.
- Have your local doctor keep your child's vaccine list up-to-date and give a flu shot each year.

## Car Seats

All states have laws that require babies and toddlers to be properly restrained in a car safety seat that is correct for their age and weight. Have all children age 13 or younger ride in the backseat. Use your seat belt to set a good example.

## Medical Alert Identification

You may want to buy your child a medical identification (I.D.) bracelet or necklace. In case of a car accident or other emergency, healthcare workers will know your child has had a heart transplant. Find out how to order it at [www.medicalert.org](http://www.medicalert.org) or ask your child's doctor or nurse.

## Nutrition

Eating healthy food helps your child's body grow and heal. The body needs protein, carbohydrates, fats, vitamins and minerals. The dietitian will check your child's nutritional status. The dietitian will teach your family about the right foods or formulas for your child's special needs. The dietitian will also check your child's diet and growth rate after transplant.

Before a heart transplant, some children may need to be on a low-salt diet. Your child's doctor will decide if a low-salt diet is needed. Many children are very thin and find it hard to eat enough every day. These children need to eat small, frequent meals of high-calorie foods. A list of low-salt foods and high-calorie foods will be given to you.

After the transplant:

- Have your child avoid any uncooked or raw foods such as clams, oysters or sushi.
- Help your child eat a balanced diet that includes fruits and vegetables.
- Stay with a "no added salt" rule.
- Avoid chips, sodas, excess fruit juice and other snack foods. They are empty calories and do not provide good nutrition.
- Have your child eat more healthful foods by eating them yourself and setting a good example.
- Your child's weight will be checked during clinic visits to make sure he is growing well. Our goal is for your child to reach his or her ideal body weight.
- Avoid force-feeding your child any food. This may cause your child to dislike eating which may result in malnutrition.

- Your child may dislike foods he once enjoyed. He may begin to like new foods. Be sure to support your child during this time of change.
- If your baby is bottle-fed, give him or her formula or milk in a bottle. We do not recommend giving your baby soda and juice as it has no nutritional value. Typically children with heart disease need as many nutritional calories as possible, so we do not want them to fill up on juice and soda.

## Tube Feedings

Some children need so many calories to grow and heal that it is impossible for them to eat enough during the day.

- Tube feedings make it possible for a child to receive extra formula or supplements through a thin, flexible tube that passes through the nose and into the stomach.
- Tube feedings can boost calories and improve weight gain. The tube feedings can even be given at night during sleep.
- Many parents say that their child has more energy when on tube feedings.
- Your child's doctors and nutritionist may advise tube feedings before or after the transplant. The nurses will help you learn more about tube feedings if your child needs them.

## Exercise

In the hospital, your child will begin an exercise program, which must be continued after discharge.

- For young children, the program consists of play therapy.
- For older children and teenagers, a structured exercise program is used.

Exercise helps to:

- Reverse the weakness seen with pre-transplant illness.
- Offset some of the side effects of the *immunosuppressive* drugs, such as weight gain, water retention, high blood pressure, elevated cholesterol and blood sugar and weakened bones.

A transplanted heart is described as "*denervated*." This means the nerves connecting the heart and brain were cut when the old heart was removed. This affects how quickly the new heart can speed up and slow down.

- These nerves do not typically grow back. This means that your child might feel very tired if he or she suddenly ran hard after sitting still. The *denervated* heart may not increase its pumping rate fast enough to pump enough oxygen-rich blood to the muscles.
- "Warm-up" and "cooldown" exercises allow time for the heart rate to adjust to your child's exercise level without causing weakness or fatigue.
- Five to 10 minutes of easy play or walking can be used to warm-up or cooldown and prepare for more strenuous activities.

Stop your child's exercises and call your child's transplant coordinator if any of the following occur:

- Dizziness
- Shortness of breath
- Nausea
- Being more tired than normal
- More sweating than normal

Do not allow your child to do these activities during the first six weeks after transplant:

- Heavy lifting (more than 5 to 10 pounds), pushing or pulling
- Use of a regular bicycle
- Rough play (including contact sports)

Also, do not pick your child up by the arms (or allow others to do so)

Keep your child's activity level to only warm-ups and cooldowns if he has:

- Infection
- **Rejection**
- Fever
- A resting heart rate that is more than 20 beats per minute higher than the usual resting heart rate. Contact your physical therapist with any questions about your child's exercise program.

## Sunscreen

Sun exposure happens all year, not just during the summer. The best way to prevent skin damage is to limit the time spent in the sun. Because of side effects with your child's medicine, sunscreen must be used. Choose one with an SPF of 30 or higher. Use it often, even if your child will only be in the sun a short time. To prevent sunburn, your child should:

- Wear clothing that protects the skin, such as a hat, long pants and long sleeves
- Put sunscreen on exposed skin 30 minutes before going outdoors and put it on again as the package directs. This usually means it needs to be put on every two hours and after playing in the water
- Use sunscreen for all children, regardless of skin color

If your child develops new or suspicious-looking areas on his or her skin, see a **dermatologist** (skin doctor).

## Dental

Routine dental visits should begin by age 2. Dental visits are advised every six months. Your child may need dental checks every three months if his or her medicine, such as cyclosporine, has caused overgrowth of gum tissue.

- Keep your child's teeth, mouth and gums clean. This helps reduce the chance of an infection.
- Make sure your child brushes and flosses his or her teeth twice a day.
- Use a soft toothbrush and gently brush up and down. This may help keep your child's gums from overgrowing.
- Your child should see a dentist regularly.
- Please check with a transplant coordinator before sending your child to the dentist for the first time after the transplant.

## Hearing Care

Yearly hearing exams are advised. Some of the medication your child takes or may have received during the transplant can cause hearing loss.

## Vision Care

Your child needs regular vision check-ups. Children who are on prednisone should be treated each year by an **ophthalmologist** (eye doctor).

## Gynecology

If your child is female and older than age 18 or is sexually active, she should see a **gynecologist** (women's health doctor) each year. Immunosuppressive medication can make your child prone to infections. This is also a good time to discuss birth control options. Unplanned pregnancies can be dangerous to your child and to the fetus.

## Ear/Body Piercing and Tattoos

Your child should not get any ear or body piercing or tattoos until you talk to the transplant doctor. This is not a needed medical treatment, and it could put your child at risk for infection.

