

# **Pediatric Liver Transplant**

A Guide for Patients and Families



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## INTRODUCTION

Welcome to the Liver Transplant Program at Children's Mercy Kansas City. We offer complete pre- and post-transplant services for children requiring liver transplant. Children's Mercy is the region's exclusive pediatric medical center and health care network. Our physicians, nurses, and staff are all trained specifically to work with children. Our focus is on caring for our patients in a friendly, family-centered environment.

### **Our Promise to You**

The Liver Transplant Team wants to provide you and your child with high quality, family-centered care. Together, our team can give you the support you need during your child's treatment.

### **About the Family Notebook**

This handbook provides information about the liver and transplant process. It includes detailed information about the care of your child after transplantation. This knowledge is important to help ensure a healthy life for your child. Although your child's local doctor, along with the transplant team, will be directing your child's care, you play a vital role.

This manual does NOT replace instructions given to you by your child's health care team. It is not meant to be medical advice or a complete resource for all information on liver transplant. Your child's doctor is the best source of information about what is right for your child's medical treatment. If you have any questions about this manual, please ask the Liver Transplant Team.

As you work through the handbook there will be words that are **bolded** and *italicized* that can be found in the glossary for a more in-depth explanation.

## Liver Transplant Team Directory

### Transplant Surgeons

Richard Hendrickson, MD

### Transplant Hepatologists

James Daniel, MD

Ryan Fischer, MD

Voytek Slowik, MD

### Transplant Nurse Coordinators

Megan Faseler, RN, BSN, CPN, CCTC

Andrea Bennett Wieser, MS, PA-C

Molly Hufferd, BSN, RN, CPN, VA-BC

Misty Uhl, RN, BSN, CPN

### Liver Nurse Coordinators

Gayla Cheadle, RN, CPN

Kelly Hames, RN, BSN, CPN

Angela Tendick, RN, MSN, CPNP

Karie Robinson, RN, MSN, CPNP

Infectious Disease Doctor: Christopher Day, MD

Transplant Pharmacist: Dan Heble, PharmD

Social Worker: Amanda Stasi, LCSW

Transplant Psychologist: Jamie Ryan, PhD

Nutrition Services: Jennifer Morton, RD and Hannah Krohne, RD

Spiritual Services: Claudia Hubbard, MDIV, BCC

Child Life: Melanie Weinrich, CCLS

Financial Coordinators: Yvetta Jackson, Elaine Gibson

## Phone Numbers

Liver Transplant Office.....	(816) 460-1010
Liver Transplant Fax.....	(816) 302-9676
Liver Care Center .....	(816) 302-3410
Children’s Mercy Hospital Operator.....	(816) 234-3000
Children’s Mercy Outpatient Pharmacy.....	(816) 234-3055
Children’s Mercy Outpatient Lab .....	(816) 234-1530
5 Sutherland Tower .....	(816) 234-1510
Pediatric Intensive Care Unit.....	(816) 234-3500
Ronald McDonald House.....	(816) 842-8321

### Transplant Coordinator Office Hours

Monday through Friday 8:00 am until 4:30 pm

After hours, weekends, and holidays, dial (816) 460-1010 and ask for the Liver Coordinator on-call to be paged.

## FAMILY COMMITMENT

The choice to allow your child to have the evaluation for transplant and actual listing for transplant is a very tough decision. We know this is a stressful time and will do our best to help you in any way we can. However, the demands of a liver transplant do not stop at the hospital door. This is a major event that will affect every person involved with your child, especially every family member. Caring for a child with a transplanted liver is a lifelong commitment. In fact, the hardest work starts after your child goes home from the hospital.

Adherence, formerly known as compliance, is defined as how a patient follows through with medical advice given to them by their medical team. The transplant team considers adherence very seriously because we believe it will affect your child's outcome after transplant. Transplant patients are required to follow a complex self-care regimen before and after transplant. Patients are expected to participate in and cooperate with medical recommendations throughout the transplant experience. Families are expected to support and monitor their child's self-care program as directed by the medical team. The transplant team will outline adherence guidelines they would like your child to follow.

Your child will have to attend many follow-up visits, complete follow-up tests on schedule, and take many medicines on a strict schedule. The overall success of a transplant depends much more on long-term care and follow-up than on the transplant surgery itself.

The support of family and friends is very important to the success of the liver transplant. Knowing when and how to ask for help can make life easier for you, your child and your family.

It is important to keep siblings aware of the situation. Some children imagine things as being worse than they really are. You may have to talk to them and help them to understand what is going on. Siblings need to know they are part of the "family team" and they are loved and valued, even though the sick child may need the most attention. Children require different amounts and types of information based on their age. The child life specialist can help with discussion geared towards siblings.

## Life-Long Follow-Up

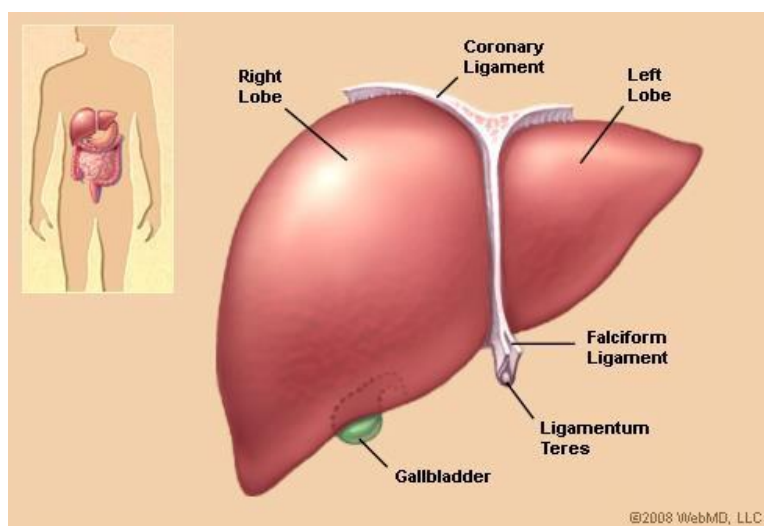
It is very important to watch for problems after surgery. This is required of all transplant recipients. The first year after transplant is hard and you will need to make many visits to the Transplant Clinic. If you live more than two hours away, you and your child may consider relocation or staying closer for a period of time after transplant. There may be rooms at the Ronald McDonald House or hotel rooms nearby. A list of hotels that provide discounts is available through the Social Work Department.

