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**INTRODUCTION**

This handbook is used to provide education to pre and post liver transplant patients and their families. It is yours to keep. The handbook has instructions on diet, medications and activity after your child leaves the hospital. It also gives you blank forms to keep track of your child's temperature, blood pressure, weight, and medicines that your child will be taking. These records are **very important** in helping us know how to best take care of your child according to his or her needs. **Please read this notebook regularly and carefully, and be sure to bring this information with you when you come to all clinic visits. You will be tested on the information that is in this book. We have organized this book to have key points at the beginning of each section to help point out what you need to learn.**

Although liver transplant doctors and transplant coordinators will be in charge of much of the care for your child, you also have a *very* important part to play. You have already done a great job of caring for your child's medical needs. Now, we will help you learn how to take care of your child after a liver transplant.

Always feel free to ask *any* questions that you have. No question is too small or unnecessary. Doctors, Transplant Coordinators, Dietitians, Psychologists, Social Workers, and Child Life Specialists are here to help you in the care of your child. It is okay to feel nervous about going home. Your transplant team is always here to help you.

**IMPORTANT PHONE NUMBERS**

Children's Medical Center Dallas Main Number.....	214-456-7000
Liver Transplant Clinic.....	214-456-8600
Liver Transplant Office FAX.....	214-456-6443
Toll Free Number.....	800-846-6768

**Transplant Clinic Location:**

**Solid Organ Transplant (SOT) B2300**

Children's Medical Center of Dallas

1935 Medical District Drive

Dallas, Texas 75235

Phone 800-846-6768 or 214-456-8600

Main Fax 214-456-8405

**Office Hours:**

**\*\*Monday through Friday 8:30 a.m. until 5:00 p.m. \*\***

After hours, weekends, and holidays, dial 214-456-7000 and ask for the Liver Coordinator on-call.

**It is very important to contact the Liver Transplant Coordinator if your child becomes *ill* with any of the following:**

- Temperature greater than 100.5 by mouth or under the arm.
- Vomiting or diarrhea.
- Dizziness
- Decreased appetite
- Decreased energy
- Increased puffiness of the face, hands, feet or body
- Need to urinate with more frequency or burning with urination.
- Signs of respiratory infection (cough, sore throat, green or yellow sputum)
- Signs of wound infection (redness, swelling, warm to touch, tender to touch)
- Clay-colored or yellow/white stools
- Yellow eyes
- Tea-colored urine

## ***The One for Children.....The One for Transplant***

One of the largest comprehensive pediatric transplant centers in the country, working **to make life better for children.**

The *Solid Organ Transplant Center* at Children's Medical Center provides complete care for pediatric patients needing heart, kidney, liver, and intestinal transplantation. Focused on patient family-centered care, the dedicated team of transplant specialist will support, guide, educate, and care for you and your child through the stages of transplant.

As the pediatric teaching hospital for The University of Texas Southwestern Medical Center, Children's is committed to clinical excellence and advancing research. Children's offers more than 50 subspecialty programs across two campuses and satellite outpatient centers across North Texas. This allows for nearby, continuous, and complete care of your child within the Children's system. Our mission is going beyond expectations of treatment and care for children needing organ transplant. The Solid Organ Transplant Program strives to advance the medical, social, and scientific aspects of pediatric transplantation....to make life better for children.

Our program has performed more than 1000 transplants. This is a rare accomplishment in the field of pediatric transplant. Listed below are accomplishments of the transplant program at Children's.

### ***Kidney Transplant***

More than 400 pediatric kidney transplants have been completed at Children's since the program started in 1979. Children's has constantly been a leader in the number of pediatric kidney transplants performed in Texas.

### ***Liver Transplant***

More than 450 pediatric liver transplants have been completed at Children's since its first liver transplant in 1984. Children's has the highest number of pediatric liver transplants in Texas. In 2006, the state's first pediatric liver-heart transplant was performed at Children's.

### ***Intestinal Transplant***

The first pediatric intestine transplant in North Texas was performed by Children's in 2006. Since the program's start, Children's has performed the most pediatric intestinal transplants in the state. The Intestinal Transplant Program is managed jointly with the Intestinal Failure Program.

### ***Heart Transplant***

Children's has performed more than 160 heart transplants since completing Dallas' first pediatric heart transplant in 1988. Children's has the highest number of pediatric hearts transplanted in Texas, with the most organs transplanted for patients younger than age 5. In 2006, Children's performed the state's first pediatric heart-liver transplant. In 2008, Children's also transplanted the state's smallest transplant recipient.

### THE TRANSPLANT TEAM

Liver transplantation is a procedure that requires the knowledge of many specialists trained in medicine, surgery, and immunosuppressive management. For this reason, we use a team to coordinate your child's care. In addition, all of the liver transplant team members are pediatric experts.

The professional members of this team include: doctors (MD), advanced practice nurses, transplant coordinators, nurses, social workers, psychologists, dietitians, pharmacists, child life specialists, chaplains and others who have been trained to meet the special needs of pediatric liver transplant patients and their families. The transplant coordinators and doctors are always available to answer your questions about transplant. A brief description of some of the transplant team members follows.

#### ***Pediatric Gastroenterologists***

The transplant gastroenterologists are pediatric gastrointestinal doctors with expert knowledge in liver transplant. He or she will work with your child's pediatrician and/or referring gastroenterologist. After liver transplant, your child will require routine follow-up with the transplant team. They will manage your child's liver care, and will work closely with you and with your child's pediatrician or referring gastroenterologist to be sure all your child's medical needs are met.

#### ***Transplant Surgeons***

The transplant surgeons are the doctors who will transplant the new liver into your child's body. The transplant surgeons are specialists in abdominal and vascular surgery. The transplant surgeons will also care for your child on a daily basis following transplant. The surgeon will make rounds every day to check on your child and review lab test results and other procedures.

#### ***Transplant Advanced Practice Nurse***

Transplant Nurse Practitioners are nurses with a higher degree of education and practice experience. Physician Assistants have a Master's degree and work under a doctor. They help the family understand their child's specific needs. They collect patient history, do physical exams, diagnose acute (short term) and chronic (long term) illnesses, and order or perform diagnostic tests for the pre (before) and post (after) transplant patient.

#### ***Transplant Coordinators***

The transplant coordinators are experienced registered nurses who are responsible for organizing all parts of the transplant process, from referral by the local doctors, to evaluation, and on through post-transplant, discharge and follow up care. The transplant coordinator works with the cardiologist, your local doctor, transplant doctor and surgeons to coordinate or organize your child's care. The coordinator is always available to answer any questions you may have about transplant, and the transplant process

#### ***Financial Coordinators***

A Financial Coordinator is available to help families with financial concerns throughout the transplant process. The financial coordinator will call your insurance company to get a benefit

summary and find out if approval is required for evaluation and transplant. At the time of evaluation, a financial coordinator will review the details of your benefits and identify other financial resources. The financial coordinator will help you when applying for state/federal programs (i.e. Medicaid, Supplemental Security Income). Should you have any questions about your health insurance, we encourage you to call your financial coordinator.

### ***Social Workers***

A social worker will help you deal with the many stresses that come with the transplant and hospitalization of your child so you won't have to face the difficult times alone. A social worker can help you find the resources you need before transplant surgery like transportation, lodging, and financial assistance. A social worker can also give counseling and emotional support to help lessen any emotional distress you feel. The social worker will also help arrange your child's discharge from the hospital and make the right appointments to outside community resources if needed.

### ***Psychologists***

As part of the evaluation process, all children and families will see one of the transplant team psychologists. The team psychologists are experts in child development and behavior and in helping children and their families deal with the stresses associated from liver transplant. Your child will get a complete developmental exam before the transplant. This will provide the baseline for future yearly exams after the transplant.

Many children with long lasting illnesses show small developmental (age-related) delays, and if these are found, more help will be needed. The psychologist will ask about any concerns you have about your child's emotional status and behavior. Many parents find it helpful to talk about their concerns with an expert who may be able to make some suggestions that can make a difference to them and their child's adjustment to the transplant.

The team psychologist is also there to help other members of the family. A transplant is not just surgery; it is a special experience that affects every family member. The psychologist has worked with many transplant patients and is qualified to help you and your loved ones get the most from the new opportunities that transplant offers.

### ***Dietitians***

A registered, clinical dietitian will help evaluate your child's nutritional status before the transplant and follow him or her throughout the transplant period and after surgery. The dietitian will keep detailed records of your child's height, weight, and muscle growth. The dietitian will also work closely with you to develop the best diet for your child. For younger children, the dietitian will tell you how to mix formulas, which may need to be changed from time to time as your child's nutritional status changes. Like the other members of the transplant team, the dietitian is experienced in developing special diets for children with kidney disease. The dietitian provides expert nutritional advice for your child's needs.

### ***Transplant Pharmacist***

The transplant pharmacist is responsible for identifying, preventing and fixing possible and actual medication problems. He or she is a resource to the medical team while your child is in the hospital. The transplant pharmacist's role is to also teach your child and family about the medications.

### ***Care Teams***

Your child will have a care team during his or her inpatient stay at Children's. The care team will be responsible for creating the plan of care for your child. You will be asked to help with this plan so that we can best meet your child's needs. The care team will also be responsible for checking vital signs; giving medications; monitoring I.V. lines, dressings, and drainage tubes; tracking daily intake, output, and weights, ordering lab tests, and performing procedures. Your care team will always be available to answer questions, explain treatments and procedures, and offer help to make your stay as comfortable as possible.

### ***Child Life/Child Development Specialists***

Your child will need help to emotionally prepare for the transplant surgery and the hospital stay. A child life specialist is someone that will explain all the pieces of medical equipment and procedures to a child in words he or she can understand. This process includes "medical play", a time when the child can see and touch different pieces of medical equipment, under the child life specialist's supervision, and pretend to be a doctor or nurse for a stuffed animal. This allows the child to express his or her fears and worries about the hospital and the child life specialist can address those worries with the child.

Other activities with the child life specialist may include a tour of the surgery area and the intensive care unit (ICU) and viewing children's videos about what to expect during a hospital stay. During your child's hospital stay, a child life specialist will be available to direct supervised play time in the hospital's playroom and organize special events for the children at the hospital.

### ***Chaplains***

Hospital chaplains are available to help patients and families with the faith and spiritual questions that may come up during the course of the transplant experience. At Children's Medical Center, pastoral care provides daily chapel services, regular pastoral visits, supportive counseling and parent support groups.

The pastoral care department helps persons from all faith traditions. Their goal is to help you find the spiritual support you need during a hospital stay. The chaplains can also help you by contacting your minister or other clergy from home or a clergy person from your faith tradition.

### ***Other Staff Members***

Many other specialists trained in pediatrics will help care for your child. These specialists include pathologists (microscope doctor), radiologists (x-ray doctor), infectious disease doctors (germ doctor), renal doctors (kidney doctor), cardiologists (heart doctor), respiratory therapists (breathing specialist), and physical and occupational therapists (body movement specialist). Other staff members, such as interns and residents (doctors in school), often are with your doctor on rounds. These are graduate, licensed doctors who are getting more training in specialized medical or surgical skills under the supervision and direction of the transplant team.

Your transplant team wants you to be involved in the care of your child. It is important for you to ask the team questions you may have and tell them about any changes in how you feel. The best way to remember your questions or concerns is to write them down in a journal or on a notepad when you think of them. When the doctors make rounds, you can discuss each item on your list with the transplant team.

**BASIC LIVER FUNCTION**

***Key Points:***

- *How the liver works*
- *What are the reasons the liver stops working?*
- *What happens when the liver fails?*

***Liver Function***

The liver is the largest and one of the most complex organs in the body. The normal liver is a soft, smooth organ. It is in the upper right portion of the abdomen, below the diaphragm. It is connected to the small intestine by bile ducts. The liver has two lobes that are divided into sections.

Major blood vessels supply a large amount of blood to and from the liver. The blood provides food and oxygen to the liver cells. The liver's job is weakened when blood flow, to or from the liver, is blocked.

The liver performs metabolic activities and the bile ducts provide a way for the body to remove waste products and send digestive aids to the intestine.

The liver is made up of cells called **hepatocytes**. These cells do many jobs including:

- Producing clotting factors, blood proteins, bile and more than 1,000 different enzymes
- Breaking down old red blood cells into a substance called bilirubin
- Breaking down cholesterol
- Storing many substances, such as starch (glycogen) for quick energy, vitamins, protein and fat
- Keeping normal blood sugar (glucose) levels
- Regulating several hormones
- Removing wastes
- Removing drugs and poisons

The liver has two special features. First, blood comes from the portal vein. This vein collects blood from the stomach, intestines, spleen and pancreas and sends it through the liver. Then the nutrients are checked before they are given to the rest of the body. This process can expose the liver to high levels of any medicine that is taken by mouth. For example, if a patient were to take too much Tylenol or any drug, it could harm the liver or stop working.



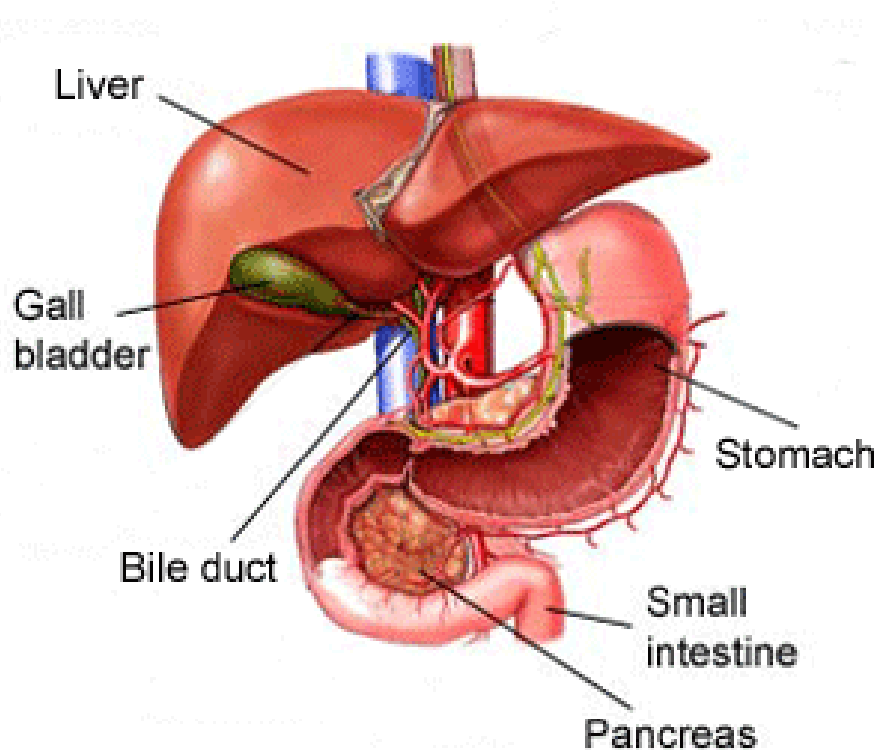
The second special feature of the liver is bile ducts, which carry bile from the liver to the small intestine. The liver cells (hepatocytes) produce a yellow-green colored fluid (bile) that collects in the bile ducts. Bile helps the body absorb fat and vitamins from the intestines. It also contains waste products that are picked up in the blood.

Bile is made of two important substances, **bile salts** and **cholesterol**. Bile salts, also called bile acids, are the body's cleaners and play an important role in the breakdown and body's use of fat and fat-soluble vitamins. Cholesterol also helps with fat absorption.

The gallbladder is connected to the liver and stores the bile until it is needed for digestion. During digestion, the gallbladder squeezes and pushes the bile through the common bile duct and into the intestine to help in the digestive process.

Bilirubin is a normal waste product resulting from the breakdown of old red blood cells. High bilirubin levels indicate liver injury. When there is too much bilirubin in the body, the patient's skin turns a yellow-green color. This is called **jaundice**. This is a common sign of liver illness.

With so many important activities occurring in the liver, it is easy to understand why liver illness can harm many parts of the body.



### ***Liver Dysfunction***

Liver dysfunction or damage happens if: (1) liver cells are destroyed or are unable to work correctly. (2) bile ducts are destroyed or blocked, and/or (3) blood flow to or from the liver is slow or blocked. Since injured liver cells can't work and get rid of waste products, including bilirubin, jaundice occurs. Some examples of liver dysfunction are inflammation of the liver from a virus, scarring of the liver and metabolic diseases such as tyrosinemia and alpha-1 anti-trypsin deficiency. Some examples of blocked or destroyed bile ducts are biliary atresia, Alagille's Syndrome, intrahepatic cholestasis syndromes, and choledochal cysts. Portal vein thrombosis happens when blood flow is slow or stopped to the liver.