## School and Day Care

Talk to your transplant coordinator about when your child will be ready to return to school, preschool or day care. The transplant coordinator can also advise you of any special plans that may be needed. The goal for all transplant children is to attend school full time. This helps your child keep up with learning, socializing and physical activities.

Levine Children's Hospital also offers a hospital school program to help with studies when your child is in the hospital. Your transplant coordinator, social worker or hospital school program coordinator can help you with plans for your child's return to school. This may include letters, guidelines and options to help explain why your child may:

- Need to return to school part time
- Not be able to receive certain vaccines that are needed to enroll in school
- Have limits on contact sports
- Need home-care school options for when your child is ill or unable to attend school full time

## Travel Tips

As your child feels better and returns to a regular schedule, your family may want to travel or take a vacation. Please call your transplant coordinator before travel.

- If your family chooses to fly by airplane, take your child's medication in a purse or carry-on bag. This is helpful in case your checked luggage gets lost in flight.
- Bring extra medicine in case of travel delays.
- Carry an up-to-date list of all of your child's medicine in case of an emergency.
- Have your child wear a medic alert bracelet and carry an identification (ID) card.
- Include the phone number of the transplant team.
- Talk with the transplant coordinator before your child goes to an amusement park. There are certain rides that may not be advised for transplant patients.

## When Should I Call the Transplant Coordinator?

Please call the transplant office or the on-call transplant coordinator any time you have questions or concerns about your child's health. Call the transplant coordinator immediately if your child has:

- Weight gain of more than 1 to 2 pounds in 24 hours
- Weight gain of more than 2 to 3 pounds within 48 hours
- Irregular heart beat or palpitations
- Cough, trouble breathing, sore throat, chills, breathing fast or mucus production that might be signs of a lung infection
- Nausea, stomach pain or a decrease in appetite that lasts more than 24 hours
- Diarrhea or vomiting
- Blood in the urine or bowel movements
- Painful urination
- Decrease in urine output or less frequent wet diapers
- Tiredness or increased naps
- Constant headaches or flu-like symptoms
- Exposure to chickenpox
- Any unexplained rash
- Swelling around the eyes, feet, hands or stomach
- Vomiting within 30 minutes of taking medicine
- Dizziness or blackout spells

A transplant coordinator will return your call within 20 minutes. If your concern cannot wait 20 minutes, consider it an emergency.

In case of an urgent concern or emergency, call 911 or take your child to the nearest emergency department right away.

Please notify a heart transplant coordinator as soon as possible if your child requires an emergency department visit.

# MEDICATION

## What Medication Will My Child Take?

After a heart transplant, your child will take a lot of medication for the rest of his or her life. This medication is very important. They will help keep your child from rejecting the new heart and keep him or her in the best possible health.

As time passes, your child's doctor may decide that some of the medications may be decreased or stopped. Until your doctor makes any changes, give your child all of his or her medication on a regular schedule. Never give your child any over-the-counter medications until you check with the transplant coordinator.

Examples of medication your child may take:

### IMUNOSUPPRESSANTS

#### CYCLOSPORINE/SANDIMMUNE<sup>®</sup>, NEORAL<sup>®</sup>, GENGRAF<sup>®</sup>

**Purpose:** Helps keep your child's body from rejecting the transplanted heart.

**How to Give:** Liquid cyclosporine has an oily base and strong taste. Your child can take it by itself or mixed with apple juice, orange juice or milk.

- If you use a syringe to give the medicine to your child, give it first. Then draw up milk or juice in the same syringe to give to your child. This ensures that all medicine is given.
- This medicine also comes in a capsule (pill) form. The capsule can be taken like any other capsule.

**Possible Side Effects:** Increased blood pressure; swollen gums; upset stomach; slight tremors or shaky hands; excessive hair growth; increased risk of infection; and low magnesium levels.

#### Special Notes

- Your child will take this medication for the rest of his or her life.
- Give this medicine the same time and way each day. It may be given with or without food, as long as you do it the same way each day.
- Do not change the way your child has been taking cyclosporine without first talking to the transplant coordinator.
- Do not change this drug unless your child's doctor or transplant coordinator tells you to change it.
- Do not store it in the refrigerator.
- Once the bottle is opened, it is good for two months. Write the date it was opened on the bottle.
- Children absorb cyclosporine into their blood at different rates. Blood tests are done at the hospital to check the level of cyclosporine in your child's blood. The dose may be changed based on your child's results. On days of the blood tests and biopsies, bring your child's medicines to the hospital to give after the lab tests and biopsies.
- If your child takes antacids, do not give them within two hours of cyclosporine because they affect the absorption rate of the drug.

#### TACROLIMUS/PROGRAF<sup>®</sup>

**Purpose:** Helps keep your child's body from rejecting the transplanted heart.

**How to Give:** Give every 12 hours.

**Possible Side Effects:** Mouth sores, diarrhea, diabetes, abnormal lymphoid growths (Post-Transplant Lymphoproliferative Disease).



### AZATHIOPRINE/IMURAN®

**Purpose:** Helps keep your child's body from rejecting the transplanted heart.

**How to Give:** Give it with other morning medication. It comes in 50 mg tablets or in a liquid form.

**Possible Side Effects:** Nausea, vomiting, diarrhea, ulcers, easy bruising, liver problems, decreased ability to fight infection and mouth sores.

#### Special Notes

- The liquid form is good for a limited amount of time – check with your child's pharmacist.
- It may be given with or without food.
- Store the liquid in the refrigerator.
- It can cause the number of white cells to drop. White blood cells fight infection. Your doctor may stop azathioprine/Imuran® if your child's white blood cell count falls too low.

### MYCOPHENOLATE MOFETIL/CELLCEPT®, MYFORTIC®

**Purpose:** Helps keep your child's body from rejecting the transplanted heart.

**How to Give:** Give it every 12 hours.

**Possible Side Effects:** Nausea, diarrhea, diabetes (blood sugar problems), weakness and tremors.

### SIROLIMUS/ RAPAMUNE®

**Purpose:** Helps keep your child's body from rejecting the transplanted heart.

**How to Give:** Give it once a day.

**Possible Side Effects:** Nausea, diarrhea, acne, sleeping problems, wound healing problems, increased triglycerides (a type of fat), mouth ulcers, bone aching and pneumonia (a lung infection).