Our Commitment to You	Your Commitment to Us
<ul style="list-style-type: none"> <li>• We will provide the best care possible for your child.</li> </ul>	<ul style="list-style-type: none"> <li>• We expect you to be on time for your appointments, biopsies, and lab draws.</li> </ul>
<ul style="list-style-type: none"> <li>• We will treat you in a respectful manner.</li> </ul>	<ul style="list-style-type: none"> <li>• We expect you to get testing done when it is requested.</li> </ul>
<ul style="list-style-type: none"> <li>• We will make every effort to be on time for appointments with you.</li> </ul>	<ul style="list-style-type: none"> <li>• We expect at least 24 hour notice to refill prescriptions and/or to cancel appointments and tests.</li> </ul>
<ul style="list-style-type: none"> <li>• We will return your call promptly.</li> </ul>	<ul style="list-style-type: none"> <li>• We expect you to have a working phone with a personalized voicemail.</li> </ul>
<ul style="list-style-type: none"> <li>• We will be honest, upfront, and keep you informed to the best of our abilities.</li> </ul>	<ul style="list-style-type: none"> <li>• We expect you to call us with questions, and leave a message if we are not immediately available.</li> </ul>
<ul style="list-style-type: none"> <li>• We will not discuss your child with other families.</li> </ul>	<ul style="list-style-type: none"> <li>• We expect you to keep us updated on phone/address/insurance information.</li> </ul>
<ul style="list-style-type: none"> <li>• We will treat your child and family as individuals and tailor a plan of care to address your needs.</li> </ul>	<ul style="list-style-type: none"> <li>• We expect you to discuss questions/concerns about your child with the transplant team, not other families.</li> </ul>
	<ul style="list-style-type: none"> <li>• We expect you to respect the privacy of other families.</li> </ul>

## NEED FOR TRANSPLANT

### What is the liver and what does it do?

- The largest and one of the most complex organs in the body
- Located in the upper right side of the body, below the ribs
- Divided into two sections, called lobes that are subdivided into segments
- The only organ in the body that can regenerate (grow back)



Liver functions	How this affects the body
Helps the body digest, absorb, and store food and nutrients	The liver makes <b>bile</b> which helps digest food, absorb nutrients that nourish the body, and stores starch needed for quick energy.
Filters harmful chemicals	The liver helps remove harmful chemicals from the blood. Chemicals can be made by the body (ammonia) or put in the body (alcohol, drugs, and poisons).
Helps with clotting	The liver makes proteins that help blood to clot normally. Clotting happens when blood changes from a liquid to a solid, such as when a scab forms over a cut.
Makes albumin	Albumin is a blood protein that helps carry medicines and other things through the body. When albumin levels drop, fluid may accumulate in the ankles, lungs, or abdomen.



## What happens when the liver fails?

- If the liver is not absorbing or storing enough nutrients and vitamins from food, your child may not grow or develop normally.
- Blood may not clot as fast as it should which can cause your child to bruise more easily or take longer to stop bleeding after an injury.
- When the liver cannot process waste products, your child may have a buildup of the following:
  - **Bilirubin**, which can cause the skin and eyes to turn yellow (also known as **jaundice**).
  - **Ammonia**, which can cause irritability/fussiness or sleepiness (also called **hepatic encephalopathy**).
- Your child's stomach may get bigger because of extra fluid in the abdomen. This is called **ascites**.
- Your child may have more infections, especially in the ascitic fluid.
- Your child's skin may itch.
- Your child may develop **portal hypertension**, causing the spleen to get bigger and the veins in the **esophagus** and stomach to swell. These swollen veins are called **varices**. If the varices rupture, your child can have life threatening bleeding.

A liver transplant is offered not only to help a child live longer, but also to improve their quality of life.

Liver transplant is offered when no other medical or surgical options are available to fix a failing liver, but comes with many new responsibilities and challenges.

## Common causes of liver failure

Medical condition	What this means	Impact on the liver
Alpha-1-Antitrypsin Deficiency (A1A)	Caused by low levels of a protein (alpha-1-antitrypsin) that is made in the liver. Passed from parent to child.	When the body lacks alpha-1-antitrypsin, materials that break down protein attack other body tissue and cause liver damage.
Autoimmune Hepatitis	Because of a problem with the <b>immune system</b> , immune cells attack healthy liver cells.	Liver cells are damaged by the body's own <b>immune system</b> .
Biliary Atresia	<b>Bile ducts</b> carrying bile from the liver do not form normally before birth.	<b>Bile</b> trapped inside the liver causes scarring in the liver.
Alagille's Syndrome	<b>Bile ducts</b> become blocked and cause a backup. Associated with heart problems, unusual facial features, and other system involvement.	<b>Bile</b> is trapped inside the liver and causes scarring.
Cystic Fibrosis (CF)	CF affects the respiratory and digestive systems, and causes the body to produce an excess amount of mucous.	Excess mucous causes the bile ducts to become blocked and inflamed. This causes liver damage.
Fulminant (Acute) liver failure	The liver quickly fails because of severe damage to the liver cells. The cause is often unknown.	The liver cells die and are unable to function normally, causing problems with essential body systems.
Hemochromatosis	The body has a problem breaking down iron. Iron builds up in the liver.	-Iron is normally stored in the liver, kidneys, and heart; however, large amounts can cause damage. -Neonatal hemochromatosis occurs before birth and can lead to end stage liver disease.