Liver cells can also be damaged when toxic substances build up in the blood, such as with galactosemia, tyrosinemia or glycogen storage disease; when toxic drugs are swallowed such as alcohol or acetaminophen (Tylenol); or when a virus infects the liver such as hepatitis A, hepatitis B, hepatitis C, Cytomegalovirus (CMV) and others.

Other substances, such as drugs and toxins (e.g., ammonia), which are normally removed by the liver, begin to build up in the blood. Because the damaged liver can't remove drugs from the blood properly, normal drug doses can be deadly for some liver disease patients. Ammonia and other toxic substances that build up in the body can cause a brain illness called **hepatic encephalopathy**.

After the liver is injured, a repair process starts. When we injure our skin, scar tissue forms as it heals. Likewise, with liver damage, scar tissue called **fibrosis** forms in the liver. A large amount of scar tissue is called **cirrhosis**. A liver with cirrhosis is hard and bumpy. Cirrhosis destroys liver cells and blocks blood flow through the **portal** vein to the liver, leading to **portal hypertension**.

The increase in portal blood pressure causes abnormal blood vessels, like varicose (enlarged and wormy like) veins, to develop in the abdomen, particularly in and around the esophagus. These abnormal blood vessels are called **varices**. Varices in the esophagus can break and cause severe bleeding in the stomach. Varices in the abdomen make surgical procedures more difficult. Portal hypertension and esophageal bleeding is only one of the many problems caused by severe liver disease.

If the liver continues to be damaged other problems begin. A damaged liver cannot produce as many blood proteins, particularly albumin, as a normal liver, causing the body to hold onto fluid. Salt and water balances are upset in the damaged liver, which causes more fluid to build up in the arms and legs (edema) and abdomen (ascites). Fewer blood clotting factors, or blood proteins, increases the likelihood of bleeding. A damaged liver also cannot control blood sugar (glucose) levels properly and can cause a condition called hypoglycemia (low blood sugar) to develop. Other complications/problems of liver failure include:

- increased infections (seen in ascites fluid)
- kidney failure
- anemia (low levels of normal red blood cells)

- abnormal periods for girls
- altered testicular function
- change in hair growth
- severe itching (pruritus) -- due to more bile salts in the blood
- poor nutrition (child will not want to eat) – which will cause fatigue (tiredness), weakness and apathy (laziness)

Patients can have all or some of these problems.

## LIVER TRANSPLANT EXPLAINED

### ***Key Points:***

- ***What is a Liver Transplant?***
- ***Where do livers come from?***
- ***How long have liver transplants been performed?***
- ***The Good and Bad of getting a Liver Transplant***
- ***Who pays for a Transplant?***

### ***What is a liver Transplant?***

Transplant is the surgical placement of a healthy liver from a human or deceased donor into your child's body.

### ***Where do livers for transplant come from?***

A liver for transplant can come from two sources:

1. A living donor can be either a person who is closely related to your child (living related or LRD), or a person who is not related by blood (living non-related LNRD), but who has a strong emotional bond with the recipient. **At this time, Children's Medical Center Dallas does not offer living donor liver transplants.**
2. A deceased donor is a person who has recently died, and the family has agreed to donate the organs for transplant.

### ***How long have liver transplants been performed?***

The first liver transplant was performed in the United States in 1963.

### ***What are the advantages of liver transplant?***

Although close medical supervision is still needed, after a successful transplant, your child will resume a more normal life, including the following:

- ◆ Improved quality of life
- ◆ Fewer diet and fluid limitations
- ◆ Improved growth (when on low dose steroids)

### ***What are the disadvantages of liver transplant?***

A transplant doctor will go over the list of risks and problems before you decide on transplant. Although not all transplant patients experience all of the following, you need to be aware of some of the disadvantages:

- ◆ Medicine needed to prevent or stop the body from rejecting the new liver have unwanted side effects
- ◆ Complex medical follow-up
- ◆ Rejection may happen even though your child takes medicine to prevent or stop rejection
- ◆ Increased risk of infection (special care must be taken to avoid contact to other people who are sick)
- ◆ Increased risk of cancer
- ◆ Cataracts (cloudy spots in the eye)
- ◆ Joint and bone disease
- ◆ Weight gain
- ◆ Diabetes may be caused by steroids (medication taken to prevent rejection)

### *Who pays for transplant?*

- ◆ The Financial Coordinator will discuss your insurance coverage with you during the evaluation.

Each child is different. In general, Medicare, Medicaid, or most insurance plans cover the cost of transplantation for the recipient. The coverage for the cost of a liver from a deceased donor depends on the individual insurance policy. A Financial Counselor or your Social Worker is available to help you through this involved process.

## **THE TRANSPLANT EVALUATION**

### ***Key Points:***

- ***There are many tests that are needed before transplant***
- ***A committee reviews the test results to see if transplant will be an option for your child***

### ***Introduction***

The evaluation may show other medical problems that need to be treated before transplant surgery. Occasionally, the pre-transplant evaluation will uncover a problem that removes transplant as a treatment option.

Long term illness can be very stressful for both the child and the family because it can change the family's lifestyle in many ways. Therefore, in addition to checking the patient's physical status, we need to fully understand the patient's support systems, skills and developmental history.

We will want to get a clear picture of how stress is handled by the family and who will be available to provide emotional support for the child and the family.

### ***What are the steps of the transplant evaluation?***

Once financial coverage has been verified from your medical payment source (private insurance, Medicare, Medicaid, etc), the medical evaluation can begin.

### ***The Evaluation***

Your child will either be admitted to Children's Medical Center of Dallas for the liver transplant evaluation, or the evaluation may take place as several doctor's visits' if your child's condition allows. A full medical, psychological, and social evaluation will help us completely understand your child and his or her liver disease and the stress it will place on your family.

Our pediatric specialists and advanced practice nurses will complete the evaluation. The work-up involves interviews with our gastroenterologist, transplant surgeon, cardiologist, dietitian, psychologist, pediatric dentist, social worker, child life specialist, anesthesiologist, chaplain, financial counselor and other specialists if necessary.

### ***Function of the Liver Transplant Selection Committee***

Once the medical evaluation is done, your child's case will be presented to the Liver Transplant Selection Committee. This committee meets weekly and is made up of the team that evaluated your child. The committee will decide if your child requires transplant and how soon one may be needed. The committee also decides how to keep your child in the best health possible until transplant.

*What tests are done during the evaluation?*

In addition to the interviews, your child will have blood tests which include, but are not limited to a complete blood count, blood type, liver function tests, metabolic tests, trace element levels, fat-soluble vitamin levels, HIV testing and testing for immunity to several important viruses. Other tests that will be performed include a chest X-ray, bone X-ray, electrocardiogram (EKG), abdominal ultrasound, nutritional assessment, and developmental and psychological assessments. In addition, other tests such as an arteriogram or abdominal X-rays may be required and can lengthen the evaluation. These and other tests are explained below. Your child may not need all of these examinations.

**Chest X-ray** -- This is a black and white picture that shows the shape and size of the heart and lungs. This only takes a few minutes and it is not painful.

**Bone X-rays** -- Black and white pictures that can show any problems with your child's bones and help determine their bone age. This helps measure your child's potential for future growth. Each x-ray takes only a few minutes and it is not painful.

**Electrocardiogram (EKG)** -- provides a graphic record of electrical activity in your child's heart. Several "stickers" (also known as leads) will be placed on your child's chest and connected to a machine that receives the electrical impulses from your child's heart. The machine will record on paper a graph of your child's heart activity. When the test is over, the stickers will be removed. This take only takes a few minutes. It is not painful.

**Echocardiogram (ECHO)** -- The cardiologist uses sound waves (ultra sound) to draw a picture how effectively your child's heart is pumping blood. This is similar to what doctors use to see unborn babies when the mother is pregnant. Your child will lie on a bed and lubricating jelly will be placed on his/her chest. The technician will slide a transducer probe (which looks like a microphone) over the chest area. The test does not hurt and takes about 20 to 40 minutes. In order to get a true study, the child must be very still during the echocardiogram. Therefore, drugs that make your child sleepy may be given if your child is very active or anxious.

**Abdominal Ultrasound (Sonogram)** -- Like the echocardiogram, this procedure uses sound waves (ultra sound) to look at the liver, bile ducts and vessels that give blood to and from the liver. This is similar to the Echocardiogram. Your child will lie on a bed and lubricating jelly will be placed on his/her stomach area. The technician will slide the transducer probe over the stomach area. This test does not hurt and will take about 20 to 40 minutes.

**CT scan** -- A computerized picture which shows the size and shape of the liver as well as the major blood vessels of the liver. Contrast (a white medication) may be injected into your child's bloodstream to better look at his or her organs. In order to get a true picture, your child must lie very still during a CT scan. Therefore, sedation (drugs that cause your child to become sleepy) may be given if your child is very active or anxious.

**Cholangiogram** -- This study provides a picture of the bile ducts.

**Liver Biopsy** -- During this test, doctors take a small sample of liver tissue with a special needle. Your child will be given sedation (medicine that will put them to sleep). The needle will be inserted into the liver through the skin. The liver is located on the right side of your child's stomach under their rib cage. The needle will pull out a small piece of the liver. This piece will be sent to a lab where the doctor (pathologist) looks at it under a microscope. A pathologist looks at the piece of liver tissue to figure out the cause and how much of the liver is damaged. The procedure takes 30-60 minutes total. Your child will be monitored after on the floor before you take them home.

**Gastrointestinal Diagnostic X-rays** -- This test takes many black and white pictures of your child's esophagus, stomach, and intestines. Your child will need to swallow a white medication (barium) or have that medication put in their bottom. The medication will make the GI tract (esophagus, stomach, and intestines) easier to see on the x-ray. The doctors use this test to see if there are any problems with these organs.

**Endoscopy** -- A procedure in which a flexible camera tube is placed down the throat, through the stomach, and into the small intestine to find the cause of bleeding or to evaluate ulcers (sores in the lining of these organs).

**Arteriogram** -- Contrast medication is injected into blood vessels to find out if there any artery or vein leading to or from an organ that is not getting blood flow.

**Pulmonary Function Studies** -- These tests measure how the lungs take in and release air. It also shows how the lungs take oxygen from the air and deliver them to the body. Your child will have to breathe into a mouthpiece. The mouthpiece is connected to a machine that will tell the doctors how your child's lungs are working.

**Renal Function Studies** -- Depending on the kind of your child's liver disease, the transplant team may also do kidney tests to determine the kidney's ability to handle fluid loads.

**Magnetic Resonance Imaging (MRI)** -- This test uses radio waves, a powerful magnet, and computers to produce a detailed body image picture. The MRI does not use radiation. MRI allows the radiologist to examine your child for special problems that may not show up on other studies such as a CT scan or ultrasound. An MRI will be done if the radiologist is unable to confirm that your child's portal vein and inferior vena are open using ultrasound. These vessels feed the liver with food. To get a true image, your child must lie very still until the test is completed. Therefore, sedation (drugs that make your child sleepy) may be given if your child is active or anxious.

### ***Immunizations***

It is very important all family members and the child have their immunizations up-to-date at all times. At the time of transplant, you child will start taking immunosuppressive medications, which reduce the chance of your child's body rejecting or fighting its new liver. These medications also keep your child's body from fighting other diseases and infections. Because of these medicines, it will be easier for your child to catch colds and viruses after transplant.



The age at which a vaccine is given, the length of time required after the vaccine for it to work, and the vaccinations requiring "boosters/more doses" vary for different immunizations. Immunization requirements can also be different for different geographic locations. More immunizations may be needed depending upon the type of travel being taken; such as traveling to countries outside the United States, or living in countries other than the United States. Some immunizations also require a waiting period after vaccination before the liver transplant can be done.

Your local doctor can tell you what immunizations are needed and when they should be given, both for the child and the rest of your family.

You will need to bring a copy of your child's immunization records to your evaluation appointment.

## **FINANCIAL AGREEMENT**

### ***Key Points***

- ***You must notify your coordinator if you lose your insurance coverage immediately***
- ***Transplant is expensive and a big commitment for life***
- ***Transplant requires insurance coverage***
- ***Medications for the first month after transplant can cost up to \$15,000***

Transplants are life changing. It is a serious lifetime commitment and is expensive. The decision for transplant is a partnership between you, your doctors, and the transplant team.

It is important to keep insurance coverage to support the cost of the transplant and for on-going care and medications.

It is important that you understand the rules and requirements of your current insurance plan.

If your insurance changes or is cancelled, please call your transplant financial coordinator, **immediately**. If you know it will be cancelled call the financial coordinator **before** it is cancelled. Your failure to do so can result in an insurance denial. You will be responsible to pay all charges for the transplant and test(s).

Not notifying your transplant team of insurance changes can also change listing status.

Please be aware that Children's Medical Center at Dallas is unable to pay for your medications. Your Transplant Financial Coordinator can help you in reviewing the other options to insurance plans.

### WAITING FOR TRANSPLANT

We know that waiting for an organ to become available is a difficult and stressful time during the transplant process. As a parent, you may feel a sense of hopelessness and loss of control. We will do whatever we can to decrease your anxiety and to allow you to continue your normal activities. Please contact your transplant social worker when you have these feelings.

#### ***What happens after the transplant evaluation?***

After the evaluation, the transplant team will discuss your child and the results of the transplant evaluation. At this time, the team will decide whether or not your child is a transplant candidate. The team will discuss the urgency of your child's case and decide how to keep your child growing and in the best possible health until the transplant operation.

If your child is approved for transplant, he or she will be placed on a waiting list. If your child is placed on the **inactive** list, this means your child is either doing well and does not need a transplant at this time or may be temporarily too sick to transplant. Your child will be placed on the **active** waiting list if he or she has complications and the transplant team feels his or her medical condition requires a liver transplant.

*Portions of the following information are adapted from Transplant Living's website at <http://transplantliving.org/beforethetransplant/allocation/matchingorgans.aspx>.*

#### ***How does the waiting list work?***

The U.S. Department of Health and Human Services' Health Services & Resources Administration (HRSA), United Network for Organ Sharing (UNOS) keeps a centralized computer system called UNet<sup>SM</sup>. Transplant centers can access this computer network 24 hours a day, seven days a week.

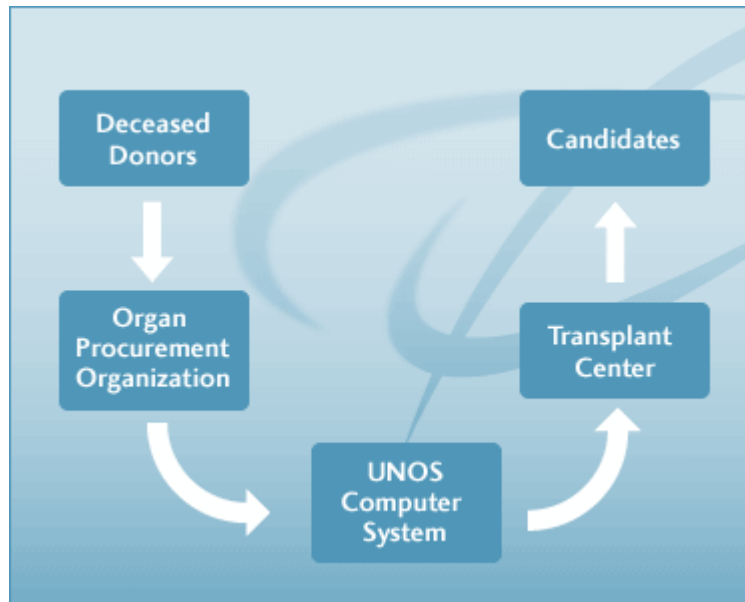
UNet connects all transplant hospitals and organ procurement organizations in a safe, real-time place. Because UNet uses the Internet, it gives access to many transplant professionals. However, in order to protect the private medical records, all users must use have a secure password.

#### ***Matching Donor Organs with Transplant Candidates***

When a deceased organ donor is identified, an organ recovery coordinator from an organ procurement organization (OPO) accesses the UNet system and enters medical information about the donor. The system uses this information to match the medical information of the candidates (your child) waiting against those of the donor. The system then creates a ranked list of patients who are fit to receive each organ. This list is called a "match run." Factors affecting ranking may include:

- tissue match (Comparison of your child's tissues versus the donor's tissues)
- blood type (A, B, AB, O)
- length of time on the waiting list
- immune status (viruses or infections your child has had or immunizations your child has received)

- distance between the potential recipient and the donor
- degree of medical urgency (for heart, liver, lung and intestines)



The first person on the list receives the organ offer. Often, the first transplant candidate will not get the organ for one of several reasons. When a patient is selected, he or she must be available, healthy enough to undergo major surgery and willing to be transplanted immediately. Also, a laboratory test to measure compatibility between the donor and potential recipient may be required. If the organ is refused for any reason, the transplant hospital of the next patient on the list is contacted. The process continues until a match is made. Once a patient is selected and contacted and all testing is complete, surgery is scheduled and the transplant takes place.