### PREDNISON

**Purpose:** A steroid used with other medication to keep your child's body from rejecting the transplanted heart.

**How to Give:** Comes in a 5 mg pill or liquid form. Your child may swallow or chew the pill, or you can crush it and add it to a small amount of juice.

#### Special Notes

- Do not stop or change this medicine unless your child's doctor tells you to do so.
- Give with meals to decrease stomach problems.
- Your child should use sunscreen when in the sun.
- Help your child control his or her eating by giving small, healthy meals often during the day.
- Control your child's access to food – especially when first on prednisone. This is when he or she will feel most hungry.

## BLOOD PRESSURE MEDICATION

### AMLODIPINE/ NORVASC®

**Purpose:** Used to treat high blood pressure.

**How to Give:** Comes in 2.5 mg, 5 mg and 10 mg tablets. Some pharmacies can make this drug into a liquid, if you ask them.

**Possible Side Effects:** Low blood pressure, headache and foot and ankle swelling.

**Special Note:** If prescribed once a day, you may give it to your child in the morning or in the evening.

### NIFEDIPINE/PROCARDIA®

**Purpose:** Used to treat high blood pressure. (Cyclosporine, tacrolimus and steroids may raise blood pressure).

**How to Give:** Comes in 10 mg or 20 mg capsules; or 30 mg, 60 mg or 90 mg extended release tablets (Procardia XL).

**Possible Side Effects:** Rosy- or red-colored skin, low blood pressure, swelling of the legs, headache, and dizziness or a light-headed feeling especially when standing quickly from a seated position.

#### Special Notes

- Do not crush or break tablets.
- Capsules may be punctured, and you may put solution under your child's tongue.
- For smaller doses, follow the advice of your child's nurse or doctor.

### FUROSEMIDE/LASIX®

**Purpose:** Used to remove extra fluid from your child's body.

**How to Give:** Comes in 20 mg, 40 mg or 80 mg tablets or 10 mg/one cc liquid. The tablets may be swallowed, chewed or crushed and mixed with juice.

**Possible Side Effects:** Weakness, dizziness, muscle cramps and nausea.

## ANTI-INFECTIVE MEDICATION

### MYCOSTATIN/NYSTATIN

**Purpose:** Used to treat or prevent mouth sores and thrush (a yeast infection in the mouth).

**How to Give:** Give to your child after meals and at bedtime.

**Special Note:** Your child may "swish and swallow" the liquid. It is often used during the first month after transplant and then stopped unless your child has thrush.

### TRIMETHOPRIM-SULFAMETHOxazole (TMP-SMz)/BACTRIM®

**Purpose:** Used to prevent pneumocystis pneumonia and toxoplasmosis.

**How to Give:** Comes in tablet or liquid form. It is usually given three times a week on Mondays, Wednesdays and Fridays for one year post-transplant. Your transplant coordinator will advise you when to stop using this medicine. It may be given in the morning or in the evening.

## OTHER MEDICATION

### RANITIDINE/ZANTAC®

**Purpose:** Used to prevent and treat stomach ulcers.

**How to Give:** Comes in 75 mg, 150 mg tablets or liquid. It may be given with other morning and evening medication.

**Possible Side Effects:** Dizziness, headache, nausea and vomiting.

**Special Note:** This medicine is stopped once your child's prednisone dosage is lowered. The transplant coordinator will advise you when to stop giving it to your child.

### MAGNESIUM OXIDE/MAG-Ox®

**Purpose:** Used to increase magnesium levels (cyclosporine and tacrolimus lower magnesium levels).

**How to Give:** Comes in 400 mg tablets. Your child may swallow or chew the pill, or you may crush it and add to a small amount of juice.

**Possible Side Effects:** Diarrhea, nausea and stomach pain.

### BABY ASPIRIN

**Purpose:** Helps keep blood clots from forming.

**How to Give:** Comes in 81 mg tablet form. Your child may crush, chew or swallow the tablet.

**Possible Side Effects:** Stomach upset, bruising and bleeding gums.

**Special Note:** Give your child baby aspirin with food or milk to reduce stomach upset. Stop this medicine one week before your child has any surgical procedures. Restart it when your doctor advises you to do so.

### PRAVASTATIN/PRAVACHOL®

**Purpose:** Used to lower cholesterol and is important for lowering your child's body's *immune system*.

**How to Give:** Comes in 10 mg, 20 mg tablets. You may crush this pill and mix with water, juice or pudding.

**Possible Side Effects:** Muscle and joint pain and changes in liver function.

**Special Note:** Call the transplant coordinator if your child has any muscle or joint pain. Your child's labs will be checked often to check liver function.

## TREATMENT OF REJECTION

### METHYLPREDNISOLONE/SOLU-MEDROL®

**Purpose:** A steroid used to treat moderate and severe episodes of *rejection*.

**How to Give:** This medicine is given through an I.V., once a day for three days. Your child may receive it as an outpatient in the transplant clinic or through a home healthcare agency.

**Possible Side Effects:** Headache, sensitivity of the eyes to the sun, weight gain, mood swings and shortness of breath.

**Special Notes:** Report any breathing trouble your child may have. Your child will need a repeat biopsy one week after stopping treatment to make sure the *rejection* has resolved.

### ORTHOCLONE OKT3/MUROMONAB-CD3B

**Purpose:** Treats repeated episodes of *rejection* or *rejection* that causes heart failure.

**How to Give:** Your child's doctor must give Orthoclone OKT3/Muromonab-cd3B through an I.V. in the hospital.

**Side Effects:** Fever, chills, nausea, vomiting, tremors, trouble breathing and headache.

**Special Notes:** Your child must be hospitalized for at least three days.

### THYMOGLOBULIN ATG

**Purpose:** Treats repeated episodes of *rejection* or *rejection* that causes heart failure.

**How to Give:** Your child's doctor must give Thymoglobulin through an I.V. in the hospital.

**Side Effects:** Fever, chills, nausea, vomiting, tremors, trouble breathing and headache.

**Special Notes:** Your child must be hospitalized for at least three days.

## HELPFUL HINTS

- Know the medication that your child is taking and their side effects.
- Keep a list of your child's medicines with you at all times.
- Tell the transplant coordinator if your child has any side effects.
- Keep records of what medication your child is taking, including the time and dose.
- Talk to the transplant coordinator before adding, stopping or changing any medicine.
- Keep medication in a dry place, away from heat or light, and out of the reach of children.
- If your child misses a dose, **do not** double the dose, but give the next dose as directed.
- If your child misses two doses, call the transplant coordinator.