Hepatitis A	A <b>virus</b> carried in contaminated food or water	The liver becomes inflamed. Symptoms can be mild to severe, but usually last less than two months.
Hepatitis B & C	<b>Viruses</b> carried by infected blood or body fluids	The liver becomes inflamed, causing long-term symptoms that may be severe.
Liver Cancer	<b>Hepatoblastoma</b> , the most common liver cancer in children, develops when cells in the body begin to grow out of control.	The cancer cells can spread to other organs.
Wilson's Disease	A rare inherited (passed from parent to child) disease in which copper collects in the liver	Extra copper can cause damage, scarring, and liver failure.

If your child's problem is not listed in the chart above, please ask your nurse or doctor to write down the name of the problem below:

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## THE TRANSPLANT EVALUATION

### Why does my child need an evaluation?

A liver transplant evaluation lets health care professionals decide if a transplant -

- Is possible
- Is the best treatment option
- Is the right option for your child at this time

The evaluation also helps the team to see if your child will have any special needs at the time of or after the transplant.

### Where will the evaluation take place?

Most patients have their evaluation done as an outpatient over two to three days, but more time may be needed depending on your child's medical condition. If your child is already admitted as an inpatient, the evaluation may be done while he/she is in the hospital.

### How do we prepare for the evaluation?

To help make the evaluation process as smooth as possible:

- Bring your insurance or Medicaid card and your child's immunization (shot) records to the clinic visit.
- Arrive on time. If you are late, we may need to reschedule your evaluation.
- Please leave young siblings at home, if possible. Your focus needs to be on learning about the transplant.

## What happens during the evaluation?

Your child will have a variety of meetings and tests that may include:

### Appointment in the Liver Care Center that includes:

- A physical exam, medical review, and surgical history
- Evaluation by the transplant surgeon and liver doctor
- Visit with the transplant coordinator

### Blood Tests

- Blood type (will be done twice if your child has never had their blood type checked)
- Blood chemistries such as **sodium, potassium**, and kidney function tests
- Blood counts such as **hemoglobin, hematocrit**, and **white blood cell counts**
- Liver function tests
- Blood for viruses, such as **EBV, CMV, Varicella, HSV**, and **HIV**
- **Coagulation** studies such as PT/PTT/INR/Fibrinogen, etc.
- Vitamin levels
- Tests for tuberculosis

### Imaging Studies

Chest X-ray: determines if your child's lungs and heart are healthy

Ultrasound with doppler: done with sound waves and checks the liver and surrounding blood vessels

CT scan: looks at the shape and size of the liver and major blood vessels around the liver. It may be done if the ultrasound does not give the transplant team the needed information.

Magnetic resonance imaging (MRI): looks at the liver and major blood vessels around the liver. It may be done in place of a CT scan.

Bone X-rays: checks your child's bones for rickets and bone age

## Heart and Breathing Tests

Electrocardiogram (EKG or ECG): records the electrical activity of the heart

Echocardiogram (ECHO): an ultrasound of the heart that shows how well your child's heart "pumps"

Pulmonary Function Tests (PFTs): checks lung function

## Procedures

Liver biopsy: checks the liver tissue itself. The doctors take a small sample of liver with a special needle. The tissue is sent to the laboratory for testing. Your child will be asleep during this procedure.

Endoscopy: checks for **varices** in the **esophagus** and stomach. The doctor looks into the esophagus and stomach by inserting a small, flexible tube. Your child will be asleep during this procedure

Cholangiogram: if needed, this test checks the **bile ducts** for any blockages

Dental exam: to evaluate and treat any dental problems prior to the transplant

Your child may not require all of these tests. The transplant team will decide which tests your child needs based on his/her disease and medical condition.

## Consultations

As part of the evaluation, your child will meet with several members of the transplant team, including the **Anesthesiologist**, Infectious Disease doctor, Dietitian, Social Worker, Pediatric Psychologist, Financial Coordinator, Child Life Specialist, and Chaplain. Additional evaluations are done on an as needed basis and may include a visit with a **cardiologist**, **nephrologist**, and/or **hematologist**.

## The transplant team

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**Transplant Surgeons.** The doctor who will perform the liver transplant surgery, provide ongoing care to your child after surgery, as well as work with your local doctor to meet your child's long-term medical needs. Transplant surgeons are skilled in pediatric surgery, especially procedures of the liver, gallbladder, and blood vessels.

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**Transplant Hepatologists (Liver Doctors).** The primary doctor who will care for your child from evaluation to transplant. After surgery, they will work with the transplant surgeon and your local doctor to ensure the best possible medical care for your child. Transplant doctors are skilled in treating children with liver disease before and after transplant.

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**Transplant Coordinators.** Registered nurses or advanced practice providers who coordinate all aspects of the transplant process both before and after the surgery, including discharge and follow-up care. While one coordinator will have primary responsibility for your child's care, you may have contact with all of the nursing staff over the course of your child's treatment.

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**Liver Coordinators.** Registered nurses and advanced practice providers who coordinate your child's care from referral until liver transplant. The coordinator works with the hepatologist, your local doctor, and the transplant team to coordinate care. They can help you to understand your child's disease/transplant process, medications, and treatment plans.

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**Infectious Disease Doctor.** A doctor trained to identify and treat infections in the *immunocompromised* patient. They see all patients during the transplant evaluation to review vaccination records and infection history. After transplant, they work with the doctors to manage any infections that may occur.

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**Transplant Pharmacist.** A pharmacist with specialization in transplant medicines who will arrange for your child's medicines and provide you teaching on dosing, side effects, and administration times.

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**Social Worker.** A social worker will assist your family in understanding the impact of your child's disease, as well as provide counseling and support to help relieve emotional distress. They can also help find resources (e.g., transportation, lodging, and financial assistance) and make referrals to community agencies if necessary.

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**Psychologist.** An expert in child development and behavior who helps children and their families cope with the stress related to transplantation and can provide strategies for managing the prescribed treatment regimen. Your child will receive a thorough psychosocial assessment as part of the transplant evaluation.