### *The Five Steps of the Matching Process*

1. **An organ is donated.** When the organ becomes available, the OPO managing the donor sends information to UNOS. The OPO procurement team reports medical and genetic information, including organ size, condition, blood type and tissue type by entering this information into UNet.
2. **UNOS generates a list of possible recipients.** The UNOS computer creates a list of possible transplant candidates who have medical and biologic profiles that match with the donor. The computer puts the candidates in order by this biologic information, as well as clinical characteristics and time spent on the waiting list.
3. **The transplant center is notified of an available organ.** Organ placement specialists at the OPO or the UNOS Organ Center contact the centers whose patients are on the local list.
4. **The transplant team considers the organ for the patient.** When the team is offered an organ, it decides its acceptance or refusal of the organ based upon medical criteria, organ condition, candidate condition, staff and patient availability and organ transportation. By policy, the transplant team has only one hour to make its decision.

5. **The organ is accepted or declined.** If the organ is not accepted, the OPO continues to offer it by following the list until it is matched with a recipient.

### ***Multiple Listing***

A patient may wish to be listed at more than one transplant center. However, each center decides who it accepts as candidates and has the right to decline patients who are listed at other centers. Caregivers/Parents should inform the centers they contact of their multiple listing plans. Waiting time starts after each center evaluates a patient and places him/her on the organ transplant waiting list.

### ***Transfer of Waiting Time***

If a patient would like to change transplant centers, the patient may transfer his or her primary waiting time to the new center upon listing at that center. The parent should then notify his or her child's original center of the need to be removed from that center's waiting list.

### ***What about transportation to the transplant center when a liver becomes available?***

Your transplant coordinator will tell you when you need to arrive at the center. You should arrive at the transplant center as soon as possible once a potential donor for your child has been identified. It is important you have a reliable car or ride to get your child to the hospital.

You can drive to the hospital if your child is at home and you only live a few hours away. Otherwise, you will need to know the plane flight schedule to Dallas from your home and be ready to take the next available flight to either Dallas/Fort Worth Airport or Love Field. At the airport, you can take a taxi or the "Super Shuttle" van to the hospital. It is important for you to find out the cost of travel ahead of time and be prepared for these costs when your child is asked to come to the hospital for transplant. If your child is hospitalized at your local hospital, we may need to have your child transferred to Children's by ground or air ambulance. It is important for you to contact your transplant coordinator if your child is admitted to another hospital.

### ***How will the transplant center reach me if an organ becomes available?***

We will need to be able to reach you 24 hours a day. If the transplant team is not able to reach you, your child may miss the organ transplant.

At the time of listing for transplant, you will be asked to provide a list of telephone numbers that will provide multiple ways of reaching you and your child's caregivers. It is also necessary to provide a telephone number of a close relative or family member (your "backup" person).. This person should be able to reach you directly. Since the transplant center needs to know the current working number that you can be reached on at all times, if your contact numbers should change please inform us at **Transplant Center's phone number 1-800-846-6768 or 214-456-8600** immediately.

### ***How do I handle the stress of waiting for a transplant?***

Waiting for a donor liver to become available can be extremely stressful. However, there are many resources available that can help you cope with this difficult period. Your transplant team can help meet your needs and answer any questions you may have along the way. Don't hesitate to talk with a social worker, psychologist, religious counselor or friend about what you are feeling. Often simply talking with someone can provide relief for much of the stress and put your

concerns in perspective. Your social worker can provide programs and people in the community for further support. Support groups can also help reduce stress.

***What are support groups and how can I get involved?***

Support groups are offered to families of children hospitalized for liver transplant and those being evaluated for transplantation. These casual groups serve as a resource to help families handle individual and social concerns that often happen with hospitalization and liver transplant. Families in the same situation meet to share stories and worries within a safe and friendly environment. The social worker can help you find any support groups that may be available in your local area as well.

***Is it normal to feel guilty about the donor family?***

In order for liver transplantation to happen, it requires the death of one person to save the life of another. Feelings of guilt about the death of the donor are a normal emotion.. Talk with members of the transplant team about how you are feeling and remember the organ donors are choosing to give your child one of the greatest gifts -- the gift of life.

***Can a transplant ever be canceled?***

Although it is rare, it is possible that you could come to the hospital only to find out the surgery has been canceled. Although many tests are done on the donor, it is only after a transplant surgeon has seen and examined the liver that we can decide whether the donor organ is acceptable. Your child will also be examined before the transplant surgery, and certain problems may require the transplant to be canceled. (See "Pre-Operative Preparation" in the Transplant Surgery section).

## TRANSPLANT SURGERY

### ***Introduction***

Dr. Thomas Starzl established the concept of liver transplantation in 1963. Early results of transplant in humans were discouraging, as the survival rate one year after transplant was only 25 to 30 percent. However, transplant became more successful when doctors began using the immunosuppressant drug Cyclosporine in 1981. This drug helps reduce the chance the transplanted organ will be rejected. Since the early '80s, the one-year survival rate has improved to a level of 75 to 80 percent. Today, liver transplant is no longer considered experimental surgery but rather an accepted treatment for people with end-stage liver disease.

Sometimes the liver disease becomes so bad that it causes major liver damage that cannot be improved by medication or surgery. Transplantation is then needed. Transplant in children happens at an early age because many of these diseases begin showing symptoms in the newborn period. Transplant offers liver disease patients the chance to have a normal, active, independent life. However, transplant requires many lifestyle changes including temporary changes in the patient's diet, frequent visits to doctors for follow-up, frequent lab work, and taking medicine on a regular basis for life.

### ***Notification***

A transplant coordinator will contact you when a good donor has been identified for your child. Your coordinator will ask several questions. Your coordinator will need to know if your child has had a recent fever, cold, flu, rash, or recently been exposed to a disease that can be spread from person-to-person, such as chickenpox or measles. He or she will also tell you when you need to arrive at the hospital. Once you are told that a liver is available, do NOT give your child anything to eat or drink.

When you arrive at Children's Medical Center, go directly to Admissions on the first floor of Tower D. Once admitted, a staff member will go with you to the Gastroenterology (GI) floor. The nursing staff on the gastroenterology floor will care for your child before the surgery, after the transplant, and when your child is released from the pediatric intensive care unit (PICU).

### ***The Gastroenterology Floor***

The Gastroenterology floor contains a treatment room, 2 nurse's stations, 18 patient rooms, and a playroom.

Each patient room has a sofa that makes a bed, a bathroom with a bathtub and shower, storage drawers, closet, television, TV/nurse call light and a telephone. To place an outside telephone call, dial "9" first. Calls are connected to patient rooms from 8 a.m. to 8 p.m. daily, but you may call outside the hospital at any time.

### ***Pre-Operative Preparation***

Before surgery, an anesthesiologist and a pediatric resident or nurse practitioner/doctor assistant will see your child and do a brief medical history and physical. An intravenous (IV) line will be inserted and routine pre-surgical tests will be done, including a chest X-ray and blood work. If, during this time period, any sign of active infection and/or a serious medical problem is found, the transplant may need to be cancelled.

We know that canceling the transplant can be an upsetting experience for you and your child. It is important to keep in mind that we need to make certain that both the donor liver and your child are in an acceptable condition to be successful. It is rare that transplant surgery is cancelled. If this happens, your child will be discharged and reactivated on the transplant list when appropriate.

If your child is cleared for transplant, he or she will stay on the gastroenterology floor until called to the operating room. In many cases, you will come to the hospital during the late evening and the transplant surgery will begin the next morning. Depending on your child's pre-operative lab work, it may be necessary for your child to have a blood transfusion of whole blood, platelets and/or fresh frozen plasma before surgery.

When it is time for the transplant surgery, your child will be taken from the gastroenterology floor to the operating room, located on the second floor of Children's Medical Center. There is a comfortable waiting area nearby for parents and family members to stay while the transplant is in progress. An operating room nurse will show you to this waiting area.

After your child is taken into the operating room, you should try to catch up on your sleep or get something to eat. Be sure to tell the operating room desk where you will be if you leave the waiting area.

### ***The Operation***

Liver transplant is considered to be the most difficult of all transplant operations. The surgery is performed under general anesthesia (pain and "sleepy" medication that completely puts your child to sleep) and usually lasts between 8 to 18 hours. An operating room nurse will give you updates on your child. If you have any concerns during the operation, a social worker and chaplain are available at any time.

Once your child has received general anesthesia and is asleep, the transplant team will start the operation. During the operation, many things such as your child's pulse, heart, blood pressures and breathing will be continuously monitored. Many blood tests such as calcium, potassium and glucose will also be monitored in the operating room.

The transplant surgeons will make an incision in the upper part of your child's stomach area, from right to left, occasionally with a vertical incision up to the sternum (breast bone). This is sometimes referred to as a "Mercedes" incision because it looks like the Mercedes symbol. Once the donor liver arrives in the operating room and is determined to be an acceptable fit, the surgeon will remove your child's liver. This is done by cutting the muscles that hold the liver in the body as well as some of the major blood vessels including the hepatic artery, portal vein and



inferior vena cava. Parts of these vessels do stay in your child because they are necessary to connect with the donor vessels. These blood vessels are clamped while your child's liver is cut out to prevent bleeding. There are four blood vessels that connect the liver to the rest of the body. After the donor's vessels have been connected to your child's vessels, the transplanted liver's bile ducts will be connected to your child's intestines. Bile, the substance that helps in the absorption of fats and minerals, will then be able to drain from the liver into the intestines.

Different types of bile duct connections are used depending on your child's type of liver disease, or the size of his or her bile ducts. The most common pediatric bile duct (tube) connection is called a "Roux-en-Y (pronounced roo-en-Y). The Roux-en-Y was named for Dr. Cesar Roux, the surgeon who developed this technique. This involves bringing a portion of the small intestine up to the bile duct of the transplanted liver. Once the procedure is completed, the shape resembles a "Y." A small plastic tube, called a stent, will be placed inside across the suture line between the intestine and the bile duct. This prevents the area from closing off and blocking bile flow while healing takes place. The stent will pass out through your child's stool within a few months after the transplant.

In some patients, the bile duct and the bile duct of the transplanted liver will be large enough to connect the two ducts directly together.

Once the bile duct connection is completed, and any bleeding has been controlled, drains will be placed and the incision site closed. When the transplant surgery is over, the transplant surgeons will look for you in the waiting room so they can talk to you about the operation. If you decide to leave the waiting area, please notify the desk at the OR where you will be, so we can find you. It is helpful to leave your cell phone number with the OR desk. After surgery, your child will be transported to the Pediatric Intensive Care Unit (PICU).

### ***Risks of Liver Transplant Surgery***

- Surgical risks of the liver transplant operation include, but are not limited to, death during the operation and in the postoperative period, vessel and biliary complications, infections (pneumonia, intra-abdominal infection, and wound infection), and the need for blood transfusions with the possibility of a transfusion reaction (your child may have an allergic reaction to a blood transfusion) and possible exposure to HIV or hepatitis or other viral infection.
- Risk of arterial and portal vein thrombosis which are life threatening and may require immediate re-operations. Arterial and portal veins deliver oxygen to the liver and move blood from the liver. Thrombosis is a clot formation where those veins or arteries are blocked or clogged off. If blocked, the liver can no longer get oxygen and it can damage the liver. If the liver is seriously damaged immediate re-transplantation is required.
- Anticoagulation in the postoperative period to prevent vascular thrombosis carries the risks of bleeding in the abdominal surgical site or the head. Anticoagulation is where a medication is given that keeps the blood from forming a clot. It's important to keep blood flowing to the new connection sites in the new liver. However, this makes the blood unable to clot anywhere in the body. Your child can bleed out of any cut or hole

that they may have, for example the incision site, or from nose, mouth, IV sites. This may require immediate re-operations or blood transfusions.

- Soreness in the back of the throat after surgery because of the placement of the breathing tube, pain in the incision area, and possible back pain from lying on the operating room table for a long time.
- There is no guarantee that the liver transplant will work right away and there is a risk the transplanted liver will never function; although, this risk is less than 5%. When a liver is first placed in a patient and does not work it is called primary non-function. The treatment for primary non-function is to transplant a new liver again (re-transplantation). In about 5-25% transplant surgeries, there may be infection, vascular or biliary problems which may require one or more re-operations or re-transplantation.
- The patient survival rate one year after transplant surgery is greater than 70%. The results at Children's Medical Center, as well as national averages are published by the Organ Procurement and Transplant Network at <http://optn.transplant.hrsa.gov/>. The organ donor risk factors that affect the success of the liver transplant include the accuracy of the donor history, the condition of the organs, the age of the donor, the cold time (or amount of time from the procurement "when the liver was removed from the donor" to the implantation "when the liver was connected to your child"), the chance of the recipient having the HIV virus, other infectious diseases and cancer, if the disease or cancer was not found in the donor before transplant.

### NUTRITION

Nutrition (food) plays an important role in getting ready for transplant and healing after transplant. It is also important to keeping your child's body in good health years after transplant. A dietitian (food specialist) will be available to work with your child both in the hospital and in the outpatient clinic. The dietitian will work with your family to put together a food plan designed for your child and his or her special needs.

#### ***Pre-Transplant***

Children with liver disease often have trouble growing before transplant for many reasons. The liver has many jobs related to nutrition, including the breakdown and use of carbohydrates, protein, fat, and fat soluble vitamins. In children with liver disease, the liver is not able to perform these jobs very well. Children with liver disease use more calories than other children their age and may feel full with smaller amounts of food or formula. Children who have jaundice may not be able to digest and absorb all of the fat and fat soluble vitamins they eat. This happens when there are not enough bile salts being sent from the liver into the intestines. When your child does not digest and absorb fat, he or she cannot use the calories that fat gives to the body. This can lead to slower than normal growth or weight loss. Your child may start to look skinny and not grow like other children without liver disease. Fat soluble vitamins are also important for your child. The fat soluble vitamins are vitamins A, D, E, and K. Vitamin A is important for growth, vision (eyes), and the skin and hair. Vitamin D is important for growth of your child's bones. Vitamin E is important for the growth of muscles and nerves. Vitamin K plays an important role in helping the blood to clot. If your child has low blood levels of these vitamins, extra vitamins will be given.

Because of the reasons above, your child may need extra nutrition or special types of formula to help them grow. Examples of these types of nutrition are:

#### ***Oral diet and supplements:***

##### ***Infants***

- If your child is less than 1 year of age, he or she may be getting breast milk or infant formula. Breast milk may need to have formula added to it to increase the amount of calories your child drinks. Formula may be mixed with higher calories to give more nutrition in the same amount of formula.
- If your child is unable to breakdown and use fat, a formula with a special type of fat is needed. Medium chain triglycerides (MCT) are a special type of fat that can be used without bile salts. An example of this special formula is Pregestimil.
- Talk with your dietitian or doctor about when to start solid foods if your child is not taking them already.

### ***Children***

- Along with meals, your child may need oral supplements (liquid drinks your child can take by bottle or cup) to help with weight gain.
- Oral supplements are drinks that can raise the number of calories your child takes in each day. Examples of oral supplements for children are Pediasure, Boost Kid Essentials, and Carnation Instant Breakfast.
- If your child is unable to breakdown and use fat, a supplement with a special type of fat is needed.

### ***Teenagers***

- Older children and teenagers may also need oral supplements, such as Carnation Instant Breakfast, Boost, or Ensure.
- Oral supplements with higher amounts of medium chain triglycerides (fat that can be used without needing a healthy liver) may also be needed.

### ***Tube feeding***

- If your child will not drink oral supplements, or needs more calories than oral supplements can provide, a feeding tube may be needed.
- A feeding tube is a flexible tube that is placed through the nose into the stomach or intestines.
- A feeding tube allows your child to get more nutrition during sleep or after meals.
- Your family will be actively involved in making a food plan that works for your family.

### ***Parenteral nutrition***

- Parenteral (food given through an IV) nutrition is only used if your child is unable to tolerate nutrition through his/her gastrointestinal tract.
- Parenteral nutrition is a fluid run through a vein that provides all the nutrition your child needs. It contains protein, fat, carbohydrates (sugars), vitamins, minerals, and electrolytes.

### ***Immediately After Transplant***

Nutrition immediately after transplant is different for every child. Some children are ready to eat a few days after surgery and others may need a tube feeding or parenteral (IV) nutrition until they are able to eat. Your child and their medical course after transplant will shape the food plan. The medical team will let you and your child know when he/she is able to start eating after transplant. Once your child is able to start eating, he/she will first receive clear liquids. Examples of clear liquids are juice, clear sodas, popsicles, broths, water, tea, and jello. The nurse will watch for vomiting, stomach aches, and diarrhea. If your child does not have any of these

problems, your child will be able to start eating a greater variety of foods. Your dietitian will talk with you about what foods your child can and cannot eat.