### Time to give the medication

- Ask your child's doctor or pharmacist for the best time to take each medicine.
- Call the transplant coordinator or your doctor if your child vomits the medicine less than 30 minutes after it was taken.

### Ways to give the medication

- Check with your child's pharmacist or doctor to find out if your child is taking any time-released medicine. Some time-release medicine cannot be crushed or opened.
- Some medicine can be crushed and put in a small amount of food (applesauce, ice cream, juice or flavored syrup). Use a small amount because your child may not want to finish all the food.
- Some medicine can be crushed and put in a gel cap for older children who can swallow a capsule.

### Other medication

- Some over-the-counter medicine can change the effects of prescription medication. Be sure to keep track of all medicines given to your child.
- Ask the transplant coordinator before you give your child any medicine for coughs or colds.

- Call the transplant coordinator if a pediatrician or other doctor starts any medicine. The transplant team needs to keep a complete record of all of your child's medicine and illnesses.
- If you take your child to a local doctor or emergency center, ask the staff to call his or her transplant coordinator. This will help your child's doctor deliver the best care by having a complete picture of his or her health.
- Do not give your child any herbal medicine, teas, nutritional supplements or any other natural or herbal treatments without checking with your transplant doctor or transplant coordinator.

If you have any questions about any medication or treatments, please call the transplant coordinator.

### Medicine Refills

- Call your pharmacy a few days ahead to refill your child's prescriptions. This ensures the pharmacy has enough medicine in stock for your child.
- Check the bottle for the correct dose and strength each time your child's medicine is refilled. The amount to take may change if the prescription is filled with a different strength tablet or liquid.
- Your child needs his or her blood work checked often, right after the transplant. Medicine may need to be changed based on blood work results. The transplant coordinator will contact you to change your child's dose.
- A refill from the pharmacy may not be the same as your child's current dose. If you have questions about the dose of any medicine, call the transplant office or have your pharmacist contact the office.
- Some medicine needs to be approved before it can be refilled. This process may take several days.



# HELPING YOUR CHILD COPE

## How Can I Help My Child Cope?

A transplant changes the life of your child and family. You may ask:

- What does my child know or understand about his or her transplant?
- How will my child feel about treatment?
- How can I support my child?

Your child's personality, age, support system and treatment will affect how he or she copes with having a transplant. When children are faced with stress, their normal behaviors may change. They may become more dependent on adults and act younger than their age. Your child may not know how to handle his or her feelings.

You know how your child handles stress. Work with your healthcare team to find new ways to help your child cope. Child life specialists can also help.

## Guidelines to Support Your Child

### Infants (birth to 12 months)

Your baby expects you to meet his or her needs. He does not understand a heart transplant.

An infant will:

- Rely on you for food, comfort, play and care.
- Learn about his or her world through senses such as smells, colors and tastes.
- Develop trust in familiar people and things.
- Respond to new people and environments.

COMMON ISSUES AND FEARS:	HOW YOU CAN SUPPORT YOUR BABY:
Separation from familiar people	<ul style="list-style-type: none"><li>• Be with your baby as much as possible</li><li>• Leave something of yours when you go, such as a picture or shirt</li><li>• Rock or hold your baby. Keep familiar blankets and toys in the room</li></ul>
Fear of strangers	<ul style="list-style-type: none"><li>• Have the same people care for your child inside and outside the hospital as much as possible</li><li>• Limit the number of people and voices in the room</li></ul>
Development	<ul style="list-style-type: none"><li>• Allow your baby to explore toys with his or her hands and mouth – be sure toys are clean and do not have small pieces that could be a choking hazard</li><li>• Use gentle touch and massage to comfort your baby</li><li>• Play games with your baby like you would at home</li></ul>
Sense of safety	<ul style="list-style-type: none"><li>• Keep your baby's crib as a safe place – ask if staff can use the treatment room for painful procedures (this may not be possible every time)</li><li>• Wake your infant before a painful procedure</li><li>• Continue or develop familiar feeding, bedtime and bathing routines</li></ul>

## Toddlers (12 months to 3 years)

Toddlers begin to do more on their own.

- Your child may say, “me do” or “no.”
- Let him or her do things on his or her own. He or she may show feelings by his or her actions.
- Help him or her to understand how his or her body works.
- Explain the transplant in terms your child can understand. Toddlers think they make things

COMMON ISSUES AND FEARS:	HOW YOU CAN SUPPORT YOUR TODDLER:
Fear of separation or fear of strangers	<ul style="list-style-type: none"> <li>• Be with your child as much as possible</li> <li>• Have the same people care for your child when possible</li> <li>• Provide security objects such as a blanket or stuffed animal</li> <li>• When leaving, tell him or her where you are going and when you will be back</li> <li>• Leave something personal when you go, such as a picture or shirt</li> </ul>
Loss of control	<ul style="list-style-type: none"> <li>• Allow your child to make choices, but do not offer a choice when there is not one</li> <li>• Give your toddler a job to do</li> <li>• Allow him or her to play and be in control of the game or activity</li> </ul>
Loss of normal routine	<ul style="list-style-type: none"> <li>• Maintain normal eating, sleeping and bathing routines as much as possible</li> <li>• Let him or her play with favorite and familiar toys</li> </ul>
Behavior changes	<ul style="list-style-type: none"> <li>• Give him or her safe ways to express anger and other feelings, such as painting or building blocks</li> <li>• Tell your child it is OK to feel mad or sad</li> <li>• Spend time with your child and offer reassurance</li> <li>• Set limits with your child and give discipline when needed – he needs limits to feel safe</li> <li>• Praise your child whenever possible</li> </ul>
Fear of treatment	<ul style="list-style-type: none"> <li>• Assure your child that he did nothing wrong</li> <li>• Keep security objects nearby such as a blanket, pacifier or stuffed animal</li> <li>• Use simple words, pictures or books to tell what will happen</li> <li>• Tell him or her what will happen just before the treatment</li> </ul>

## Preschoolers (3 years to 5 years)

Preschoolers take pride in being able to do things for themselves.

- Preschoolers learn more words to say what they think and feel. Your child might use play to express himself or herself.
- Your child may think the hospital is punishment for something he or she did wrong.
- He or she may get confused by adult words and make up reasons for what happens.