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**Dietitian.** A registered dietitian will evaluate your child's nutritional status throughout the transplant process and work with you to develop a diet that meets your child's nutritional needs.

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**Child Life.** These professionals help prepare your child emotionally for transplant surgery and the hospital stay, and are also available to help with sibling adjustment and coping. During the hospital stay, a child life specialist will be available to direct supervised playtime in the playroom or bedside, assist with distraction techniques during procedures, and coordinate special events.

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**Chaplain.** Hospital chaplains are available to assist families with the faith and spiritual issues that may arise throughout the transplant experience. They assist persons from all faith traditions, and their goal is to help you find the spiritual support you need. The chaplain can also help by contacting your minister or other clergy from home or a clergy person from your faith tradition.

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**Financial Coordinators.** A financial coordinator is available to help 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. They will help you when applying for state or federal programs, if applicable. If you have any questions about your health insurance, we encourage you to call your financial coordinator.

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**Other Staff Members.** Additional specialists trained in pediatrics will help care for your child, including pathologists, radiologists (x-ray), hematology (blood) doctors, renal (kidney) doctors, cardiologists (heart), respiratory therapists, and physical and occupational therapists.

Interns, residents and fellows (doctors in school) often are with your doctors 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.

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## What happens after the evaluation?

After the tests and consultations, the Liver Transplant Selection Committee meets to decide if your child needs a liver transplant, how soon, and what he/she needs to be in the best health possible for a transplant. Members of the committee include all members of the ***multi-disciplinary team*** that participated in your child's evaluation.

The committee can make the following recommendations:

- Accepted: The patient is a candidate for transplant and should be listed now
- Deferred: Additional information and/or testing are needed, or the patient is not yet sick enough for transplant
- Denied: The patient is not considered an appropriate candidate for transplant, either because he/she is too sick or there is a problem with another organ

The transplant coordinator will contact you by phone with the committee's recommendations

Your child will go on the transplant waiting list only if the transplant team agrees that transplant is the best option for your child, and you agree for your child to have the transplant.

If you agree for your child to have the transplant, the coordinator will then request pre-approval from your insurance company or state Medicaid program for the transplant procedure. This may take 1-2 weeks.

## Who is a candidate for liver transplant?

A child should be listed for transplant when liver failure is either unavoidable, about to happen or has already happened and the child has complications of end stage liver disease. Some of those complications are listed on page 9.

## Why would my child not be a candidate for liver transplant?

Some of the reasons a child may not be a candidate for liver transplant include:

- Infection that is outside of the liver
- **Malignancy** outside of the liver
- Active substance abuse (alcohol, narcotics)
- Additional organs have failed, such as heart, lungs, etc.
- Technical impossibility as determined by the transplant surgeon
- Additional life-limiting medical condition(s)
- History of patient or parent non-adherence with medical care and/or medications

Should your child not be a candidate for transplant, the transplant physician and transplant coordinator will discuss the reasons with you and review options for your child's care.

## Financial Information

### How much does a liver transplant cost?

The average cost of a liver transplant in the U.S. is around \$700,000. A Financial Coordinator at Children's Mercy will meet with you during the transplant evaluation to assess your financial status and discuss payment options.

### We have Health Insurance:

The financial coordinator will contact the insurance company to check if liver transplant is a covered benefit and whether Children's Mercy is an in-network provider. They will also check your deductible, out of pocket expenses, lifetime maximum benefits, and prescription drug coverage.

The transplant coordinator will send the appropriate medical information to your insurance company to obtain approval for the transplant procedure. They may also require prior approval for the pre-transplant evaluation.

It is YOUR responsibility to notify the transplant coordinator or financial counselor as soon as you are aware of any changes in insurance, including loss of coverage and/or changes in coverage or carrier. Even with good insurance, it is helpful to have funds available for food, housing during transplant, travel expenses, and deductibles/co-pays. Check with your insurance company about available benefits.

### We have Medicaid:

The financial coordinator will confirm active coverage by Medicaid on a monthly basis until the time of transplant.

The transplant coordinator will obtain prior approval from Medicaid for the transplant procedure.

It is YOUR responsibility to keep your Medicaid active and to notify the financial counselor immediately if it becomes inactive for any reason.

### We don't have Health Insurance or Medicaid:

A financial coordinator will meet with you and review your financial status to see if you qualify for financial assistance.

## Insurance Reference

It seems impossible for anyone to remember everything about their insurance. This reference page will help you keep important information at your fingertips.

Call your insurance company or employee benefits coordinator at work and get the facts in terms you can understand. Keep this sheet in this notebook and a copy in your child's bill folder. Fill one out for each insurance policy covering your child.

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**Insurance Company** \_\_\_\_\_

**Policy Holder** \_\_\_\_\_

**Policy #** \_\_\_\_\_ **Group #** \_\_\_\_\_

**Effective Date** \_\_\_\_ / \_\_\_\_ / \_\_\_\_

**Deductible \$** \_\_\_\_\_

**Policy Limits** \_\_\_\_\_

<u>Percentage Covered</u>	<u>Amount Covered</u>
---------------------------	-----------------------

% _____	\$ _____
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% _____	\$ _____
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**Out Patient % covered** \_\_\_\_\_

**Day Surgery % covered** \_\_\_\_\_

**Psychiatric care % covered** \_\_\_\_\_

**Does this policy require a second opinion?**

**Does this policy require pre-certification?**

**Pre-certification phone #** \_\_\_\_\_

**If I have any questions or problems, whom do I call?**

**Name** \_\_\_\_\_ **Phone #** \_\_\_\_\_

## How does the waiting list work?

Once insurance/Medicaid approval has been received, your child's name and information will be placed on the national transplant waiting list. The transplant coordinator will contact you by phone when your child has been placed on the wait list and will also send you a formal letter by mail.

Donor organs are distributed according to a national system run by the United Network for Organ Sharing (UNOS). Your child will be given either a **PELD** (if under 12 years of age) or **MELD** (12 years and older) score. This score is used to measure how urgently a patient needs a transplant. Your child's **PELD/MELD** score will change over time. The transplant team will keep you updated as changes occur.