### ***Post-transplant***

The basic rules of diet after liver transplant are:

1. Reach and/or continue a normal body weight for age.
  - If your child is underweight, it is important to work towards gaining weight. Normal body weight saves enough fat and protein for protection during periods of stress or infection.
  - If weight loss is needed, your dietitian will decide the right amount of calories to help with weight loss.
  - Long term use of immunosuppression medicines can cause weight gain. Weight will be tracked during follow-up visits and changes in diet will be made by your dietitian. The dietitian is here to help you and your child with changes or options with foods.
2. Focus on fruits and vegetables.
  - Fruits and vegetables are full of vitamins and minerals, fiber, and are low in calories.
  - Half of your child's plate should have fruits and vegetables at meals.
  - Give your child fruits and vegetables at snack time.
3. Control the cholesterol and fat your child eats.
  - A small amount of cholesterol and saturated fat in the diet is suggested.
  - Polyunsaturated fats are replaced for Trans and saturated fats. These will help lower blood cholesterol levels.
  - Immunosuppression medicines can raise cholesterol levels. It is good to follow a low fat and cholesterol diet even if blood cholesterol levels are normal.
  - You can look at the label on the food package to see how much Trans and saturated fats food has in it. Your dietitian can help you with this information.
4. Control the amount of salt (sodium) your child eats..
  - The use of prednisone (steroids) causes your body to hold onto salt (sodium).
  - Too much salt may cause your child's body to hold onto water. Your child may look "puffy".
  - You should try to limit the amount of salt your child eats. This will help your child not hold onto extra water. It will also help your child keep their blood pressure normal.
  - Salt replacements that contain the mineral potassium should not be eaten. Some of the medicines your child will take can cause high potassium levels in the blood. This can be harmful to your child.
  - Your dietitian will teach you which foods should be avoided and ways to use herbs and spices for seasoning.

5. Limit sugar and sweets.
  - Prednisone may cause an increase in blood sugar and triglyceride levels.
  - You should try to limit sugars and sweets.
  - Focus on whole grains. Choose 100% whole grain cereal, rice, pasta, breads, and crackers.
  
6. Drink plenty of liquids, especially water.
  - It is important to encourage your child to drink water. Drinking the right amount of water during the day will also help flush the medicines through the kidneys.
  
7. Practice washing and cooking food correctly.
  - Immunosuppression medicines put your child at higher risk of catching an infection.
  - Cook foods to the right temperatures.
  - Do not give your child raw fish and seafood, unpasteurized milk and juices, uncooked eggs, and unwashed fruits and vegetables.
  - Your dietitian will give you information to help you learn these tips.

MEDICATIONS

**Key Points:**

- ***Know what medications your child takes for rejection***
- ***Learn what your child's medications are treating***
- ***Know the main side effects of your child's meds***
- ***Know what time to give the medications***
- ***Learn how to give the medications to your child***
- ***Learn how to store the medications***
- ***Know which meds cannot be given together***

Medications are critical to the success of your child's liver transplant. Without these medicines, the body will reject the new liver. The body's response to the new liver is to fight it off as it would a cold or virus. Medicines are given to your child's specific needs to prevent the body from fighting or rejecting the new liver. The medicines must be taken as directed; do not change or stop giving your child's medicines unless told to do so by a member of the transplant team. We expect parents and eventually the child, to understand the way each medicine works; so please be sure to ask questions to be sure you are clear on any information given to you. Understanding the medicines helps you to know the side effects when they occur. Within the first few days after transplant, your family will begin to give medications to your child, with the help of your nurse. You will be given a schedule for the medicines that you may update each time a change in medications is made.

Before discharge from the hospital, we will teach you:

1. The generic and brand names of each medicine.
2. What each medicine looks like
3. The purpose and action of each medicine
4. How to determine the correct dose of each medicine
5. Precautions required for each medicine
6. How and when to take the medicine
7. The common and uncommon side effects of each medicine

The medication schedule should be updated with each change to dose or administration time. We ask that you make any changes to the schedule in pencil so that changes are easily made. Each time a change is made in medication during hospitalization, your nurse will tell you and you should make the change on the schedule. Should you have any questions, please talk about the change with your nurse. By making the changes yourself, you will feel comfortable making changes after discharge home. During hospitalization, your nurse will make sure the entries are correct.

**Once you are at home, medications should be given according to your medication schedule given to you by the transplant team. Do not follow the instructions written on the medication bottle.**

Be sure to store all the medicines in their original containers. This will be helpful in keeping up with the expiration dates, who prescribed each drug, etc. Store all medicines away from heat, direct light and moisture, each of which can cause the drug to go bad. Always give medications at the same time of the day, every day. Each of the routine medicines needs to achieve a stable level in the blood. Monitoring of these blood levels will be done and the test results are used to make changes in medication dosages. Therefore, it is crucial that medications are given in a consistent way.

Your child must take all their medicines as they are prescribed. If your child has nausea, vomiting or diarrhea and cannot take the medicines, please contact the Transplant office immediately. If a dose is missed at the prescribed time, please contact the transplant office for instructions.

Many medications will affect the absorption of the immunosuppressive drugs or may interact with them in an unwanted way. Therefore, do not give your child any over the counter medicines or medicines prescribed by a doctor who does not know your child's medical history without first talking with the transplant team.

Always bring your child's medication schedule to the clinic so that changes may be made if needed. You and your child should keep a copy of the medication schedule at all times, should your child need to go to the hospital. If you have any questions or have trouble understanding the medication list, contact the transplant office right away. There is a transplant coordinator on call 24 hours a day to help you.

### ***General Medication Information***

- Prescription refills are handled during normal business hours, Monday through Friday. Please plan to refill your child's medications early enough so that you do not run out. It is vital the pharmacy knows that you are in need of a refill 7 days before you need it, in order to get a timely refill.
- Generic versions of brand name Immunosuppressants such as: Prograf, Neoral and Cellcept are available. It is important to stay on the brand name unless your transplant doctor tells you to take the generic.
- Always take as directed. Follow the directions given by your transplant provider, not what is printed on the label of the medicine. Since, the dose may be changed before a refill is given to you from the pharmacy.
- Do not stop taking any drug without being told to do so.



- Do not add any over-the-counter medications or supplements, including herbal remedies, unless your transplant provider knows about it.
- Contact your transplant provider if you notice any physical or mental changes in your child.
- Take doses at the same time every day to avoid missing doses.
- If your child vomits within thirty minutes of taking their immunosuppressive medications give the dose again. If your child vomits after thirty minutes of taking the second dose, do not give a third dose, and call the transplant coordinator. Please contact the transplant coordinator if your child keeps vomiting.
- Keep medicines away from heat, light and moisture (such as the bathroom vanity or kitchen cabinets).
- Call your pharmacy if any medicine doesn't look "right" for any reason.
- Do not try to make up for missed doses unless told to do so by your transplant provider.
- 1 cc is the same as 1 ml
- Check expiration dates on all medicines. Throw away and replace medicines that have expired.
- **Do not give your child any drugs containing an NSAID (non steroidal anti-inflammatory drug) such as: Ibuprofen, Motrin, Midol, and Aleve unless told to or approved by your transplant doctor. NSAID's used together with Prograf or Cyclosporine can cause renal (kidney) problems.**

### *Immunosuppressive Drugs*

Some common transplant medicines are Prograf (Tacrolimus), CellCept (Mycophenolate Mofetil), Neoral (Cyclosporine), Prednisone and Imran (Azathioprine). They all act to suppress the immune system and prevent rejection. Your child will need to take immunosuppressant medicines after transplant for as long as they have their transplanted organ. These are powerful drugs, with many side effects, and they must be taken exactly as prescribed.

If your child's immune system is not suppressed enough by the medications, it will be able to destroy (reject) the transplanted organ. If your child's immune system is suppressed too much by the medications, it will not be able to protect him or her from infection and may also result in other unwanted and dangerous side effects. Therefore, you must follow the medication schedule exactly as directed. **Under no circumstances** should you change the dosage of these drugs without instructions from your doctor or the transplant office.

The following is a list of medications which are commonly prescribed to post-transplant patients. The medications prescribed for your child will be personalized to meet his or her individual needs. This list is meant for informational purposes only. Your transplant providers and

transplant coordinators will provide education and ensure that you develop a good understanding of the medicines your child is taking.

## **Prograf (Tacrolimus)**

### ***Purpose***

Prograf is an immunosuppressive drug. Prograf helps prevent rejection by suppressing the activity of the immune system.

### ***Description***

Prograf currently comes in 0.5mg and 1 mg white capsules and 5 mg grayish/red capsules. Prograf is also available as a 0.5mg/ml compounded suspension, prepared by the pharmacy.

### ***When to Give***

Prograf must be given as ordered. Most children will be given two doses each day; the first at a set time in the morning with the second dose given 12 hours later. It is essential that you follow the dosage schedule as directed.

### ***How to Give***

If your child can swallow pills/capsules, he/she will swallow the appropriate number of capsules as directed. (Examples: 3 mg dose = three 1 mg capsules; 6 mg dose = one 5 mg capsule and one 1 mg capsule). If your child is taking the suspension, you will be taught to draw up the right amount using a syringe. Be sure to **shake** the bottle well before drawing up the dose. (Example: 2 mg dose = 4 ml of Prograf suspension).

### ***Side Effects***

These side effects have been associated with Prograf. As with Neoral (Cyclosporine), many of these side effects will be more obvious when the level of the drug is high; they will most likely decrease when the drug dose is reduced. **Do not ever** change the dose on your own; you will be putting your child's transplanted organ at risk.

- Increase in blood sugar.
- Low magnesium level in the blood.
- High potassium level in the blood.
- Inability to sleep.
- Tremors of the hands. This is a common side effect that will decrease over time as the Prograf dose is reduced.
- Diarrhea; sometimes with nausea and vomiting
- High blood pressure. Your child may be on medicines to lower blood pressure. If he or she has many headaches or dizziness spells, you should call your transplant provider because these may be signs of high blood pressure.

- Increased risk of infection. Any fever, cough, rash or mouth lesions should be reported to the transplant provider. You must call your transplant provider right away if your child has been around someone with chickenpox and he or she has never had chickenpox.
- Potential damage to the liver or kidneys. There will not be any specific symptoms you will notice. Your child may have elevations in certain blood work results, such as BUN, creatinine, potassium and liver function tests.
- Potential for post-transplant lymphoproliferative disease (cancer)

***Storage***

- Store at room temperature.

***Precautions:***

- Avoid grapefruit and grapefruit juice.
- If using the liquid form, do not give after the expiration date on the bottle.
- If using the liquid form, carry an extra bottle when traveling.
- Always keep medicine with you in carry-on luggage when traveling. This way, you will have it in case your check-on luggage is lost.
- Some drugs interfere with Prograf blood levels. Your doctor will have information on how certain drugs affect Prograf. You should not add any over-the-counter medicines or change any other medicines unless told to do so by your doctor or the transplant team.
- If your child vomits within thirty minutes of taking their immunosuppressive medications give the dose again. If your child vomits after thirty minutes of taking the second dose, do not give a third dose, and call the transplant coordinator. Please contact the transplant coordinator if your child keeps vomiting.
- Wait half an hour and then give one to two ounces of fluid
- If your child keeps the fluid down for 30 minutes repeat the dose of medication.
- If vomiting continues, call your transplant coordinator.
- If your child has diarrhea you must call your transplant coordinator. **Persistent diarrhea can increase the blood level of Prograf, which may increase the risk of harmful side effects.**

## Neoral (Cyclosporine)

### *Purpose*

There are two forms of Cyclosporine: Sandimmune and Neoral. These are not the same. **Neoral** is a more absorbed form of Cyclosporine and is given to suppress the immune system and to prevent rejection. It should **not** be given with Sandimmune. It is similar to Sandimmune, but they are **not interchangeable**.

### *Description*

Neoral comes in 25mg and 100mg soft gelatin capsules. Neoral is also comes as a 100mg/ml micro-emulsion oral solution.

### *When to Give*

Neoral must be given as ordered. Most children will be given two doses each day; the first at a set time in the morning with the second dose given 12 hours later. It is important that you follow the dosage schedule as directed

### *How to Give*

If your child can swallow pills/capsules, he/she will swallow the appropriate number of capsules as directed. If your child is taking the suspension, you will be instructed to draw up the right amount using a syringe. Be sure to **shake** the bottle well before drawing up the dose.

The suspension could be given straight using an oral syringe or the dosage syringe that came with Neoral (not a plastic or Styrofoam cup). To make the solution easier to take, it may be mixed with orange juice, or apple juice in a glass container at room temperature. After drinking the mixture, rinse the container with a little extra juice and drink the rinse. This will ensure that the entire dose of Neoral was given.

### *Side Effects*

- Increased Hair Growth
- High Blood Pressure
- Tremors, fine shaking of the hands may occur while on this medicine and/or immediately after taking the medicine. If it worsens and/or interferes with your daily activities, contact the transplant office
- Gum Swelling/ Sensitivity to Hot and Cold
- Decreased Ability to Fight Infection
- Potential for post-transplant lymphoproliferative disease (cancer)

### *Storage*

- Store at room temperature.

### *Precautions:*

- Avoid grapefruit juice.

- Drink right after mixing. Do not mix **in advance** or it will form clumps.
- If using the liquid form, do not give after the expiration date on the bottle.
- If using the liquid form, carry an extra bottle when traveling.
- Always keep medicine with you in carry-on luggage when traveling. This way, you will have it in case your check-on luggage is lost.
- Some drugs interfere with Neoral blood levels. Your doctor will have information about how certain drugs affect Neoral. You should not add any over-the-counter medicines or change any other medicines unless told to do so by your doctor or the transplant team.
- If your child vomits a dose of Neoral try the following:
  1. Wait half an hour and then take one to two ounces of fluid.
  2. If fluid is tolerated for 30 minutes repeat the dose of medication. When giving liquid Sandimmune, many children retain the Sandimmune better if it is given mixed in soda instead of milk.
- If vomiting continues, call your transplant coordinator.
- If you have diarrhea you must call your transplant coordinator. **Persistent diarrhea can affect the blood level of Neoral, which may increase the risk of harmful side effects.**
- Avoid rinsing the dosage syringe provided by Neoral as this will cloud the syringe. If syringe becomes wet or needs cleaning, it must be completely dry before using it again.

## Steroids (Methylprednisolone, Prednisone, Prednisolone)

### *Purpose*

Steroid medicines are like the hormones our bodies produce normally. Steroids help to prevent and treat rejection by suppressing the immune system.

### *Description*

Methylprednisolone will be given in 4 mg tablets.

Prednisone will be given in 20 mg, 10 mg, 5 mg, 2.5 mg, or 1 mg tablets. In smaller children, a liquid preparation containing 1 mg/ml or 5mg/ml will be used.

Prednisolone will be given in 3mg/ml solution.

### *How to Give*

The total prescribed dose of steroids should be given once each morning. The tablets may need to be divided in half to obtain the right dose. For example, if 5 mg tablets are given and your

child's dose is 7.5 mg, you would give 1 1/2 tablet. It can be irritating to the stomach and should not be given on an empty stomach. After breakfast is an ideal time to give the Prednisone.

### *Side Effects*

Steroids can cause a number of side effects. Some of the side effects include:

- Fluid/salt retention. This may cause the body to hold on to fluids and cause swelling of the hands or ankles (edema) and increase blood pressure.
- Increased appetite. This can lead to unhealthy weight gain.
- Increased fat deposits. This can occur in the face (called "moon face"), over the upper back and abdomen.
- Increased stomach acid. This may cause or worsen ulcers. An acid reducer is given while your child is on higher doses. Do not give Prednisone on an empty stomach.
- May slow the healing process.
- Decreases the body's ability to fight infections.
- Muscle weakness and weakened connective tissue. This may cause "stretch marks."
- Acne.
- In large doses, steroids can affect bone growth.
- Eye changes. Steroids may cause cataracts or glaucoma. Routine eye exams should be done as instructed by your ophthalmologist. Your child should be seen by an ophthalmologist if any problems occur such as blurred or decreased vision.
- Increased blood sugar. This usually happens with higher doses. In some cases, insulin may need to be given until the blood sugar returns to normal as the steroid dose is decreased.
- Increased sensitivity to the sun. Always apply a sunscreen to exposed skin when in direct sunlight for a long period of time (see "Skin Care" section).
- Mood swings-includes crying easily, giggly moods, irritable, etc.
- Insomnia or trouble sleeping.

### *Storage*

- Keep away from heat and light.

- Do not store the medicine in the bathroom, near the kitchen sink or refrigerator because moisture will breakdown the drug.
- Do not freeze the liquid preparation.

***Precautions***

Be sure to let any doctors or dentists scheduled to treat your child know that he or she is taking steroids, especially before any invasive procedures or skin tests.

**CELLCEPT  
(Mycophenolate Mofetil)**

***Purpose***

CellCept is another immunosuppressant drug that helps to prevent rejection. It can be used with other immunosuppressant medicines such as Neoral or Prograf and Prednisone.