COMMON ISSUES AND FEARS:	HOW YOU CAN SUPPORT YOUR PRESCHOOLER:
Fear of treatment	<ul style="list-style-type: none"> <li>• Use simple words, pictures or books to tell what will happen</li> <li>• Tell your child what will happen before treatment</li> <li>• Let your child play with doctor kits and safe medical supplies</li> </ul>
Loss of control	<ul style="list-style-type: none"> <li>• Allow your preschooler to make choices, but do not offer a choice when there is not one</li> <li>• Give him or her a “job” to do</li> </ul>
Loss of normal routine or behavior changes	<ul style="list-style-type: none"> <li>• Praise your child for doing things for himself or herself</li> <li>• Give him or her time to adjust to change</li> <li>• Use play to help him or her to show feelings</li> </ul>

## School Age (6 years to 12 years)

School-age children take pride in doing things themselves.

- Your child enjoys school because it helps him or her to learn new things.
- Friends are very important.
- School-age children are able to think in terms of cause and effect. Your child has a better sense of time.
- Your child may have more words to describe his or her body, thoughts and feelings.
- Your child understands how his or her body works. However, he or she may not understand medical words.

COMMON ISSUES AND FEARS:	HOW YOU CAN SUPPORT YOUR SCHOOL-AGE CHILD:
Loss of control	<ul style="list-style-type: none"> <li>• Allow him or her to make choices, but do not offer a choice when there is not one</li> <li>• Give your child a "job" to do</li> <li>• Let him or her to practice new things</li> <li>• Let him or her to go to school or do schoolwork</li> <li>• Provide games and activities</li> </ul>
Being away from friends and school	<ul style="list-style-type: none"> <li>• Let friends visit</li> <li>• Have him or her write letters to friends and family</li> </ul>
Fear of harm to body or fear of unknown	<ul style="list-style-type: none"> <li>• Use simple words, pictures or books to tell your child what will happen</li> <li>• Tell him or her what will happen a few days before treatment</li> </ul>

## Teenagers (13 years to 18 years)

Teenagers see themselves as individuals and want to be independent.

- Friends and peers are important.
- Teenagers want to be like their friends and are concerned with how others view them.
- Illness and treatment cause teenagers to be different.
- Teenagers are able to see things from many points of view.

COMMON ISSUES AND FEARS:	HOW YOU CAN SUPPORT YOUR TEEN:
Loss of control or independence	<ul style="list-style-type: none"> <li>• Allow your teenager to make choices</li> <li>• Let him or her to be active in school and social activities</li> <li>• Involve him or her in the treatment plan</li> <li>• Include him or her when talking to the medical team</li> <li>• Have him or her do self-care as much as possible</li> </ul>
Body image or self-esteem	<ul style="list-style-type: none"> <li>• Give your teenager chances to talk about physical and emotional changes</li> <li>• Talk with him or her about his feelings</li> <li>• Point out things he or she does well</li> </ul>
Loss of privacy	<ul style="list-style-type: none"> <li>• Respect his or her need to do things by himself or herself</li> <li>• Knock before entering his or her room</li> </ul>
Separation from peers	<ul style="list-style-type: none"> <li>• Provide time with peers</li> <li>• Allow friends to visit and call</li> </ul>
Concern for the future	<ul style="list-style-type: none"> <li>• Answer questions openly and honestly</li> <li>• Help your teenager plan for the future</li> <li>• Have your teenager keep doing normal activities</li> </ul>
Behavior changes	<ul style="list-style-type: none"> <li>• Give your teenager safe ways to express feelings, especially anger</li> <li>• Assure your teenager that his or her feelings are normal</li> </ul>



## Why You Should Talk to Your Child About His or Her Transplant

Many parents want to protect their child by not telling him or her things that could be scary. Your child is more afraid when he does not know what is happening. Benefits of talking to your child about transplant include:

- Building trust in you and hospital staff
- Knowing what to expect
- Correcting false ideas about transplants by giving honest information
- Increasing cooperation during treatment
- Giving him or her a sense of control

Your child can also learn how to get through hard situations.

It may be hard to tell your child about his or her transplant. Children know when something is wrong and may feel lonely and separated from family and friends.

- Think about your child's age when choosing words to explain the transplant. Child life specialists can help you find ways to explain tests and treatments.
- Children learn from doing, seeing and hearing things many times. You may need to explain the transplant again and again.

## How to Talk to Your Child About a Transplant

The items below may help you talk with your child and answer his or her questions about the transplant. Answer his or her questions honestly.

- A transplant is no one's fault. Many children believe a transplant is caused by something they did, said or thought. Explain that what your child thinks, says and does will not cause him or her to need a transplant. It is no one's fault.
- A transplant is not contagious. Your child did not "catch" the need for a transplant from someone else.
- Tell your child how healthy bodies work. Avoid using "bad" and "good." Instead use "sick" and "healthy."
- Talk to your child about his or her feelings. Let him or her know that any feeling is normal. Many times children feel angry, guilty, sad, lonely, scared and sometimes even happy. Be honest with your child about your feelings and how your child can express feelings.

## How Do I Discipline My Child?

- A transplant can disrupt your family routine.
- Your child is the center of attention and may receive gifts. Although he or she may feel sick, gifts and attention are fun. It is easy for him or her to feel special and want special treatment to last.

Discipline can be a problem when special attention stops.

- Your child's illness can make discipline hard. Pain and side effects of treatment can make any child short-tempered. He may act more helpless when he or she feels sick. Medications may also cause your child to feel ill-tempered.
- You may feel helpless when you see your child in pain or discomfort. You want to help him or her by giving special rewards. These feelings are normal. Keep the same rules he or she had before the transplant.

Keep these ideas in mind to provide limits:

- Set clear limits your child can understand.
- Know that limits may need to change as your child receives treatment.
- Praise him or her and give rewards for good behavior.

# CARING FOR THE WHOLE FAMILY

## Coping With Your Feelings

Since your child was diagnosed, your life has changed. A transplant brings changes to your home life, including new stresses. Every family is unique. Your family may feel fear, anger, depression and guilt. By sharing these feelings, you may find it easier to cope with change. Your child's healthcare team is here to listen to your concerns and help you in any way they can.

## Fear

The time of diagnosis is often the hardest. Fear of the unknown may be overwhelming. This may be the first time your child has been in the hospital. This can be stressful to you and your child. You may also have fears about treatment, costs or how to help your child cope with a transplant. Talk about these fears and get them out in the open.