The priority exception to the **PELD/MELD** score is a category known as Status 1.

- **Status 1A** - Patient suddenly develops liver disease, such as fulminant (acute) liver failure. Patient will not survive more than 7 days without a transplant.
- **Status 1B** - Similar to Status 1A, but for patients with chronic liver disease, or special diagnoses such as hepatoblastoma or some metabolic diseases.

## How does the UNOS donor matching process work?

1. The donor's medical information is put into a computer program
2. The computer then performs a "match run"
  - Think of the list as a "pool" of patients that UNOS searches in for a match
  - The liver is offered to the patient who has the highest PELD/MELD score
  - Other factors include:
    - Location of the donor and the patient
    - Amount of time the patient has been on the waiting list
    - Blood type:
      - *Same blood type*: Blood types are O, A, B and AB. Liver transplants are usually performed with the same blood type. This also includes O which is the "universal donor" and can be given to types A or B.
      - *Different blood type*: Under urgent conditions, your child may receive a different blood type liver, such as blood type A to type O.
3. UNOS notifies the Liver Transplant Team that a liver is available

4. The transplant doctor and surgeon review the donor information and decide whether or not to accept the organ. The decision is based on donor factors that may affect the condition of the liver and if it is the best match for your child.
5. The transplant coordinator notifies you that an organ is available

### **Multiple listing**

A patient can 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 should inform the centers they contact of their multiple listing plans.

If you are interested in having your child listed at another center, you must first:

- Check with your insurance company to see if they will cover the cost of the transplant at another center, including the cost of the evaluation.
- Have your child evaluated at each center according to their protocol. Some centers will accept testing that was done elsewhere.

You will be provided with additional information about this at the time of evaluation. If you have any questions, please contact your transplant coordinator.

### **Deceased organ donation**

Liver donors can be anyone (a child or an adult) whose brain has been so damaged by injury or disease that the brain dies, even with the best medical care. This stage is called “brain dead.” The deceased donor might have been injured in a car accident or a fall or drowning, for instance, or they might have had a brain tumor or other serious medical condition affecting their brain.

Although the donor is no longer alive, their major organs can be saved for a short time with machines and medications so that they can be removed and transplanted into someone else. The donor’s organs are removed only with the permission of their family. Donor families often see the donation of their family member’s organs as giving the gift of life to another person.

Your child may get a whole liver or part of one depending on the size of the available donor. This will be discussed with you at the time of evaluation.

**About the donor**

Families often want to know information about the donor, such as age and cause of death. For privacy reasons, we cannot give out this information. Families may also feel guilty about the death of the donor. We encourage you to talk about your feelings and to consider writing a letter or thank you note to the donor family. The transplant coordinator can give you additional information to help you write the letter.

## PREPARING FOR LIVER TRANSPLANT

### How long does it take to get a liver?

There is no way to know how long your child will need to wait for a donor liver; it could be a few days or many months to years. Your child's wait time can depend on their age, weight, blood group, and status (MELD/PELD score) on the waiting list.

The wait for transplant can be an anxious and emotional one. It is important to continue to find balance and a sense of normalcy for yourself, your child, and the rest of your family.

### While you wait for a transplant

#### Stay in touch

- To help us be able to reach you at all times, provide phone numbers for:
  - Home
  - Work (both parents)
  - Cell Phones (both parents)
  - Relatives, Friends, Neighbors
- Keep your cell phone turned on, charged, and with you at all times.
- Notify the transplant office if your phone number or address changes and if you plan to go out of town (vacation, business, etc.).

#### Make a plan to get to the hospital the day of transplant

- Check that your vehicle is working well and ready for the trip at any time. If your vehicle is not reliable, make plans for a relative or friend to be "on call" should you need help getting to the hospital.
- Arrange childcare or babysitting for any other children.
- Pack a bag for the hospital stay ahead of time.

#### Make sure your child is ready

- Notify the transplant team of any changes in your child's health, including illness or infection (such as a cold or sore throat), as this may delay the surgery.
- If your child gets sick, seek treatment right away to ensure they will be ready for transplant when a donor liver is available.
- Check with the transplant office before your child receives any immunizations, as he/she cannot be transplanted for one month after certain vaccines.



### Help your child stay in good shape for the transplant

- Encourage healthy foods, drink supplements, and/or continue tube feedings as directed by the physician and dietician.
- Keep your child's routine as normal as possible, including attending school and staying involved in any activities.
- Talk with your child about the transplant. Let your child voice his/her feelings, fears or concerns. Let him/her ask questions and be honest with your answers.

### **When the call comes**

When an appropriate donor is identified, you will receive a call from the transplant coordinator. The coordinator will also:

- Check that your child does not have a fever, cold, runny nose, etc.
- Check that your child has not received any recent immunizations
- Have your child stop eating and drinking to prepare for the surgery
- Provide instructions on where and when to arrive at the hospital. You will have plenty of time, so please drive carefully and obey all traffic laws!

### **Preparing for surgery**

You will need to be at the hospital several hours (possibly as long as 24-48 hours) before the surgery. That time is spent preparing your child and the organ for the procedure and making sure both are in acceptable condition for surgery. It is rare, but surgery can be canceled if there are concerns with the donor liver or your child. The transplant team will keep you informed of the plans for surgery.