***Description***

CellCept comes in 250 mg, blue and brown, gelatin capsules, 500mg, purple tablets or 200mg/ml suspension.

***When to Give***

CellCept must be given as ordered. Most children will be given two doses each day. The first dose is given at a set time in the morning with the second dose given 12 hours later.

***How to Give***

Separate Cellcept from magnesium by 2 hours before or after.

If your child can swallow pills/capsules, they will swallow the right number of pills/capsules as directed, followed by a moderate amount of liquid.

If the child is unable to swallow the capsules, and unable to get the liquid version, we suggest the following:

- Open capsules and place in a very small amount of pudding, chocolate syrup, applesauce or ice cream. Make sure the child eats all of the medicine mixed food.
- Open capsule and place in a small amount of juice (apple, orange or grape). Do not use grapefruit juice.

Note: For each capsule there should be 2 ml of liquid, followed by a moderate amount liquid.

If you are having trouble giving the medicines, please call the transplant office.

***Side Effects***

The most common side effects of CellCept are:

- Diarrhea
- Nausea/ Vomiting
- A decrease in the white blood cell (WBC) count. The greater the immune system is suppressed the higher the risk of infection

**Imuran (Azathioprine)**

***Purpose***

Imuran is an immunosuppressant drug that helps to prevent rejection. It can be used with other immunosuppressants such as Neoral, Prograf and Prednisone.

***Description***

Imuran comes in 50mg, 75mg and 100mg tablets. Imuran is also available as a suspension mixed by a pharmacy.

***When to Give***

Imuran should be taken once-a-day, at the same time each day.

***How to Give***

If your child can swallow pills/capsules, they will swallow the right number of pills/capsules as directed.

***Side Effects***

- Decreased ability to fight infection due to lowered white blood cell count.
- Decreased platelet count which interferes with the body's ability to clot.
- Nausea/vomiting
- Mild rash
- Fatigue or weakness



## Rapamune (Sirolimus)

### *Purpose*

Rapamune prevents rejection by suppressing the body's immune system.

### *Description*

Rapamune comes in a 1mg tablet or 1mg/ml solution.

### *When to Give*

Rapamune should be taken once-a-day, at the same time each day.

### *How to Give*

- You may take Rapamune with or without food; but **take it the same way every day**.
- If you are taking Cyclosporine, you must take **Rapamune four hours after** your dose of Cyclosporine. Unless you have been told differently by your transplant team.
- Oral Solution: **The oral liquid medicine must only be mixed with water or orange juice.**

### *Side Effects*

- Rash/acne
- Increase cholesterol/triglycerides
- Increase blood pressure
- Decreased ability to heal wounds
- Edema

### *Storage*

- Tablets: Store tablets at room temperature in a closed container, away from heat, moisture, and direct light.
- Oral Solution: Store in the refrigerator. Do not freeze.

## Nystatin (Mycostatin)

### *Purpose*

Nystatin is an antifungal medicine used to help prevent thrush, an oral fungal infection. It will be prescribed until your child's immune system is strong enough to prevent thrush infection. Thrush appears as a white coating on the tongue or inside the cheeks.

### *Description*

Nystatin may be given as a liquid, pastille (like a lozenge) or tablet. Each 1 cc (1 ml) of liquid contains 100,000 units of Nystatin; each pastille contains 200,000 units; and each tablet contains 500,000 units.

### *How to Give*

Always shake the liquid well before giving. The solution should be swished around in the mouth before swallowed. The pastille or tablet should be sucked on so they slowly dissolve in the mouth. The pastille should not be chewed or swallowed because it will not be as effective. For difficult cases, it may be necessary to dip a soft bristled toothbrush in the liquid Nystatin and brush the tongue.

### *Side Effects*

Nystatin is virtually nontoxic and is tolerated well by all age groups. Large doses have sometimes produced diarrhea, nausea and vomiting.

### *Storage*

The liquid should be stored at room temperature. The pastilles should be refrigerated.

### *Precautions*

- If other medicines are due to be given at the same time, Nystatin should be given last.
- Your child should not eat or drink anything for 30 minutes after taking Nystatin

## **Diflucan (Fluconazole)**

### ***Purpose***

Fluconazole is an antifungal medicine used to help prevent thrush, an oral fungal infection, as well as other fungal infections. It will be prescribed until your child's immune system is strong enough to prevent and fight fungal infections. Thrush appears as a white coating on the tongue or inside the cheeks.

### ***Description***

Fluconazole may be given as a liquid or tablet.

### ***How to Give***

Give as directed

### ***Side Effects***

Fluconazole **increases** available Prograf and Cyclosporine to the body. As a result, levels of Prograf and Cyclosporine will be checked and doses adjusted.

### ***Storage***

- Store tablets in dry place, protected from light
- Store suspension away from light

## **Trimethoprim and Sulfamethoxazole (Bactrim, Cotrim, Septra, TMP-SMX)**

### ***Purpose***

Trimethoprim and Sulfamethoxazole is an antibacterial combination drug. It is used to prevent a serious lung infection (*Pneumocystis jiroveci* pneumonia) in immunocompromised patients. It is also prescribed to treat and/or prevent other types of infections, such as urinary tract infections.

### ***Description***

Trimethoprim and Sulfamethoxazole are ordered by the amount of trimethoprim. It comes in regular strength tablets (400mg/80mg), double-strength tablets (800mg/160mg) and as a suspension (200mg/40mg/5ml).

### ***How to Give***

Give as directed. Shake suspension well.

### ***Side Effects***

Some of the side effects from trimethoprim and Sulfamethoxazole include:

- Nausea, vomiting, anorexia
- Allergic skin reactions (rash or hives)
- Decreased WBC, Anemia & low platelet count
- Elevation of BUN and creatinine
- Sun sensitivity

### ***Storage***

- Store tablets in dry place, protected from light
- Store suspension away from light

### ***Precautions***

- Keep child well hydrated (drink plenty of fluids)
- Stop medication and call the doctor at the first appearance of skin rash or any sign of adverse reaction such as bloody urine, difficulty breathing, fever, chills or severe fatigue. Otherwise, do not stop taking medication unless told to do so by the transplant team.

## **Ganciclovir and Valganciclovir (Valcyte)**

### ***Purpose***

Ganciclovir is an anti-viral drug used to prevent and/or treat infections from common viruses like Cytomegalovirus (CMV) and Epstein Barr Virus (EBV).

### ***Description***

Ganciclovir is given in an intravenous (IV) preparation. Valganciclovir is the preferred oral version of Ganciclovir and comes both as a 50mg/ml suspension and a 450mg tablet.

### ***How to Give***

Give as directed.

### ***Side Effects***

Some of the reported side effects include the following:

- Low white blood cell count
- Birth defect (birth control needed for at least 30 days after therapy for women and 90 days after therapy for men)

### ***Storage***

Protect suspension and tablets from light and moisture.

### ***Precautions***

There are no special precautions with the oral preparation.

## **Acyclovir/Valacyclovir (Zovirax)**

### ***Purpose***

Acyclovir is an anti-viral drug used to prevent and/or treat infections from common herpes viruses such as herpes simplex & varicella-zoster (chicken pox). Valacyclovir is a special tablet version of acyclovir that allows for better absorption of the medicine.

### ***Description***

Acyclovir comes in 200mg, 400mg and 800mg tablets or 200mg/5ml suspension. It is also given as an ointment for herpes skin lesions and as an intravenous (IV) preparation.

Valacyclovir comes in a 500mg and 1000mg tablet.

### ***How to Give***

Give as directed. Administration of intravenous (IV) Acyclovir, when necessary, will be arranged.

### ***Side Effects***

Based on experience with patients in the U.S., adverse side effects are not likely. Some of the reported side effects include:

- Fever
- Headache
- Confusion, dizziness
- Diarrhea, nausea
- Low white blood cell count
- Hair loss (alopecia)
- Itchiness (pruritus), rash

### ***Storage***

Protect capsules and tablets from light and moisture.

### ***Precautions***

There are no special precautions with the oral preparation.

- An elevation of BUN and creatinine can occur with IV preparation. These will be tested if your child needs to get IV Acyclovir.

**Acid Reducing Agent  
(Prevacid, Nexium, Prilosec & Protonix)**

***Purpose***

Immunosuppressive medications can increase stomach acid and can cause or worsen ulcers. An acid reducing drug will reduce this stomach acid. The acid reducing drug may be stopped when the risk of ulcer formation is lessened.

***Description***

They come in capsules, oral dissolving tablets and suspensions.

***How to Give***

Give as directed.

***Side Effects***

When taken as directed, they usually do not cause any side effects.

***Storage***

Keep away from heat, light and moisture.

**Phosphorous Supplement**

**(Phos-NaK packet, K-phos Neutral, K-phos Original, Sodium Phosphate and Potassium Phosphate)**

***Purpose***

Phosphorous is an important mineral for many functions of the body. A phosphorous supplement is used to treat low phosphorous.

***Description***

They come in powder packet, dissolvable tablet, suspension and regular tablet.

***How to Give***

Give as directed. Dissolve 1 Phos-NaK packet with 75ml of water before giving and give tablet with a full glass of water.

***Side Effects***

Monitor for diarrhea

***Storage***

Keep away from heat, light and moisture.

***Precautions***

Separate from magnesium by at least 1 hour due to decreased absorption.

**Magnesium Supplement**  
**(Magnesium Oxide, Magnesium Hydroxide, Magnesium Gluconate,**  
**Magnesium sulfate)**

***Purpose***

Magnesium is important for many functions of the body. A magnesium supplement is used to treat low magnesium.

***Description***

They come in tablet, suspensions and intravenous (IV) formulations.

***How to Give***

Give as directed.

***Side Effects***

Monitor for diarrhea

***Storage***

Keep away from heat, light and moisture.

***Precautions***

Separate magnesium by at least **2 HOURS** from Cellcept and **1 HOUR** from Phosphorous supplements.



## **Aspirin (81mg Baby Aspirin)**

### ***Purpose***

Aspirin is used to prevent blood clots.

### ***Description***

Aspirin comes in many different formulations and the 81mg baby aspirin is the preferred formulation.

### ***How to Give***

Give as directed.

### ***Side Effects***

Based on experience with patients in the U.S., adverse side effects are not likely.

### ***Storage***

Keep away from heat, light and moisture.

### ***Precautions***

There are no special precautions with the oral preparation.

## **Dipyridamole (Persantine)**

### ***Purpose***

Dipyridamole is used to prevent blood clots.

### ***Description***

Dipyridamole comes in 10mg/ml solution and 25mg, 50mg and 75mg tablet.

### ***How to Give***

Give as directed.

### ***Side Effects***

- Bleeding Gums
- Bruising

### ***Storage***

Keep away from heat, light and moisture.

### ***Precautions***

There are no special precautions with the oral preparation

**PEDIATRIC INTENSIVE CARE UNIT**

### ***Introduction***

Having a child in the pediatric intensive care unit (PICU) can be a very stressful experience. Feelings of fear, isolation and confusion are normal and common. At Children's, we try to reduce your fears and give you the support you need.

You are an important member of your child's health care team. Your role is to show emotional support for your child and have choices in your child's care.

Children's PICU is a 22-bed unit that offers care for critically ill children with all types of diseases and conditions. The care and treatment involves both special equipment and a highly trained staff.

The ICU is a very critical area. The rules in the ICU are different than on the floor. ICU Rules include:

#### ***Visitors:***

- Only one parent can spend the night in the room
- The waiting room has reclining chairs to sleep in.
- There is a closet and family phone for you to use in your child's room. Family and friends can call you on this phone.

#### ***Food/Drinks:***

- Food is not allowed at all in the ICU room. Only bottled water is allowed.
- You are allowed to eat in the waiting room. It has a food and drink vending machine.

#### ***Showers/Bathrooms:***

- There are two family shower/bathrooms in the PICU
- Any items you need to use to shower you will need to bring with you to the hospital
- Pack a bag for yourself that may include: shampoo, conditioner, soap, deodorant, hairbrush/comb, hairdryer, toothbrush, tooth paste, contact cleaner, reading glasses, change of clothes, socks, shoes and your phone charger.

### ***Equipment***

The specialized equipment in the PICU helps us watch your child's heart rate, breathing rate, blood pressure, and temperature more closely. The equipment also helps monitor how the main organs are working like the heart, lungs, liver and kidneys). Alarms on the monitors alert us to any changes in your child's condition that need attention. Sometimes these alarms will sound when a child moves around or when a wire becomes loose.

### ***PICU Staff***

As with all other members of the transplant team, the PICU professionals are specially trained to handle the unique physical, mental and emotional needs of children.

The PICU medical and nursing staff is made up of highly skilled professionals specifically trained in pediatric intensive care who will work together to care for your child. The intensive

care nurses will adjust your child's care to meet his or her physical and psychological needs. Your child will have one nurse when he/she comes back from the OR.

### ***Respiratory Therapists (RT)***

Respiratory therapists are another important part of the PICU health care team. They are specially trained to care for the breathing needs of your child. Respiratory therapists work around the clock, along with nurses and doctors, to help your child breathe. The therapists provide chest physiotherapy (CPT). This is a process of clapping their hands on a child's back or chest to help him or her to cough up mucous. The therapists also give aerosol treatments, which deliver medication (albuterol) in a fine mist, through a mask over the child's nose and mouth. RT's also set up the breathing machine that your child may be on when they arrive back from the OR. A breathing machine (ventilator) helps your child breath if they are too weak to do it on their own.

### ***Child's Appearance after Surgery***

When your child arrives in the PICU, he or she will have a lot of tubes and lines attached. Until your child is fully awake, he or she will need a ventilator to help with breathing. The ventilator is connected to a breathing tube, which goes from the mouth to the windpipe.

Because this tube passes through the vocal cords, your child will not be able to talk while the breathing tube is in place. The PICU staff will help you communicate with your child by writing notes, drawing pictures, making hand signals or nodding yes or no. Once your child can breathe on his or her own, the breathing tube will be taken out and replaced by an oxygen mask placed loosely over his or her nose and mouth.

A soft, plastic nasogastric (NG) tube will be placed through your child's nose to his or her stomach. This tube lets air out of the stomach during and after surgery. This tube will stay in place until your child can eat or drink. This may take several days after surgery.

Your child will also have multiple intravenous (IV) lines in both arms and in the neck. Some of these are special lines that help us to watch the blood pressure and monitor heart function. They are also used for giving IV fluids and medications, as well as drawing blood samples. These lines will be removed when they are no longer needed.

A urinary catheter, called a Foley, will be inserted into your child's bladder to drain urine. The urine will drain into a closed bag hanging on the side of the bed. This will help us keep track of the total amount of urine your child is peeing.

A large dressing (bandage) will cover your child's surgical cut. There may be three drain tubes from around the cut. These tubes are connected to plastic ball-like containers, called Jackson-Pratt (J-P) drains. These tubes are in place to drain off the extra blood or fluid that is common after transplant surgery. These tubes will be removed, one by one, the first week after transplant.

There may be soft cloth ties around your child's wrists and/or ankles in order to help remind him or her not to pull at any of the tubes, wires or IVs.

If your child is in pain or restless, medication will be given to make him or her as comfortable as possible and allow for plenty of rest.

### ***PICU Waiting Room***

The PICU waiting room has been set up to offer a quiet area for families who have children in the PICU. We ask that you help keep a quiet space by limiting the number of visitors. And ask friends to visit before 8 p.m.

Children get sick easily because their immune system “fighting system” is not strong like an adult. Young children carry lots of germs from playing and touching things. Children are not allowed to visit in the PICU waiting room. However, the patient's brothers and sisters are allowed to visit. Children have to be 3 and older to visit the PICU. .

Lockers and recliners or sofa bed are available to sleep in. However, space is limited so we can only give one locker to each family. The PICU waiting room assistant (conciierge) can help you with the lockers. The conciierge may also help you by taking telephone messages, helping you find nearby restaurants, or helping you find the hospital laundry room.

Several telephones are located in the PICU waiting room for family use. The phone at the conciierge desk is used by the doctors and nurses to call families. We ask that you limit your time on these phones. Public telephones are available for families to use without a time limit. You can use your cell phone in the waiting room.

If you are away from the hospital and want to check on your child, call 214-456-7882 at any time and ask for your child's nurse. The PICU staff will not give information about your child to anyone but you. You will be given the last four numbers of the medical record number as a password. The nurse will ask for these numbers when you call to check in on your child.

### ***Visitors***

Although visiting the PICU is not easy, it is very important for your child's healing time. We know that at this time it is hard to control your emotions and have the strength to give to your child's care. We support the parent or the child's caretaker to visit the intensive care 24 hours a day. Family members or friends over the age of three can visit between 8 am and 8 pm. Visitors may be limited to four people at one time. All visitors including parents or the caretaker will be asked questions about being sick. If you have been around adults or children that are sick do **not** visit. If you are sick do **not** visit. If you have fever, do **not** visit. If you have a runny nose or feel like you are getting sick do **not** visit. The patients in the ICU are very sick. We want to try to control the chance of getting the ICU staff and patients sick.