## Anger

You may feel very angry. Feeling angry is a normal reaction. Find a way to express your anger. Take a walk or talk with someone.

## Guilt

Parents may feel guilty because they did not know their child was sick. Other family members may feel guilty that they are healthy. Young children often believe they have "magical thinking" and may feel that they caused the illness. Let your family know they did not cause your child's heart failure.

## Depression or Grief

Depression is used to describe a range of emotions and behaviors. Feeling sad is a normal reaction, which may cause changes in family routine and feelings of being alone. Change can cause grief and depression. Common symptoms are:

- Crying spells
- Decreased or increased eating
- Lack of interest
- Decreased energy
- Tightness in the chest
- Headaches

All these feelings are common human emotions. You are not alone. With the support of family, friends and your child's healthcare team, most families are able to work through these emotions. They are able to regain coping skills needed to meet care demands.

Suggestions to help cope with your child's illness:

- Find a private time to talk with your spouse or a close friend. Try not to talk only about your sick child.
- Avoid talking about your child in his or her presence, unless he or she is included.
- Find ways to reduce stress. Ideas include exercising or reading.
- Take turns with your spouse or another person who can stay with your child in the hospital or go to clinic visits. This helps everyone be involved with your child's treatment. It also reduces the gap that may grow between parents when one is more involved in treatment than the other.
- Ask a member of your child's healthcare team for help and support.

- Talk with other parents of children with transplants.
- Talk with your spiritual leader.
- Attend a support group.
- Sometimes emotions become so overwhelming that it can be hard to regain balance. This is very true when there were stresses before diagnosis. If there have been other family strains or losses, mental health problems or substance abuse, counseling and medicine may be needed. Discuss your feelings with the healthcare team to get the help that you need.

### What is the Impact of a Transplant on a Marriage?

An illness can upset a family's life. You may become emotionally and physically tired. Parents often continue to work while trying to keep a normal home routine. Many couples feel the strain on their marriage. They feel angry and upset and do not have time for each other.

Suggestions that can help include:

- Assess your coping styles. It is important to know and accept how your spouse deals with stress. Each person shows feelings in different ways. Some people withdraw, others cry or get angry, some try to learn as much as possible.
- Talk to each other. The key to a good relationship is talking. The need to discuss feelings, fears and information is even more important in times of stress. Silence can make you feel distant from your partner. Sharing feelings and facts can help. This will help you make decisions.
- Change roles when needed. The stress of an illness can change the roles of family members:
  - The mother who once took care of the home may now be too busy.
  - Another family member may need to help out in the home.
  - The father may have made decisions in the past. Now the mother is with the sick child and may be the one who helps make decisions with the healthcare team.

Changes in roles can cause stress in a marriage or a family. Some short-term role changes may be needed to help the ill child. Other changes may be long-term if they help the family work together.

### What are Suggestions for Divorced Parents?

While divorce is hard on most families, problems can get worse when your child is ill. Your child may use his or her illness to bring divorced parents closer. In other cases, he may play parents against each other to feel in control. Do not let divorce affect your child's care. You are still a parent and good communication is key. Tips to help avoid problems:

- Talk with a member of the healthcare team if your child is having behavior problems.
- Provide copies of divorce decrees, custody and visitation rights for your child's medical record.
- Meet together with your child's healthcare team to help avoid confusion about his or her plan of care.
- Ask for two copies of all teaching materials so both parents have the same information.

### How Does a Transplant Affect Siblings?

Siblings (brothers and sisters) also have feelings about your child's heart disease. They may feel upset, scared and unsure of what will happen. Children of any age will sense a change in their family life. Other children may feel resentment or anger. Mom and dad are spending time with the sick child. Siblings may have problems of their own, such as depression, trouble sleeping, physical complaints or school problems.

#### How to help siblings:

- It is normal to spend more time with your sick child. Set aside time to spend with other children.
- Tell them you love them and they are special.
- Talk about the transplant so they understand. Help them learn about the illness and how it affects their brother or sister. Tell them heart disease is not contagious and they are not to blame.
- Take them to the hospital. Help them feel involved in the care of your sick child. This may help decrease fears and help them feel close to their brother or sister.
- Ask a friend or relative to stay in your home, rather than send your children elsewhere.
- Ask your children to help with chores. This makes them feel needed.
- Talk with their teachers. Teachers can support your children and let you know about any problems at school.
- Ask for help from a member of the healthcare team such as a child life specialist, social worker or child psychologist.

### How Does a Transplant Affect Grandparents?

Grandparents have many responses when they hear their grandchild has heart disease.

They may feel shock and disbelief or feel guilty for living a long life. They may also feel blame, thinking they passed heart disease through the family. Grandparents may also feel sadness, not just for their grandchild, but also for their son or daughter. Include grandparents in meetings with the healthcare team. This can help them understand the treatment plan.

Grandparents can be a great help to you. If they are still in good health, they can:

- Relieve you in the hospital or help at home
- Give your other children attention, comfort and love
- Serve as a contact person, giving others information, so you don't have to spend as much time on the phone

## Financial Resources

At times, the cost of a transplant may seem overwhelming. The heart transplant team is here to help you. A financial counselor can help you learn about your insurance benefits and payment options. A transplant financial counselor can also:

- Contact your insurance company and find out about your child's benefits
- Get approval for your child's evaluation and transplant
- Meet with you through the transplant evaluation to review your insurance benefits
- Answer benefits questions
- Help assess your financial needs
- Talk about making a long-term financial plan for your child's healthcare needs
- Help get your child into a case management program, if your insurance company has this service
- Help you learn about government programs for which you qualify
- Teach you about hospital and doctor billing practices

Financial counselors can also help you with:

- Questions regarding Medicare, Medicaid, and North Carolina's CHIPS program and hospital and doctor payment plans.
- Which government assistance your child can receive. The counselor can help you fill out forms and paperwork. There may be a lot of paperwork to complete. Fill out all the forms as soon as possible. The sooner the papers are sent, the sooner you can receive benefits. This process may take weeks or months to complete.

Please let the office know if your insurance coverage has changed. Medical bills can be confusing. Please let the financial counselor know if you are having any financial trouble with your child's medical costs.