When you arrive at the hospital, your child will be taken to a room either in the Pediatric Intensive Care Unit (PICU) or 5 Sutherland Tower (5ST) to get ready for surgery. Over the next few hours, the team will do a medical review of your child and some tests and procedures that may include:

- A medical history and physical examination
- A review of the medications your child currently receives
- Blood tests
- Placing an IV line
- Meeting with anesthesia and the transplant team

## Transplant surgery

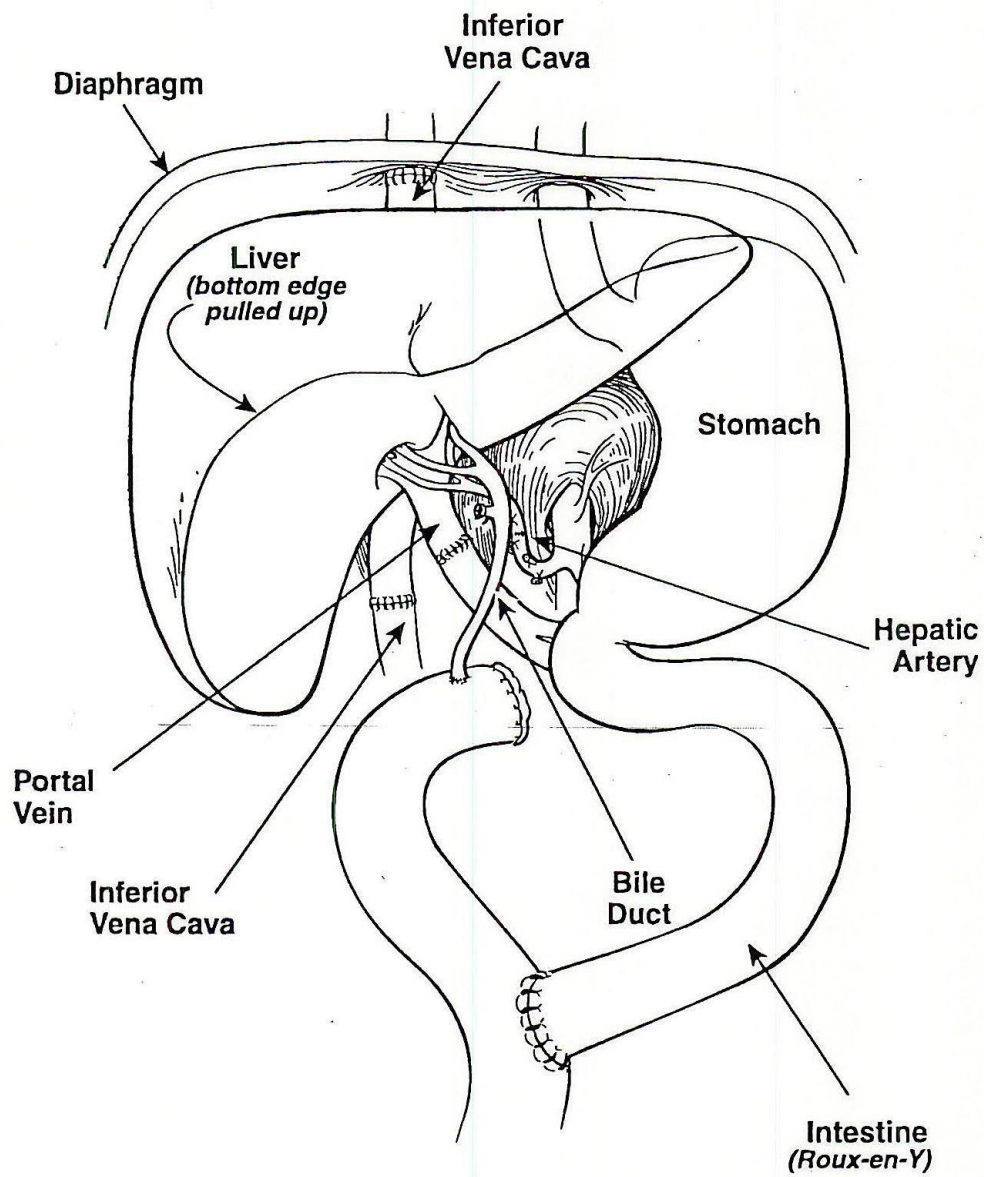
Once cleared for transplant surgery, you and your child will be taken to the PACU (Pre/Post Anesthesia Care Unit) to meet the **anesthesiologist**. After your child goes back to the operating room, you and other family members will be directed to a waiting room where you can stay while the transplant is in progress. The transplant coordinator or operating room nurse will give you periodic updates on how your child is doing and how the surgery is progressing. You are encouraged to get some rest and eat during the procedure, but please tell the operating room desk where you will be before leaving.

The transplant surgery is performed under general anesthesia and usually lasts 6-12 hours. Before the surgery starts, any tubes and equipment needed for the transplant will be placed. Your child will be asleep during this time.