All visitors must wash their hands before visiting to stop the spreading of germs.. **We encourage good hand washing at all times. Hand washing is the best way to help stop the spread of germs at the hospital or at home.**

Sometimes a visit may not be possible. The doctor maybe performing a procedure, the nurse or therapist is delivering care, or the staff is making rounds. We ask that you check with your

child's nurse before entering your child's room. You may call your child's room from the waiting room to check with the nurse before you enter the room.

It is important to visit your child in the hospital with the brother or sister. Your children at home need to see you can handle your other child being sick. Brothers and sisters have stress and worry about the sick child. You can help them feel comfortable by visiting the sick child with them. Children age 3 and older may visit their siblings in the PICU. They must first be screened by a nurse for colds and other germs. However there will be times where the hospital is limiting visitors, especially during flu season. This is for the protection of our patients and your child. Also, if children or adult visitors at any time are sick, we cannot allow them to visit. Our child life specialist can help explain to siblings what they will see and hear in the PICU. They will talk with the child to explain how they might feel during the visit. Parents are encouraged to use this service, which can help with sibling worry. Brother and sister visits are limited to one hour per day.

### ***Caring for Yourself***

While your child is in the hospital, it is important for you to take care of yourself so you will be able to care for your child. The hospital has a cafeteria and vending machines on the lobby level of the D tower and the B tower. The PICU waiting room has a comfortable place for parents to rest while their child is in the intensive care unit. A family message board is available for communication between families at the hospital and other family members at home.

You can take care of yourself by asking for help when you need it. You may find that it helps to rely on family and friends for support. It is helpful if they It also is helpful to talk with other families of children in the intensive care unit.

Most importantly, know that you are not alone. You have a health care team and family support group to help you care for your child. The social worker, psychologist and chaplain are also here to help you during this stressful time.

## **THE GASTROENTEROLOGY FLOOR**

After the intensive care unit, your child will be moved to the gastroenterology, to finish healing from surgery before going home.

### ***Kitchens***

Each area on the floor has a kitchen full of ice, milk, juice and snacks for patients. Coffee can also be found in this area. Your child will be able to order food from room service between the hours of 7 am and 8 pm at extension 6-8181. Meals are delivered 30-45 minutes after orders are placed. Parents can get meals from room service with a \$5 meal card that can be bought from the Children's Dining Car cafeteria. Each meal includes 1 meat, 2 sides, a fruit or dessert, and 1 drink.

### ***Linen***

Linen carts are located in the hallway of each area. The linen cart has bed sheets, towels and pajamas. The nurse, or unit assistant, will make patient beds daily. Parents may help themselves to towels or linens.

### ***Treatment Room***

A treatment room is in the hallway behind the main nurse's desk. This is a special room used for procedures such as starting IVs. Children are taken to the treatment room whenever possible for painful procedures. This helps them think of their rooms as a "safe" place.

### ***Play Room***

Activity, play and learning are encouraged for all patients- infants, toddlers, school age children and teenagers. You and your child can use the Play room any time. Supervised hours and special activities will be scheduled daily. At times, your child may not be able to get out of bed. Please let your child life specialist know what activities your child enjoys. Games and other activities can be brought to your child's room.

### ***School***

A school teacher will come teach your child if they miss more than four weeks during the school year. Dallas Independent School District (DISD) supplies the hospital with a teacher. This teacher has an office in the hospital. It does not matter where your child attends school. The teacher will bring books and homework to your child's room with them.

### ***Family Commitment***

It is a requirement for you to be able and comfortable in giving your child's medications before to leaving the hospital. The transplant pharmacist will meet with you to teach you all of your child's medications. The pharmacist will also help develop a medication schedule with you. You should begin learning the meds with the nurse in the ICU. This is simply learning the name of the medication. This will help introduce you to the medications. Then on the floor you should begin to tell the nurse the medication name and what the medication does for your child. Then you can begin to administer them with the help of the nurse. Your goal is to give and know your child's medications before you leave the hospital. This will help show the staff if you need more information or teaching.

Children's nursing staff supports parents to participate in their child's care. Participation means bathing and feeding your child, writing down what your child drinks and eats, weighing diapers,

encouraging deep breathing and coughing, giving a hand in dressing changes, and helping your child walk through the halls when needed. Please feel free to ask the nursing staff for help or to talk about ways you would like to be a part of your child's care. Prior to going home you will be required to complete a 24 hour "rooming in" period. This is where you will take on the total care of your child including asking for and giving your child's medications to them. We want you to become as comfortable as possible in caring for your child and following their medication schedule while you have the added support of the team.

### *Caring for Siblings*

Being in the hospital affects not only you and your child, but other members of your family as well. You may find that your children at home are also having a hard time adjusting to the situation. Brothers and sisters of the sick child may have a hard time understanding the illness. They may not understand why a long hospital stay is required. They also may not understand why their brother or sister cannot come home.

Children can react in many ways to a stressful situation. Don't be scared if you see some changes in your children's behavior. Talk with your child life specialist or transplant team psychologist if you have questions or worries about your other children.

Brothers and sisters who are at least 3 years old and who are not having any signs or symptoms of being sick may visit their hospitalized sibling and use the activity room. There are times where the hospital has a limit on visitors. An example of that time is flu season (October-March). A **visitor's pass** is required for all visitors including patient siblings. You can get a pass at the nurses' station or from your child life specialist.

### *Questions*

The transplant team looks at your child's labs, tests, and what they look like on physical exam to make a plan about his or her care. Therefore, your doctors may change the plan from time to time to changes in your child's labs, tests, and their exam.

The transplant team will always try to explain to you why different procedures or treatment changes are needed for your child. Remember to **write down any questions or concerns** you have and ask members of the transplant team for explanations.

### *Hospitalization Summary*

As discussed previously, you will be in constant communication with many health care professionals during your child's hospital stay. The team includes dietitians, physical therapists, respiratory therapists and other specialists who will all work together with the transplant surgeons and other team members. They will coordinate your child's care and try to help stress and confusion.

The process may get confusing because so many people are involved. You may hear different information from the different healthcare professionals. Remember that the transplant surgeons, GI doctors, doctor assistant (PA's) and advanced practice nurses (APN'S) are organizing the post-transplant care. If you are concerned about information you receive from other individuals, talk to your child's nurse. He or she can contact the doctor assistant or APN to clear up any confusion.



The nursing staff is always available to answer your questions, explain procedures and treatments and offer suggestions to make your stay more comfortable. You also have your transplant coordinator. The nursing staff can contact them through the paging system.

## WELLNESS

### *Infection Control Guidelines for Transplant Patients*

Multidrug-resistant bacteria (also known as MDRO's) are defined as germs that cannot be treated (resistant) with antibiotics..

Two examples are:

1. Staphylococcus Aureus(germ), resistant to Methicillin(antibiotic) (MRSA)
2. Enterococci(germ), resistant to Vancomycin(antibiotic) (VRE)

MRSA and VRE are spread by having contact with someone that has the germ or contact with dirty surfaces. If a patient tests positive to having a multidrug-resistant bacteria they are placed on "contact precautions." This is done to stop the spread of these infections. Gloves and gowns are required upon entering into the patient's room. Families and visitors are to wear gowns and gloves if holding the patient or if they will be in contact with a body fluid like changing a diaper. This is very important if they are likely to hang out with other patients and families. Sometimes gowns and gloves may not be required for visitors. Families and visitors must wash hands when entering and leaving a patient's room. The patient may also be limited on when they can leave the room.

Any patient colonized/infected with VRE is permanently colonized. This means the germ cannot be completely cleared with antibiotics. These patients should never have physical contact with other transplant patients even outside the hospital (including parties and camps.) Patients with MDRO are able to attend school. Preventing the spread of these infections is very important and hand washing is absolutely required.

### *Visitors*

- Any person with signs/symptoms of infection/sickness including cold and flu should not be allowed to visit patients in the hospital or in the home.

### *Hospital Floor*

- Patients may not sit on the floor unless it is on a blanket or play mat.
- Items that "fall" on the floor must be cleaned with alcohol wipes prior to patient use.
- Patients must wear socks or shoes when they are out of the bed.

### *Personal Items at the Hospital*

- All personal items or toys must be cleaned with alcohol wipes before touching a transplant patient.
- The number of personal items in rooms will be limited to avoid a mess and dust build up.



- Personal items that can be scrubbed (not furry, stuffed animals) are required. The number and size of stuffed animals should be limited.
- Plants and fresh flowers are not allowed in the patient's room.
- Personal comforters and clothing are to be machine or hand washed and re-washed, if dirty.
- Down comforters are not allowed. Down pillows are allowed if covered by a plastic pillow case with a zipper.
- Paper products may be taken into the room without cleansing.
- Wrapping/packaging is to be removed from gifts that have been shipped/mailed to transplant patients prior to entering the patient's room.

### ***N95 Respirator Mask***

- Patients are instructed to wear an N95 mask before leaving the car and keep the mask on until they reach their room within the hospital. N95 masks must be worn in the waiting areas.

### ***Discharge Teaching***

During your child's post-transplant hospitalization; you will increasingly become more responsible for total care of your child. The nursing staff, advanced practice nurse (APN), doctor assistant (PA) and transplant coordinators will help you with this new learning period.

Before going home, we will teach you how to give all of your child's medications, what each medication is for, and the possible side effects of each medication. We will also teach you how to recognize and report signs of possible problems. We will also teach you how to care for your child's central line, feeding tube; monitor their blood pressure and other needs that may come up. You will understand general health care guidelines and routine follow-up tests.

You will be required to provide total care for your child for at least one full 24-hour period prior to going home. This handbook contains patient sheets where you can record and keep track of the date/time of your child's medications, lab values, temperatures and weights.

Prior to discharge (going home), the transplant coordinator will give you a tour of the clinic and other areas of the hospital you will need to know for return visits.

### ***General Information***

Your child received a liver transplant to save his or her life. This may be a difficult change for both you and your child. Many things in your life were required to change to deal with your ill child and their recovery.

Your child's will not be able to fight off sickness/infections after transplant. The medication causes this response. This is needed to keep your child from fighting off the new liver. You will need to keep your child away from large crowds for 6 months after transplant. This is to help keep your child from getting sick when around people that may be sick. Your child can begin to be a part of everyday activities such as school, church, birthday parties, after school activities, sports and other events after the six month period. It may be longer if your child has problems or setbacks after transplant.

You may want to hold your child back from doing some of these activities because you have fears of infection, accidents or other problems. Use your common sense to protect your child. Remember that your child needs to be encouraged and supported in trying to succeed at a normal lifestyle.

### ***Behavioral Changes***

It's not unusual for your child to be extra needy after you return home. This is more likely if you now have to share your attention with other children. Your child received a large amount of individual attention, including media coverage, during his or her period of illness and the transplant. It may take some time before your child understands that he or she doesn't need to be the center of attention all the time.

Some children don't need to have many limits set during the time they are sick, because they don't feel well enough to "get into trouble." After the transplant they may have a much higher energy level and "act out." They can behave badly in order to work out their feelings of fear, anger, or loss of control they felt in the hospital.

Proper limit setting and disciplinary measures should help your child adjust. Encourage your child and provide appropriate outlets for energy release, such as play activities. If help is needed, professional play therapy can be scheduled.

Do not be alarmed if your child has fallen into previous behaviors. Some young children go back to using a pacifier or bottle or wearing diapers after they have been toilet trained. Older children may become more dependent on you for things they previously did themselves. Remember, it's going to take time before your child returns back to his or her "self". It is important for you to be understanding, encouraging, and supportive during this time.

The transplant process will have an effect on you and your other children. The psychologists, social workers and child life specialists at Children's Medical Center can give you some tips for helping your family make adjustments. It may also be helpful to seek professional assistance once you get home; the psychologists can assist you with this if needed.

### ***Activity***

Your child can return to his or her playing routine almost immediately. However, your child cannot be involved in any competitive sports, vigorous exercise or physical education classes until your transplant doctor approves it. Liver transplant patients are not allowed to participate in sports or activities that may cause direct injury to the stomach area such as wrestling or football. Contact sports are not allowed.

Liver failure can leave the body weak. Children that have liver disease can be behind in playing, walking and talking (motor skills). In fact, many children with liver disease have severe motor delays. After transplant, however, you will see improvements. Keep in mind that this may be a slow but sure improvement.

In addition, steroids can cause muscle weakness or floppiness. Physical therapy in the hospital helps makes the muscles stronger and "remember" there job. If your child needs more help we can help find a physical therapy clinic by your home. Usually, everyday play activity such as

riding a bike, walking and running will provide enough exercise for your child. If you have any questions or worries about your child's growth talk with your local doctor or contact the transplant coordinator.

### ***Dental Care***

Dental infections and decay can cause serious problems in transplant patients that are immune-suppressed. We recommend your child return to the dentist at 6 months after transplant and then follow yearly or as many times as needed. Before your child is scheduled to get his or her dental checkups and treatment, he or she will need to take an oral antibiotic. The American Heart Association made this recommendation/guideline to help prevent heart infections. Your dentist and local doctor will be familiar with these guidelines. If you or your dentists have any questions regarding these antibiotics, please call the transplant office.

If your child takes Cyclosporine, one of the side effects of this medication is gum hypertrophy (overgrowth). The gums look thicker than normal. Plaque makes the gums irritated/ inflamed or "angry". For this reason, your child should visit a dentist at least every six months after the transplant. If your child has a serious problem with plaque build-up, he or she will need to see the dentist every four months. Brushing your teeth every day is also very helpful in decreasing the amount of the gum hypertrophy (overgrowth).

### ***Eye Care***

Your child should have once a year eye checkups with an ophthalmologist (eye doctor). Especially, your child has problems seeing clearly or starts to squint their eyes to read.

### ***Sun Exposure***

Because your child will be taking steroids, his or her skin will be easier to burn in the sun. Many studies have shown that being in the sun too much can cause skin cancer to start. Your child will have a higher chance of getting skin cancer because he or she will be immune-suppressed.

You must keep track of your child's time in the sun and be sure to apply a sun screen lotion to all skin areas. The sun screen lotion has to have a minimum sun protection factor (SPF) of 30. Remember to reapply the lotion frequently as water and perspiration can decrease its effectiveness. Encourage your child to wear light, protective clothing, and hats to help decrease the risk of skin cancer. Also, try to limit your child's time in the sun's rays between 10 a.m. and 2 p.m.

### ***Skin Care***

If you notice any changes in your child's skin such as newly raised areas, sores that won't heal or changes in moles or warts, call your doctor. Your doctor may send you to a doctor that studies the skin- a dermatologist.

### ***Warts***

Warts are a viral infection of the skin. Besides being ugly, warts can spread, especially in a child who is immune-suppressed (a weak immune system). For this reason, you need to make an

appointment to see your local doctor or dermatologist to have a wart treated as soon as you find one on your child. This is very important since it is hard to control the warts once they start to spread.

### ***Acne***

Another side effect of the steroids is acne. To help stop this, encourage your child to wash his or her face really well, scrubbing gently with a clean, soft washcloth. Try to avoid soaps that contain creams and oils because they can make the acne worse. Try using an anti-bacterial soap. All acne areas must be washed gently many times a day to help stop infection.

If infection does occur or the acne continues to be a problem, you may need to see a dermatologist. Be sure to call the transplant office before beginning any skin treatments or prescription medicines for the acne..

### ***Hair Care***

The steroids and some other medications may cause your child's hair to break easily. Prograf can cause hair loss. Cyclosporine can cause more hair growth that is often upsetting to children, especially teenagers. Your child can have more hair on their face and underarms. This can be very embarrassing for girls. Shaving the extra hair will only make it worse. Hair removal creams may be used with caution. Be certain to follow the directions exactly and keep cream away from the mouth and eyes.

### ***Medic Alert***

It is important that your child wear a medic alert bracelet or necklace at all times. This would give important information to a healthcare worker in an emergency.

### ***Home Environment***

It is important to maintain a clean house. Wiping down hard surfaces and toys with antibacterial wipes to prevent the spread of germs is helpful. Since your child is immune-suppressed they can get sick from molds and fungus. We recommend vacuuming, changing the air duct filters and dusting to be done when your child is not in the room. Make a schedule to have them play in another room or leave the home for a few hours during cleaning time.

### ***Swimming***

Your child can go swimming in a private, chlorinated, well cleaned pool. But if they have wounds or skin sores they can't go swimming. It is best to have your child shower or rinse off when leaving a pool. Try to prevent them from swallowing water while in the pool. These steps may prevent the spread of parasites such as cryptosporidium which is a germ that can cause diarrhea and can also poison the liver.