## Insurance Companies

### Helpful hints

- Ask someone in your company's human resources department to explain your benefits.
- If your doctor or hospital is not "in-network," please contact your insurance company to discuss your co-insurance rates and out-of-pocket costs.
- Your insurance company may ask you to give them a letter of medical necessity so your child can be treated at Levine Children's Hospital. Please contact the hospital financial counselor to help you get this information from your child's transplant surgeon.
- Bring a copy of your insurance benefits with your deductible and co-payment amounts each time you visit the hospital.
- Be sure to tell the transplant office right away of any changes in your address, phone number or insurance coverage.

### Helpful hints in the billing process

You will receive bills from several places: hospital bills, known as technical or facility fees, and doctor bills, known as professional fees.

- If you have a question about a bill, please call the phone numbers listed on your billing statement.
- Make a file for hospital bills and insurance forms. This will help you to track payment, denials and requests for more information.
- You may need to call your insurance company to ask questions about the transplant. Ask to speak to someone that can answer transplant benefits questions.

Below is a list of common offices that will send you bills:

- Levine Children’s Hospital for all services received at the hospital or satellite locations
- Sanger Heart and Vascular Institute for any doctor-related services
- Levine Children’s Hospital for any radiology, pathology and anesthesiology services
- Other staff or doctors who care for your child
- Read bills closely. You may receive statements that are still pending payment. These statements are for your records and are not bills. Please respond to all inquiries from your caregiver’s billing offices or your insurance company.

## Medicaid

Medicaid is a state medical assistance program that covers most costs for hospital stays, clinic visits and medication. There are some procedures or exams not covered by Medicaid, and some must be pre-approved. Some Medicaid programs are based on family income, and others are based on medical needs. You may be able to get coverage for medical services that occur three months prior to the month your child becomes eligible for Medicaid.

Medicaid may be able to pay for:

- Doctor and hospital bills
- Up to five prescriptions each month
- Physical, occupational and speech therapy
- Adaptive equipment

We have an onsite Medicaid office on the second floor of Levine Children’s Hospital.

## Medicare

Medicare is a health insurance program for:

- People age 65 and older
- Some people with disabilities less than age 65

Medicare has two parts:

**Part A (hospital insurance) helps pay for:**

- Inpatient hospital care
- Some skilled nursing facility care
- Hospice care
- Some home healthcare

Most people get Part A as soon as they turn 65. They do not have to pay a monthly fee for Part A because they or a spouse paid Medicare taxes while they were working.

**Part B (medical insurance) helps pay for:**

- Doctors’ services
- Outpatient hospital care
- Other medical services that Part A doesn’t cover like some home healthcare

Part B helps pay for these covered services and supplies when they are medically necessary. You pay the Medicare Part B premium monthly. Premium rates can change yearly. In some cases, this amount may be higher if you did not choose Part B when you first became eligible at age 65. The cost of Part B may go up 10 percent for each 12-month period that you could have had Part B but did not sign up for it. You will have to pay this extra 10 percent for as long as you remain eligible for Medicare.

# RESOURCES

The Ricky Hendrick Centers for Intensive Care – Cardiac Intensive Care Unit is on the 6<sup>th</sup> floor of Levine Children’s Hospital. It includes:

## Sleep Rooms

- Only the parent or legal guardian of children in the intensive care unit (ICU) can use sleep rooms.
- Sleep rooms should be used only for sleeping. Meetings and visitors are not allowed.
- Cleaning takes place each day between 8 a.m. and 2 p.m. Bed linens and towels are provided.
- Families must be out of sleep rooms by 8 a.m. You must remove all of your personal items.
- You cannot have a sleep room once your child has been discharged from the ICU.
- Sleep rooms are assigned each day based on the needs of the unit.
- Contact your nurse or the unit secretary about obtaining a room.

## Showers and Restrooms

- Private showers and restrooms are available for parents and guardians.
- Toiletries, such as soap, razors and shaving cream are donated. If you need toiletries, talk with the transplant social worker or your child’s nurse.

## Washers and Dryers

- Washers and dryers are available for your use on the 6<sup>th</sup> floor. Please contact a staff person or volunteer for more information

## Family Kitchen/Lounge

Located near the “Marble” elevators, these are designed for families to relax outside of their child’s room. All lounge areas have a TV, ice machine, and coffee maker as well as a variety of seating options. There also snack areas located near the nurse’s station. These areas are equipped with a refrigerator, microwave, and ice machine.

## Also Available:

### Family Resource Library located on the 2<sup>nd</sup> Floor

The Family Library is open from 8:30 a.m. to 5:00 p.m. Monday through Friday with some additional evening and Saturday hours. It includes:

- Consumer health collection
- Recreational books for all ages
- Four computers
- Access to the Internet for e-mail and medical information searches
- Library staff to assist you with any information about your child’s diagnosis or procedures

## Roof Top Garden and Play located on the 12<sup>th</sup> Floor of LCH

There is an outside play and sitting area for families located on the 12<sup>th</sup> floor. Children need an adult with them to visit this area. Please ask your nurse or child life specialist for access to the roof garden.

# ACCOMMODATIONS

## Area Lodging

These accommodations are located near Levine Children's Hospital, and are suggestions only. The following list of accommodations are in no way affiliated with Levine Children's Hospital.

## Ronald McDonald House

1613 E. Morehead St., Charlotte, NC 28207

Guest are referred to the House by the hospital and is only for out-of-town families of sick children. The House offers an extended network of support and connection to others going through similar hardships. In return for staying at the House, guests are asked to make a small donation if possible.

## Hospitality House of Charlotte

1400 Scott Ave.

Charlotte, NC 28203

A nurturing place for out of town guests to stay free of charge while their loved one receives medical care.

Guests are referred by the hospitals, and are welcome regardless of the patient's age or diagnosis. Guest stay at the Hospitality House free of charge, but are asked to help out with daily chores such as making their bed, folding laundry, and cleaning up after themselves,



## LifeShare of the Carolinas

5000 D Airport Center Parkway  
Charlotte, NC 20208  
704-512-3303  
[www.lifesharecarolinas.org](http://www.lifesharecarolinas.org)

Organization that assists North Carolina residents who are transplant candidates or recipients.

## National Organization for Rare Disorders (NORD)

P.O. Box 1968, Danbury, CT 06813  
800-999-6673  
[www.rarediseases.org](http://www.rarediseases.org)

Manages drug cost share program for individuals who cannot afford cyclosporine.