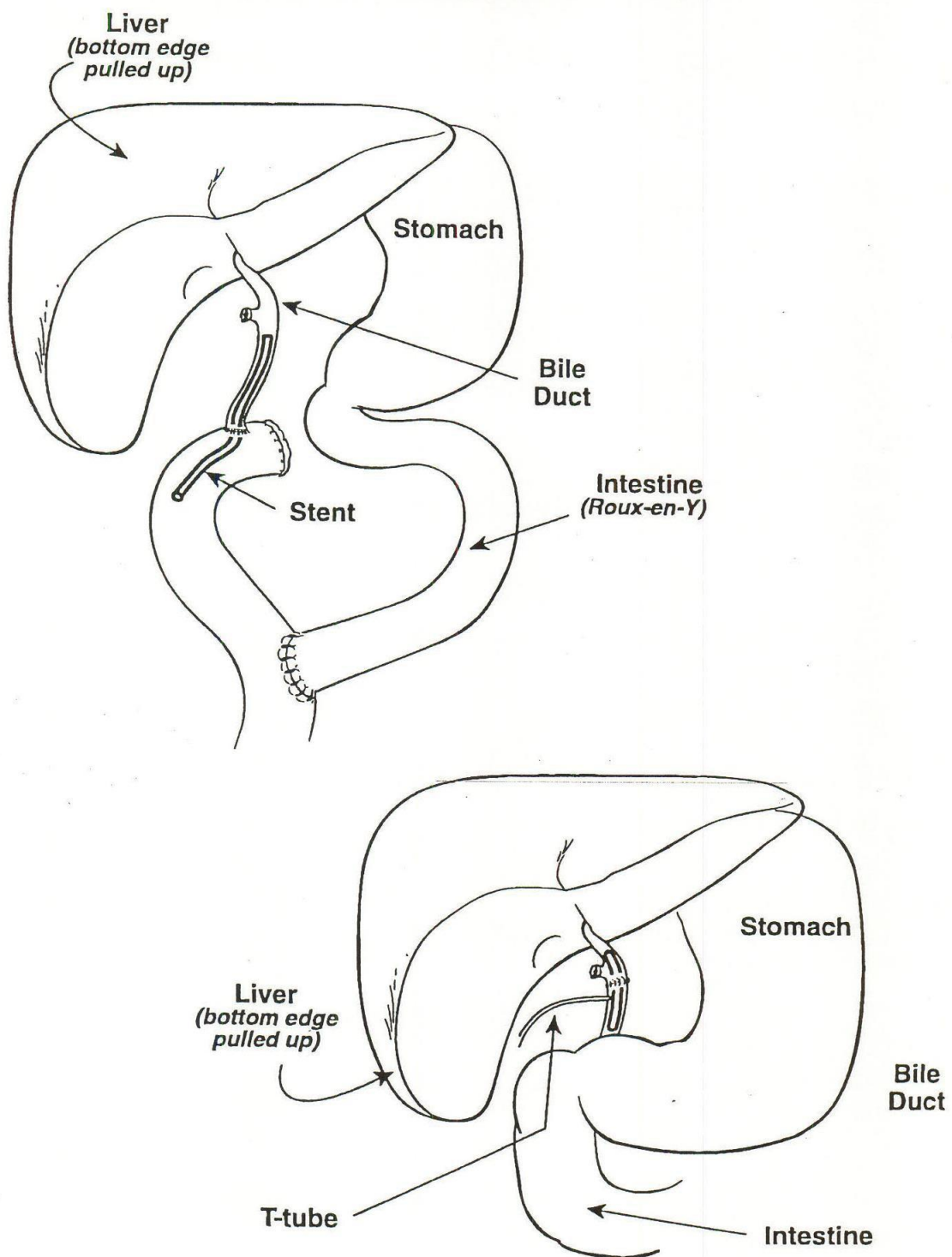
During surgery, your child's old liver is removed and the new liver is sewn in place and blood flow is returned to the new liver (See Figure 3). The **bile ducts** are connected. Two types of connections can be used depending on your child's liver disease and bile duct size (See Figure 4).

- **"Roux-en-Y"** (pronounced roo-en-y) is the most common connection where a portion of the small intestine is brought up to the bile duct of the transplanted liver. When completed, the shape resembles a "Y"
  - A stent may be placed internally to prevent the connected area from closing off and blocking bile flow during the healing process. It will pass out through your child's stool within a few months.
- An **anastomosis** will be performed if the bile ducts are large enough

Once any bleeding is controlled and drains are placed, the incision is closed. After the surgery, the surgeon will come out and talk with you about the operation, and your child will be taken to the Pediatric Intensive Care Unit (PICU). It will be about an hour before you are able to visit them.



**Figure 3. Transplanted Liver**



**Figure 4. Bile Duct Reconstructions**

## AFTER THE LIVER TRANSPLANT

### Pediatric Intensive Care Unit (PICU)

Once your child is in the PICU, the medical team will start the post-operative evaluation and treatment.

- Until your child wakes from the anesthesia, he/she will be on a breathing machine (ventilator) and will not be able to talk while the breathing tube is in place. Once breathing on his/her own, the tube will be replaced by an oxygen mask.
- A **nasogastric tube** (NG) will remain in your child's nose until intestinal function returns. The intestines tend to go to sleep with the anesthesia during surgery, and it can take them several days to "wake up".
- The **intravenous** lines (IV's) will stay in until they are no longer needed for monitoring or medication/blood administration. This may be several days.
- A bladder catheter (a soft plastic tube) will be in place for a few days to help continuously drain urine.
- Your child will have two drains placed in the abdomen to help remove excess blood and fluids after surgery. They will be removed during the first week after transplant.
- Once awake after surgery, pain medication will be given to help make your child as comfortable as possible.
- Your child will have an incision (cut) along the width of their abdomen, sometimes extending up towards the sternum (breastbone). There are multiple layers of stitches under the skin that will dissolve over time. A "glue" (called dermabond) over the top of the incision will also dissolve or peel off after 7-14 days.

The PICU and transplant team "rounds" daily between 8 a.m. and 12 p.m. to review labs and other data at the bedside and to form a plan. As an important part of the care team, caregivers are strongly encouraged to be present during rounds.

Depending on the condition, a child can stay in the PICU for a few days up to a few weeks. They will then move to the transplant floor (5 Sutherland) to continue healing before going home. During this time, you will learn about your child's medications and any care or special instructions needed prior to discharge.

## Helping your child cope in the hospital

Remember that you know what comforts your child better than anyone else - Try to remember what has worked at home or during similar medical procedures in the past. Provide praise and give frequent hugs if desired. During procedures/tests, distract your child with songs, humor, toys, or games.

Help your child understand what is happening - Explain procedures and tests using simple terms. Be honest if something is likely to hurt, but also explain its purpose and develop a plan for dealing with any pain.

Encourage your child to talk about how he or she is feeling - Remind your child that these feelings are normal and other children experience them, too.

Be patient - It is not uncommon for children to regress in unfamiliar situations that evoke fear or concern – crying, whining, acting out, bed wetting, requiring help with tasks previously done independently. If it continues to occur, it's okay to set some limits like you would at home. Also, work with the team to develop a daily routine so things are more predictable and allow your child to make choices when possible so they feel more in control.

Take care of yourself - Parents and caregivers can get distressed, too, and providing emotional support to your child can be taxing if you are stressed, worried, or not sleeping/eating. Ask for assistance from family and friends when possible, talk with other adults or staff about your own feelings, and try to make a little time for yourself even if it is going for a walk or taking a shower.