We strongly discourage swimming in a lake or pond due to the germs that live in them. Those germs are harmful to someone that is immune-suppressed.

## ***Immunizations***

Questions always come up about what immunizations your child can receive. In general, your child must **NOT RECEIVE ANY LIVE VIRUS VACCINATIONS** such as MMR (Mumps, Measles, and Rubella), the oral polio vaccine (OPV) or the Chicken Pox vaccine.

Your child may receive DPT (Diphtheria, Pertussis, and Tetanus) shots, the killed, injectable polio vaccine (IPV), the Hepatitis B vaccines, Hib vaccine and flu shots. If your child's DPT and polio immunizations are not up to date before the transplant, this should be done after the transplant. **Do not** let your child receive an MMR immunization after the transplant because it contains a live virus. (See Table I. below)

**Common Immunizations and Acceptability for Transplant Patients**

YES	NO
<i>DPT, Td, Tdap</i>	MMR (Measles, Mumps, Rubella)
Injectable Polio Vaccine (IPV) (Salk Polio)	Oral Polio Vaccine (OPV)
Hepatitis A / Hepatitis B	Flu mist vaccine (inhaled)
H. influenzae B (Hib)	Varicella (chicken pox)
Meningococcal conjugated vaccine (Menactra)	
Pneumococcal conjugated vaccine (Pneumovax)	
Gardasil ( HPV)	
Flu Shot / HINI (injectable)	
Palivizumab	
Varicella Zoster Immune Globulin (VZIG)	
Gammaglobulin/ Cytogam	

Your child will have been fully immunized before to transplantation. Once your child gets their new liver, they also receive medications that immunosuppresses them. This medicine makes it easy for your child to catch viruses. After transplant your child cannot receive live virus vaccines. If they have had all the shots for polio they should only have the Salk polio vaccine. Also, children or family at home should not receive the oral polio vaccine if the patient has not received the polio shot before transplant. Although transplant patients should not receive live measles vaccine, other members of the family should get the measles shot After transplant, your child's immunizations should be brought up to date according to the American Academy of Pediatrics list, except for the live virus vaccines. Your local doctor can help you in looking over your child's immunization records.

It is important to have your other children up-to-date on their immunizations, especially the MMR vaccine. If other family members need the polio vaccine, they must receive the injectable polio vaccine (IPV).

**FOR TEENAGERS AND YOUNG ADULTS**

### ***Key Points***

- ***Teach your kids why they should not smoke cigarettes or marijuana***
- ***Alcohol and Transplant Medications can cause liver failure and be deadly***
- ***Teach your kids why it is important to not have sex***
- ***Teach your kids why using a condom is important if they do have sex***
- ***Pregnancy and Transplant medications can cause birth defects or miscarriage***

### ***Sexuality/Puberty***

Before your child reaches sexual maturity, you will want to prepare him or her for the normal pre-pubertal and pubertal physical and emotional changes.

#### ***Female transplant patients***

For a female teenager who is not sexually active, yearly gynecological exams begin at age 18. However we suggest that a yearly gynecological exam begin at age 14-16. There is a higher chance of cancer in the patient that gets a transplant. Routine Pap Smears would help spot any abnormal results.

It is also important for your daughter to be taught self-breast exams at an early age in order to find early changes in the breast tissue.

Planning a family is of special concern to the female transplant patient. A pregnancy will put more stress on your daughter's body. We do not have enough information on which medications can hurt the developing baby. Before planning a pregnancy, she and her partner will need medical and psychological guidance.

#### ***Male transplant patients***

The male adolescent should also be taught how to do testicular self exam since they are at increased risk for cancers.

Again, planning a family will be of special concern to the male transplant patient. Medical and psychological guidance will help the couple to figuring out a plan that fits them.

### ***Sexually transmitted diseases (STD)***

Sexually transmitted diseases threaten all teenagers and young adults. The statistics nationwide are very high that a sexually active teenager will get an STD. Because of the higher chance of infection, getting an STD can be deadly for the transplant patient.

Current research looks at teenagers thoughts on their sexuality and beliefs about STDs. We know that the more information your child has about their body and about STDs, the better choices they will make. It is important to teach your children not to have sex. It is also important to teach your child about ways to protect themselves against STDs. Your child may or may not tell you if they are having sex. This makes it very important to teach your children about condoms. Your transplant social worker or psychologist can help you talk with your child about the tough subject of sex and sexually transmitted diseases.

### ***Smoking, Drinking and Drugs***

A liver transplant offers new life. Smoking, alcohol and recreational drugs all defeat the point of a liver transplant. We want your child to live their lives for the longest time possible and with the greatest joy allowable. You should teach your child to ***“Say no to drugs, smoking and alcohol”***.

Smoking harms the lungs and creates increased chance for infection. It also tightens the blood vessels of the heart, arms and legs. Smoking slows the red blood cells down from carrying oxygen. These two events limit the amount of oxygen available to the body. If there isn't enough oxygen then the body cannot heal fast. This invites germs and infections to take over. Steroids and smoking can cause stomach sores or ulcers. Smoking also damages the lungs. Each of these reasons can lead to serious illness, cancer or death. It is important to teach your child to not smoke cigarettes. This includes the electronic cigarettes, chewing tobacco, and smokeless tobacco.

Alcoholic drinks cause problems for several reasons. Alcohol and immunosuppressive medications are broken down in the liver. , The use of alcohol and immunosuppressive medications can cause permanent liver damage. Also, alcohol eats away at the inside of the stomach and can cause stomach sores. Again, this can lead to infections and problems. People who drink often do not remember to take medications, or may take too many medications. .This can cause a problem with sticking to the medication schedule. Teach your child why it is important not to drink alcohol.

Street drugs delay the brain from thinking and remembering. The liver and kidneys break down drugs. Street drugs can cause permanent damage to the liver and kidneys. Marijuana is also a drug. It can cause fungal infections from inhaling it. It is very important to teach your child why they should ***say no to drugs***.



## EXPLANATION OF LAB RESULTS

The Transplant Team tracks the following lab tests from your child's blood draws:

### *Liver Enzymes*

ALT-Alanine transaminase, AST- Aspartate aminotransferase and GGT-Gamma-glutamyl transferase-These enzymes give the doctors information about the liver. If the enzyme level is high it may mean the liver is damaged or injured. Inflamed or injured liver cells may leak higher than normal amounts of cg liver enzymes into the blood. Elevated liver enzymes can be caused by rejection and/or infections.

Bilirubin-is a natural result from the normal breakdown of red blood cells. Bilirubin is carried in the blood and passes through the liver. Once inside the liver most bilirubin attaches to sugar creating direct (conjugated) bilirubin. Then it can be sent into the bile draining into the intestinal tract. Finally, bilirubin is pooped out. A high bilirubin in the blood may mean liver damage, or problem with the drainage tubes from that carry bile into the intestines.

White blood cell (WBC) count is a count of the number of white blood cells in the blood. The white blood cells are the body's first defense "army" to fight infection or germs. Immunosuppressive therapy is very strong. It will make the white blood cell count lower than normal. A higher WBC count may point to a bacterial infection.

Platelets are a part of the blood. Their job is to stick together to stop bleeding (clot). Platelets stick to the wall of a damaged vessel and clump together. The clot they make stops the body from bleeding too much. If there are not enough platelets, lots of bleeding can occur. If there are too many platelets a clot can go to the brain or heart. This can cause a stroke or heart attack. . A high or low level of platelets may need medical attention.

Hemoglobin & Hematocrit (H&H) Hemoglobin is the main part of red blood cells. It mixes with and carries oxygen all over the body. Hematocrit is the number of red blood cells found in the blood. A drop in H&H may mean anemia or blood loss. More testing would need to be done to find the cause of a low count.

### *Electrolyte Blood Chemistry*

Sodium is a major part of the fluid in the body. It keeps the body from getting dry (dehydrated). Potassium is another part of the fluid in the body. Potassium is needed to help the muscle carry the electricity to the nerve. . Potassium also is needed to help the heart work. If the Prograf level is high it can cause the Potassium level to be too high. This can be dangerous.

Magnesium plays important job within the body. Prograf can cause magnesium levels to be low in the blood. You may have to encourage foods high in magnesium to help keep the level normal. You may also have to give your child extra magnesium pills.



***Kidney Function Labs***

BUN measures the amount of urea nitrogen in the blood. Urea is the result of protein breakdown and is formed by the liver. Urea is then moved from the blood to the kidneys and peed out. Urea is cleared by the kidneys. BUN is a good test to show how the kidneys are working.

Creatinine is the breakdown of creatinine phosphate, a high-energy mixture found in skeletal muscles. This lab gives a good picture of how the kidneys are working too.

Glucose is the level of sugar in your blood. Immunosuppressive drugs and steroids can cause a high level of sugar in your blood. We will be looking at the glucose levels on your child's labs closely.

***Drug Levels***

Prograf/Cyclosporine Trough- This test is drawn right before your child's last dose of Prograf/Cyclosporine. The lab is usually drawn right before your child's morning dose. Your child will have a goal Prograf/Cyclosporine level decided by your doctor. This goal level will change depending on how far out your child is from transplant. If your child has had any rejection the goal may be increased. If your child has been sick the goal may go up or down. It is important to remember not to give the Prograf/cyclosporine before the lab is drawn. It is also important to give the Prograf/cyclosporine every day at the same time.

## POSSIBLE COMPLICATIONS OF LIVER TRANSPLANTATION

### *Rejection*

The body's immune system is its' natural defense or army to fight diseases (germs). The immune system recognizes and tries to kill all foreign substances to protect the body. Foreign substances include viruses, bacteria, fungi and foreign tissues/organs (such as a transplanted liver). Therefore, the immune system treats your child's new liver as it would any other foreign substance - it tries to destroy it. This attack on the new liver is called rejection.

We try to avoid these "attacks" by giving your child immunosuppressive medications. However, there is still a strong possibility that your child will experience one or more cases of rejection. This can happen even if your child takes their medications perfectly.

The first rejection case usually happens between one and two weeks after the transplant. As time goes on, the chance of rejection lessens, but it can occur at any time following transplantation.

### *Signs and Symptoms of Rejection*

- Elevation of liver enzymes (see lab tests for definition)
- Fever greater than 100.4°F (38°C)
- Clay-colored or yellow/white stools
- Yellow eyes
- Tea-colored urine
- Fatigue/Tired
- Feeling sick

If any of the above signs happen, you should call your transplant team immediately.

### *Possible causes of decreased Prograf or Cyclosporine include:*

- Vomiting
- Missing doses of immunosuppression (Prograf/Cyclosporine)
- Switching to generic immunosuppression (Tacrolimus/Neoral)
- Taking a medication that lowers the level in the blood of immunosuppression
- Taking too little immunosuppression

With infection or rejection early recognition and treatment is key. This is why it is important to draw labs regularly. This will help us make sure your child is taking the right dose of Program/Cyclosporine. The liver enzymes labs also show us how the liver is working.

### *Work up for rejection*

If your child's liver function labs are high, more testing will be done to collect information to see if your child is rejecting. These tests include an abdominal ultrasound, blood tests and a liver biopsy. An abdominal (over the tummy area) ultrasound looks at the bile ducts and/or blood flow to the liver. The blood tests check for viruses. The liver biopsy looks at a piece of liver under the microscope. See page 15 for more information. All of these tests your child had before they were transplanted so they may sound familiar.

### ***Liver biopsy and treatment***

The liver biopsy is the **only** way to spot rejection. Your child will be admitted to the hospital the night before to get them ready for the biopsy. They will not be able to eat or drink anything after midnight. They will receive IV fluids for food/hydration. This can be done in one out of two places: Operating Room or Radiology. Your child will be put to sleep with medication first. Then a small needle will pierce the skin over the liver area. When the needle is pulled out a piece of the liver is pulled out with it. After the test, they will be asked to lay on their right side and hold pressure against the needle hole. Labs will be drawn four hours after the biopsy to check for bleeding. Most patients will have little or no pain and a band aid will cover the site. A pathologist (doctor) will look at the biopsy under a microscope. The pathologist will make a decision if its rejection depending on the amount of inflammation and damage that is seen. This will help the transplant doctor decide what treatment or medications to give.

The most common treatment for a rejection is large amounts of IV steroids. You may have to stay in the hospital for one to two weeks to get the medication. Your child's liver enzymes will be drawn daily to make sure the medication is working. Your child will also have their blood pressure and sugar levels monitored closely.

If the liver enzymes are not getting better a second biopsy maybe needed. If IV steroids do not work there are stronger medications available.

### ***Infection***

After undergoing transplant your child will be very immune-suppressed. This means that their army will not be as strong to fight off infections. The immunosuppression meds will be backed off after transplant as their bodies become use to their new liver. Since, your child is immune-suppressed they have a higher chance to get infections which can become deadly. For this reason, you should call your doctor if you think your child is catching a cold or becoming sick. Your doctor can figure out how serious the cold or sickness may be for your child.

If your child has any of the following signs, your doctor should be called right away:

- A temperature greater than 100.4°F (38°C)
- A cough that lasts for more than 24 hours or has mucous
- Runny Nose that becomes green or yellow
- A sore throat or headache (with a fever)
- Vomiting or diarrhea
- skin rash (with a fever)

Also, with diarrhea your child's Prograf level may get higher. Elevated higher Prograf level can cause seizures and damage to their kidneys. You will need to call the transplant coordinator immediately if your child is having diarrhea. The transplant team will find out if your child needs to come to the hospital to stay. Diarrhea can cause your child to become very dry or dehydrated. So they may need IV fluids and Prograf blood levels to be followed closely.

### ***Neutropenia***

Neutropenia is a drop in the neutrophils. Neutrophils are the white blood cells that fight off infection. This can happen because of a virus or from a medication. If the blood work shows a

low level of neutrophils (neutropenic) more testing is needed. We may order viral tests with their next blood draw and monitor their labs more closely. We may also stop or switch medications that are known to cause this problem. It is important to monitor closely for signs of infection. If your child runs a fever while they are neutropenic this is an emergency and they must go to an Emergency Room immediately.

In addition to the precautions you are already taking to prevent infection after transplant additional precautions will be required if your child is neutropenic.

**Neutropenic Prevention:**

- Do not feed your child uncooked or raw fruits or vegetables
- Strict hand washing, before each meal or snack, after bathroom and as needed
- Use clean utensils
- Do not eat or drink after others
- Take care of any wound-clean and notify doctor if does not go away
- Take care of mouth, do not floss or brush gums too much for risk(chance) of bleeding, also do not schedule regular dental appointments
- Do not touch live plants or flowers due to germs in soil and standing water
- Do not touch anyone with an infection or that has received a live virus vaccine.
- Do not touch pets, especially bird cages, or litter boxes, etc.

***Chicken Pox***

One virus to be worried about is chickenpox (varicella). The transplant team will get a varicella titer when your child starts the transplant evaluation to see if your child is safe from chickenpox.

If your child gets a rash that looks like chickenpox, call your local doctor or transplant team immediately. Your doctor will make plans to see your child in his or her office or at the Emergency Department. Chicken Pox is tested by swabbing the sore on the patient. The blood is also tested for varicella. Acyclovir (Zovirax) is the drug that treats chicken pox. It can be given in IV form or pill/liquid syrup. The doctors will look at how serious and immunosuppressed your child is to decide to give IV or pills. It is possible that your child would need to be admitted to the hospital to get IV Acyclovir until the sores have all crusted over. The immunosuppression meds may be held or dose lowered during the healing time. This will give the body its natural fight cells (WBCs) back to fight the chicken pox. This may place your child at risk of rejection so their liver enzymes will be followed closely during this treatment. Valacyclovir may be continued by pills or syrup for two weeks after no new lesions have popped up and the old lesions have crusted over.

### ***Cytomegalovirus (CMV)***

Cytomegalovirus (CMV) is a member of the herpes family. The symptoms of CMV may be very mild or may become serious if the virus attacks the blood, lungs, liver, eyes, kidney, or other organs. Like shingles, the virus can come back during times of stress or when a patient is very immunosuppressed. Fever and flu like signs (tired and not hungry) are the first symptom.

#### ***Transmission***

This infection takes repeated contact (touching) with someone who is shedding the virus. Hand-washing after contact with spit, mucous, or the mouth may prevent spread of infections. The CMV pcr blood test is completed and followed by your child's doctor to see whether or not you have CMV infection.

#### ***Treatment***

A severe CMV infection can be difficult to treat. It is important to call your liver transplant doctor immediately when you have a fever greater than 100.4°. There are medications such as Ganciclovir and oral Valganciclovir (Valcyte) available to help prevent and treat this virus. Early treatment helps to reduce the risk of serious problems.