## National Foundation for Transplants

1102 Brookfield, Suite 200, Memphis, TN 38119  
800-489-3863 or 901-684-1697  
[www.transplants.org](http://www.transplants.org)

Limited emergency grants available for medication.

## Pharmaceutical Manufacturers Association

1100 Fifteenth Street NW, Washington, D.C. 20005  
Publishes the "Directory of Prescription Drug Indigent Programs." You can get a copy by writing to the company.

## The Sunshine Foundation

1041 Mill Creek Drive, Feasterville, PA 19053  
215-396-4770  
[www.sunshinefoundation.org](http://www.sunshinefoundation.org)

National, nonprofit organization that grants wishes for seriously ill children ages 3 to 21.  
Contact the organization for more information.

## United Network for Organ Sharing (UNOS)

P.O. Box 2484, Richmond, VA 23218  
888-894-6361  
[www.unos.org](http://www.unos.org)

The **United Network for Organ Sharing** (UNOS) is the national agency that oversees organ transplant.

# WEBSITES

Levine Children’s Hospital has not reviewed all of the sites listed as resources and does not make any representations regarding their content or accuracy. Levine Children’s Hospital does not recommend or endorse any particular products, services or the content or use of any third party websites, or make any determination that such products, services or websites are necessary or appropriate for you or for the use in rendering care to patients. Levine Children’s Hospital is not responsible for the content of any of the referenced sites or any sites linked to these websites. Use of the services referenced and/or links provided in this manual is at your sole risk.

## Heart-related Sites:

### **American Heart Association**

[americanheart.org](http://americanheart.org)

### **Immunizations Contraindication**

[cdc.gov/nip/recs/contraindications.pdf](http://cdc.gov/nip/recs/contraindications.pdf)

### **National Immunization Program**

[cdc.gov/nip/default.htm](http://cdc.gov/nip/default.htm)

### **National Transplant Assistance Fund**

[transplantfund.org](http://transplantfund.org)

### **Partnership for Organ Donation**

[transweb.org/partnership](http://transweb.org/partnership)

### **Sandrine’s Gift of Life**

[sandrinesgift.com](http://sandrinesgift.com)

### **Camp Luck**

[camluck.com](http://camluck.com)

### **Children’s Cardiomyopathy Foundation**

[childrenscardiomyopathy.org](http://childrenscardiomyopathy.org)

### **Medicare**

[medicare.gov](http://medicare.gov)

### **Centers for Medicare and Medicaid Services**

[cms.hhs.gov/medicaid](http://cms.hhs.gov/medicaid)

### **Children’s Organ Transplant Association**

[cota.org](http://cota.org)

### **Kids Health**

[kidshealth.org](http://kidshealth.org)

### **Pediatric Heart Transplant Study Foundation**

[phtsfoundation.org](http://phtsfoundation.org)

- Anesthesia:** A medicine that puts your child to sleep during surgery.
- Anesthesiologist:** The doctor who puts your child to sleep during surgery.
- Bacterial Endocarditis:** An infection of the inner lining of the heart and valves.
- Cardiac Biopsy:** The removal and examination of sample tissue from the heart.
- Cardiac Catheterization:** Inserting a catheter (a small, thin flexible tube) into the heart.
- Cardiac Intensive Care Unit (CICU):** A special care area for heart patients.
- Cardiologists:** Heart doctors.
- Cardiomyopathy:** A weak or enlarged heart.
- Congenital:** Present at birth.
- Congestive Heart Failure (CHF):** Failure of the heart to pump blood well.
- Coronary Arteries:** The blood vessels that supply the heart muscle with oxygen.
- Denervated:** When a body part loses its nerve supply, usually by removing, cutting or blocking nerves.
- Dermatologist:** Skin doctor.
- Echocardiogram:** A test that records the heart's structure and function.
- Graft:** Tissue used to repair a defect.
- Gynecologist:** A women's health doctor.
- Haemophilus Influenza:** A virus that causes lung and other infections.
- Hypertension:** High blood pressure.
- Immune System:** The part of the body that helps fight disease, infection, cancer or foreign matter.
- Immunosuppressant:** A drug that lowers the body's ability to fight disease, infection, cancer or foreign matter.
- Inferior Vena Cava:** A blood vessel that returns "used" or blood without oxygen from the lower body to the *right atrium* in the normal heart.
- Inotropic Drugs:** Medication that temporarily improves heart function.
- Intravenous (I.V.):** In the vein; refers to a small needle or plastic catheter placed in the hand, foot or arm to give fluid and medicine.
- Left Atrium:** The upper chamber of the heart where oxygen-rich blood from the lungs enters the heart.
- Left Ventricle:** The lower chamber of the heart where oxygen-rich blood is pumped to the body.
- Ophthalmologist:** An eye doctor.
- Pulmonary Circulation:** The movement of blood from the heart, to the lungs, and back to the heart again. During this process, the blood picks up oxygen and gets rid of carbon dioxide.
- Pulmonary Function Test:** A breathing test.
- Region:** An area.

# GLOSSARY

**Rejection:** A natural defensive response of the *immune system* against foreign, or unknown, matter.

**Right Atrium:** The upper chamber of the heart; where “used” or oxygen-poor blood returns to the heart from the body.

**Right Ventricle:** The lower chamber of the heart; where oxygen-poor blood is pumped into the lungs.

**Septum:** A muscle wall that separates the heart lengthwise.

**Sputum:** A substance brought up by coughing or clearing the throat.

**Superior Vena Cava:** A blood vessel that returns “used” or blood without oxygen from the upper body to the right atrium in the normal heart.

**Transplant Coronary Artery Disease:** The narrowing of *coronary arteries* in a transplanted heart.

**United Network for Organ Sharing (UNOS):** An organization that helps advance organ availability and transplantation by uniting and supporting its communities. It helps patients through education, technology and policy development.

**Valves:** One-way flaps that control the flow of blood through the heart.

**Ventilator:** A machine to help breathing.

**Vital Signs:** Includes the pulse, body temperature, breathing rate and blood pressure.

Some physicians and affiliated healthcare professionals who perform services at Levine Children’s Hospital are independent providers and are not our employees .

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# NOTES

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1000 Blythe Blvd. | Charlotte, NC 28203  
704-381-2000

[levinechildrenshospital.org](http://levinechildrenshospital.org)

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[twitter.com/levinechildrens](https://twitter.com/levinechildrens)



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