### ***Epstein - Barr virus (EBV) and Post-Transplant Lymphoproliferative disease (PTLD)***

Epstein - Barr virus (EBV) is a herpes virus which happens everywhere in the world. Between 25 and 70 percent of teenagers and adults who come down with EBV form mononucleosis (Mono). Symptoms/signs of infectious mononucleosis are fever, enlarged lymph nodes and hoarseness. Enlarged lymph nodes are bumps show up under the arm pits or on the side of the throat. Hoarseness is when your child has problems making sounds with their voice. The voice can sound scratchy, weak, husky, or the sound of the voice may change.

A transplant patient is immunosuppressed which makes it easy for a virus to attack its "fight" or immune system. When the fight system is down it cannot recognize virus's as well. This lets the EB Virus multiple out of control. This is a disorder known as Post transplant lymphoproliferative disease (PTLD). This disease can present in several different ways.

#### ***Signs & Symptoms***

PTLD can be found anywhere in the body. It is important to call your transplant doctor if your child has low-grade fevers, does not eat, tired, weight loss, enlarged tonsils- snoring, pain, diarrhea, confusion, headaches, can't hear or repeat infections. If you or your doctor finds an enlarged lymph node(s) that does not go away, the lymph nodes may be biopsied for a diagnosis. Also, if your child's tonsils and adenoids are enlarged they may require tonsillectomy/adenoidectomy for to find a cause.

#### ***Treatment***

If your child has a high EBV pcr or viral count in their blood, more tests such as CT or PET scans may be ordered to assess for PTLD. If your child is diagnosed with PTLD their immunosuppressive medication(s) will be held or decreased. The next step would be to start

antiviral medications like Valcyte. Some patients will also need chemotherapy to help treat the PTLD.

### ***Ear, Nose and Throat Problems***

It is also common for children who have had a liver transplant to have repeated sinus problems or ear infections. They may never have had these infections before transplantation. They also may begin to develop problems with snoring. The snoring is often related to enlarged tonsils or adenoids that block either the tubes in the ears or the sinuses.

If your child develops repeated problems with sinusitis, ear infections, problems with mouth breathing or snoring, call your local doctor. You may also need to call an otolaryngologist (ear, nose, and throat specialist, also called an ENT specialist) to see if the adenoids or tonsils have gotten bigger. If this happens, the problem can often be easily resolved by removing the tonsils, adenoids or both (tonsillectomy/adenoidectomy).

If your child's snoring is due to large tonsils and/or adenoids, it may cause a problem with sleep not treated. Sleep apnea is when the tonsils and/or adenoids block the child's airway at night while he or she is sleeping. This can cause problems with your child's heart and may become more serious if not caught and treated with a tonsillectomy/adenoidectomy.

### ***Headaches***

Several liver transplant patients have developed migraine headaches after transplantation. Your child may need to go see a neurologist or doctor that studies the brain. This doctor may have several tests done like an EEG, CT, or MRI. These tests can help this doctor figure out possible causes of the headaches. Your child may have to take more medications for headaches after transplant.

**POST TRANSPLANT FOLLOW-UP**

You will need to stay in the Dallas area for two to four weeks after you are sent home from the hospital. We want you to be close to hospital while your child gets use to their new medications. We also want you to be close in case there is a problem with your child. Other hospitals may not have transplant doctors available.

After discharge, you will need to return to Children's two to four times each week for follow-up visits. Two of these visits will be for blood work and follow-up clinic appointments. The other visits may be for IV medications or blood and/or more lab work. The following is the schedule for these appointments unless you are told otherwise:

<b>Day</b>	Mondays	Mondays	Thursdays	Thursdays
<b>Time</b>	8:30 am	9:00am- 11:00 am	8:30 am	9:00am- 11:00 am
<b>Reason</b>	Blood work*	Follow-up Clinic	Blood work*	Follow-up Clinic
<b>Location</b>	1st B Tower (B1228) Solid Organ Transplant Clinic			

**\*Note:** Do **NOT** give the **morning Prograf (FK) or Cyclosporine dose** until **after** the blood work is drawn.

Remember that both the blood work and the physical exam are well thought out when the transplant team makes decisions about your child's care. By doing the lab work before the clinic visit, we'll have the needed results when we see your child in clinic.

During clinic visits, a nurse or medical assistant will check your child's temperature, blood pressure, pulse, and weight, and the transplant doctor or nurse practitioner will examine your child. In addition, the transplant coordinator will review your child's medications and any instructions from the doctor. **Please remember to reorder any medications several days BEFORE you run out of any of your child's medications to allow enough time for prescriptions to be filled.**

**Be sure to bring your Family Notebook and your child's medications with you to each clinic visit so that we can write any changes on your child’s chart.** If you have any questions or worries about your child, please ask the coordinator, doctor or nurse.

***Home Follow-up***

Once your child's medications and everything else is in order, you may return home. Your child will be stable when you leave Dallas, but he or she will continue to need very close follow-up at home.

It is important to your child's health that lab work is done and that your child is regularly examined by your transplant doctor. At first, blood work and doctor visits will need to be done twice a week. If things are okay after one month, these labs and visits can be done once a week. Eventually, this will be decreased to every two weeks and then to once a month. You will be notified when the visits and lab work will be changed.



**Your child's local family/pediatric “primary” doctor will be the primary medical caretaker of your child upon your return home.** The transplant team will continue to monitor your child's progress and change the immunosuppressive medications with you. We expect you to call our team to tell us of any illness and treatment that your child is getting locally.

You will be called by the transplant coordinator for instructions about medication changes and lab results. If the lab results are okay, and no medication changes need to be made, you will **not** be called (Note: no news is good news).

**Whenever you have any concerns about your child, your first call should be with your local doctor.** It is difficult for us, at Children's, to make a long distance diagnosis when your doctor can assess your child's problem in person. If your doctor has any questions or concerns, he or she may call the transplant team at Children's for consultation or help at any time. If your child lives close to the hospital you may be asked to come into the clinic.

**If you would like to speak with your child's coordinator for routine concerns such as medications, scheduling follow-up appointments, prescription refills, we ask that you call during regular business hours from 8:30 a.m. to 5 p.m., Monday through Friday.** You can also leave a message for the coordinator, via voice mail, for the coordinator who follows your child. You can also send a message myChart or Children's website. To reach a coordinator for an **EMERGENCY**, call the main hospital at 214-456-7000. The operator will page the coordinator on call who will return your call as soon as possible. If no one calls you back within 15 minutes call the hospital operator again.

### ***Return Visits***

In addition to your follow-up monitoring at home, you will need to bring your child to Children's Medical Center of Dallas for routine checkups by the transplant team. These visits will be held twice weekly after discharge from the hospital. They will be spaced out from there depending on your child's condition. Eventually, your child may only require transplant visits every 3 to 6 months or even annually or yearly. An annual clinic visit will need a longer visit time than someone whom is seen in the transplant clinic more regularly. At an annual clinic visit you should expect to see each member of the transplant team.

In addition to getting lab work, your child will be seen by a dietitian when needed during each return visit to Children's. Psychological/developmental testing is done on an as needed basis post-transplant. Other tests or procedures may need to be scheduled as well. The transplant coordinators will explain these to you.

The transplant surgeon/doctor will examine your child and discuss his or her progress with you and make any needed changes. The social worker, psychologist, child life specialist and chaplain will also be available to help with any concerns you may have regarding your child and/or your family. The transplant coordinator will talk with you about any changes and/or instructions.

Your local doctor will receive a written letter of these evaluations as soon as all test results are available.



***Adherence to the Medical Plan***

We depend on you to take an active role in your child's health care. In order for your child to stay healthy and have the best quality of life, it is very important that you follow the medical treatment plan created by you and your medical team.

- If you are unable to keep a clinic appointment or are having a hard time taking your child for labs you must tell us so we can work together to problem solve.
- If you are having difficulty handling your child's health care needs you may ask for help from anyone on the transplant team including; transplant coordinator, social worker, child life specialist or psychologist.
- If you are showing non adherence to your child's treatment plan such as: missing appointments, not having labs checked on schedule, not refilling medications, not renewing insurance or Medicaid application which result in loss of coverage, etc. This is medical neglect and child protective services (CPS) may need to become involved.

## **PEDIATRIC TO ADULT CARE TRANSITION (PACT) PROGRAM**

At some point in the future, our young adult patients will reach a point in which they would be best cared for at an adult medical center by providers who are best trained to care for adults who have had a transplant. This transition or change normally occurs between the ages of 18 and 19, at a time in which patients may be undergoing several other life changes. These may include graduating high school, moving out of the family home, beginning college, or starting a new job. We want our patients to be well-prepared to take charge of their health care needs in these new environments. We want them to begin working well with adult health care providers. We also realize that transitioning to a new medical center can be a scary and an emotional time for patients and their families. So, we have made a program to make sure that we meet all of the educational and emotional needs of transplant families as they transition to adult health care.

The Solid Organ Transplant Program utilizes the PACT (Pediatric to Adult Care Transition) program to assist patients and families. This program was developed at Children's and is utilized throughout the hospital. It was tailored by Solid Organ Transplant Program staff to meet the special needs of transplant patients. Beginning between ages 14-15, your transplant team will start talking about the transition process during your regular clinic visits. They will discuss with your family the issues related to adult health care, how to learn to manage your own health care needs, finding and using support resources, and what you need to know about your health to stay healthy in the future. At some point, you will meet with the following staff:

- Psychologist
- Child Life Specialist
- Dietitian
- Social Worker
- Doctor/Nurse Practitioner
- Financial Counselor

Each year, you will be asked to focus on learning specific information and skills to take care of your health, with the help of your family. If you need additional help with this process, SOTP staff will always be available. We may suggest more visits to help with the transition process. Around the time of your senior year of high school (or equivalent) you will be invited to participate in a PACT group day, where we will review these skills with patients and parents (separately) and allow teens/young adults to support each other as you plan your future.

For those patients with specific needs related to their independence (for example, patients with cognitive or developmental concerns), we will create a specific and appropriate transition plan with you and your family.

If you have questions about the PACT Program or would just like more information, feel free to contact Jami N. Gross-Toalson, PhD (214-456-5849) or Melanie Sweat, CCLS (214-456-6447)

## CONTACTING THE DONOR FAMILY

Although the decision to write your donor family is very personal, many transplant recipients want to know about the person who donated their organ.

If you choose to write to your donor family, the following information may make the letter easier:

### How the Process Works

Although each transplant center has different procedures for contacting donor families, the following guidelines may help you when writing a letter or card. For specific suggestions and rules, talk to your transplant team or local Organ Procurement Organization (OPO.)

#### *Mailing your card or letter:*

1. Place your card or envelope in an unsealed envelope.
2. Include a separate piece of paper with your full name and the date of your transplant.
3. Place these items in another envelope and mail them to your transplant center.
4. Allow extra mailing time. It can take several weeks for your letter to reach the donor family.

#### *Once the transplant center receives your letter:*

1. The transplant center will forward your letter to your OPO (Organ Procurement Organization).
2. A coordinator from the OPO will review it to make sure of confidentiality.
3. The coordinator will then contact the donor family to ask if they wish to accept mail from you.
4. If the donor family does not wish to communicate, the OPO will inform your transplant center
5. If the donor family does wish to communicate, the OPO will forward your letter to them.

#### *Confidentiality*

Although there is no law that a donor's family and the organ recipient cannot meet and know each other's name, all OPOs have policies to protect the privacy of both parties.

## Writing Your Letter

### *What information should I include?*

- Your first name only
- The state where you live
- Recognize the donor family's kindness and thank them for their gift
- Describe how long your child waited for a transplant and how the wait impacted him or her and your family
- Explain how the transplant has improved your child's health and changed his or her life
- Describe the impact of your child's transplant on your own family
- Explain what has happened in your child's life since the transplant
- State your child's hobbies or interests

### *What information should not be included?*

- Do not include your or your child's address, city or phone number
- Do not include the name or location of the hospital where your child's transplant surgery was performed, or the names of your transplant health care providers
- Use caution when including religious comments, as you do not know the religion of the donor's family

### *Will I hear from the donor's family?*

You may or may not hear from your child's donor's family. Some donor families may feel that writing about their loved one and their decision to donate helps them in their grieving process. Others choose not to write to the organ recipient.

If the donor family chooses to respond, they will send a letter to the OPO. The OPO will then forward the response to you.







### Attractions

Place	Location	Phone Number
Museum Railroad	Fair Park, Dallas	(214) 428-0101
Dallas World Aquarium	1801 N. Griffin St., Dallas	(214) 720-2224
Dallas Arboretum	8525 Garland Rd., Dallas	(214) 516-6500
Dallas Butterfly House	Fair Park, Dallas	(214) 428-7476
Dallas Museum of Art	1717 N. Harwood St., Dallas	(214) 922-1200
Dallas Nature Center	7171 Mountain Creek Pkwy., Dallas	(972) 709-7784
Dallas Zoo	621 E. Claredon Dr., Dallas	(469) 554-7500
Dollhouse Museum	2208 Routh St.	(214) 969-5502
Farmers Market	Bounded by Cadiz & Harwood St.	(214) 670-5879
International Museum of Cultures	7500 W. Camp Wisdom Rd., Dallas	(972) 708-7406
John F. Kennedy Memorial	Market & Main St., Dallas	N/A
Kow Bell Indoor Rodeo	1263 N. Main St., Mansfield	(817) 477-3092
Medieval Times Dinner & Tournament	2021 N. Stemmons' Freeway., Dallas	(866) 731-9313
Mesquite Championship Rodeo Fri. & Sat eves. April-Sept.	I-635, Military Parkway Exit, Mesquite	(972) 285-8777
Museum of African-American	1111 First Ave., Fair Park, Dallas	(214) 565-9026
Old City Park	1717 Gano St., Dallas	(214) 421-5141
Palace of Wax & Ripley's Believe It Or Not	601 Safari Pwky., Grand Prairie	(972) 263-2391
Perot Museum of Nature and Science	2201 N. Field St, Dallas	214-428-5555
Reunion Tower	300 Reunion Blvd., Dallas	(214) 571-5744
Museum of Nature & Science	Fair Park, Dallas	(214) 428-5555
Six Flags Over Texas	I-30 at State Hwy 360, Arlington	(817) 640-8900
Texas Hall of State	Fair Park, Dallas	(214) 421-4500
Hurricane Harbor- water park	I-30 North across from Six Flags, Arlington	(817) 265-3356
White Rock Lake	Enter at NW Hwy, Garland Rd. or Buckner Blvd.	(214) 670-4100
Wils on Block- historical tour	Swiss Ave, between Oak & Texas St., Dallas	(214) 821-3290

### SHOPPING

Place	Location	Phone Number
Bigtown Mall	U.S. 80 East & Loop 12, Mesquite	(214) 327-4541
Collin Creek Mall	811 N. Central Expwy, Plano	(972) 422-1070



## Children's Medical Center Dallas - Liver Transplant Family Notebook

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Galleria	Dallas Pkwy & LBJ Frwy., Dallas	(972) 702-7100
Highland Park Village	Preston Rd. & Mockingbird, Dallas	(214) 528-9401
Irving Mall	3880 Irving Mall (crossroads 183 & Beltline), Irving	(972) 255-0571
Mandalay Canal Shops	Hwy. 114 & O'Connor Rd., Irving	(972) 556-0111
Northpark Center	NW Hwy & N. Central Expwy, Dallas	(214) 361-6345
Prestonwood Town Center	5301 Beltline Rd., Dallas	(972) 788-4071
Town East Mall	LBJ Frwy & Town East Blvd., Dallas	(972) 270-2363
Valley View Center	LBJ Frwy & Preston Rd., Dallas	(972) 661-2939
Stonebriar Centre	2601 Preston Rd., Frisco	(972) 668-6255

### SPORTS

Place	Location	Phone Number
Top Golf Dallas	8787 Park Lane Dallas	(214) 341-9600
Dallas Cowboys Football (Aug.-Dec.)	925 N Collins, Arlington	(817) 892-4161
American Airlines Center -Dallas Basketball (Sept.-Mar.)	2500 Victory Avenue, Dallas	(214) 222-3687
Mesquite Championship Rodeo (April-Sept)	P.O. Box 176, Mesquite	(972) 285-8777
Southern Methodist Univ. Sports	P.O. Box 216, Dallas	(214) 692-2901
Texas Ranger Baseball (April-Sept)	100 Ball park Way, Arlington	(817) 273-5222

### PERFORMING ARTS

Place	Location	Phone Number
The Dallas Opera	Majestic Theatre, 1925 Elm St. Ste 400	(214) 443-1000
Dallas Repertory Theater	650 N Coit Rd, Richardson	(972) 690-4607
Dallas Summer Musicals	909 1 <sup>st</sup> Ave, Dallas	(214) 421-5678
Dallas Symphony Orchestra	2301 Flora, Dallas	(214) 692-0203
Dallas Theater Center	3636 Turtle Creek Blvd., Dallas	(214) 716-6955
Casa Manana	3101 Lancaster Ave Fort Worth	(817)332-2272