## Hospital discharge

You and another caretaker will be required to provide total care for your child for at least 24 hours prior to being discharged. At this time, a member of the transplant team will also show you where the pharmacy and outpatient laboratory are located. Once your child is stable and you are comfortable with medication administration and any lines/tubes that may still be in place, you will be discharged.

## Short-term follow-up

After leaving the hospital, you will be required to stay in the Kansas City area for approximately two weeks while the transplant team “fine-tunes” your child’s medications and makes sure he/she is doing well enough to return home. During this time, you will return to the hospital 2-4 times per week for follow-up visits, blood work, and/or other tests. If you live over 35 miles away from the hospital a referral can be made to the Ronald McDonald House for lodging.

Please bring your family notebook and all medications with you to each visit. Do NOT give your child’s morning dose of immunosuppressant (anti-rejection) medicine until after their blood is drawn. See instructions below.

### Instructions for obtaining medication “trough” levels

It is important that your child wait to take their morning dose of medicine until after the blood level has been drawn. The reason for this careful planning is that we want to know the lowest level of medicine in the blood during a 24-hour period. This lowest level, or “trough” blood level, occurs just before your child takes their next dose of medicine. Based on the trough levels of medicine in your child’s blood, the doctor may raise, lower, or keep the same dosage of medicine.

Trough levels are regularly obtained on the following transplant medications: Tacrolimus (Prograf), Mycophenolate (CellCept or Myfortic), Sirolimus (Rapamune), Cyclosporine (Neoral).

Trough levels are drawn within one hour before the medicine is due to be given. For example, if your child takes their medicine at 8 a.m., they will need their blood drawn between 7 and 8 a.m. Bring your child’s medicine with you to the hospital so that it can be taken right after the blood draw.

## Primary care

Your child’s primary care physician (PCP) will be the primary medical provider when you return home. If you have concerns about your child, first contact your local physician to have your child evaluated.

If your doctor has questions or concerns, they will contact us for a consultation which can be done any time 24 hours a day. The transplant team will be in close contact with the PCP to make medication adjustments based on lab results and your child’s progress.

## LONG-TERM TRANSPLANT CARE

### Clinic visits and routine testing

Your child will be seen in the Transplant Clinic and have lab work done often for the first six months after surgery. The visits will be very frequent for the first two to three months, and then they will spread out depending on how well your child is doing. At the end of one year, if there are no complications, your child will have labs drawn once every eight to twelve weeks and come to the clinic once a year.

Return clinic visits include:

- Lab work and other procedures
- A physical exam done by the transplant doctor or surgeon
- Meeting with the coordinator to discuss any changes and/or instructions
- If needed, consultation with transplant team members, such as the dietitian, social worker, psychologist, and/or pharmacist

A summary of these visits, along with labs and test results, will be sent to your child's PCP. If there are any changes in medications or labs, your child's PCP will be notified by phone or letter.

If you have questions for the transplant team, a coordinator will be available Monday - Friday from 8:00 a.m. to 4:30 p.m. If you call after hours or on the weekend and it is urgent, the answering service will page the transplant team member on call and they will return your call as soon as possible.

### Laboratory tests

Regular blood tests are needed after transplant and for the rest of your child's life. While the frequency decreases over time, your child may need labs done more often if he/she has a rejection, infection, or if medication changes are made.

Blood tests are used to check: how your child's liver transplant is working, the amount of medicine in your child's body to prevent rejection, signs of possible rejection, and signs of infection or other problems.

The doctor will review the lab results and decide if any changes in dosage or medication are needed.

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



Lab tests	Normal range	What it means
<b>Immunosuppressant medication levels</b>		
Tacrolimus, Mycophenolate, Sirolimus, and Cyclosporine	Depends on time since transplant	A low level increases the risk for rejection
<b>Liver Function Tests (LFTs)</b>		
Bilirubin	0.17 – 1.20	Elevation may indicate liver damage from rejection, blocked <b>bile ducts</b> , or an increase in <b>red blood cell</b> break down
Aspartate aminotransferase (AST)	12 – 50	Elevation may indicate damage from rejection, <b>hepatitis</b> , viral infection
Alanine transaminase (ALT)	5 – 50	Elevation may indicate liver damage from rejection, <b>hepatitis</b> , viral infection
Gamma-glutamyl transferase (GGT)	10 – 78	An <b>enzyme</b> that reflects bile duct function; elevation may indicate rejection, <b>hepatitis</b> , or <b>bile duct</b> obstruction
Alkaline phosphatase (AP)	140 – 400	A liver enzyme that is released when the <b>bile ducts</b> are irritated/ inflamed
<b>Basic Metabolic Panel (BMP)</b>		
Blood urea nitrogen (BUN)	5 – 20	Indicates the kidney's ability to excrete urea; Elevation may suggest kidney damage
Creatinine (Cr)	0.26 – 0.64	Elevation may indicate damage to the kidneys
Potassium (K)	3.5 – 5.2	Elevation may indicate kidney dysfunction
Glucose	65 – 110	Elevation may be seen with steroid use
Magnesium	1.6 – 2.3	A decrease can increase the risk for seizures in children taking Tacrolimus

<b>Complete Blood Count (CBC)</b>		
White blood cell (WBC)	5.5 – 15.5	Part of the <b>immune system</b> and helps fight infection. An elevation may indicate an infection or be a result of taking steroids; a decrease may indicate a viral infection or be a result of immunosuppression
Platelets (Plt)	150 – 450	Platelets help with blood clotting; a decrease may be a result of viral infection, medication, and other factors
Hemoglobin (Hgb)	Depends on age	Oxygen carrying pigment of red blood cells; a decrease indicates <b>anemia</b>
Hematocrit (Hct)	Depends on age	The percentage of the volume of whole blood made up of <b>red blood cells</b> ; a decrease indicates anemia
<b>Coagulation Studies</b>		
International normalized ratio (INR)	0.8 – 1.1	Elevation indicates an issue with the clotting of blood
<b>Viral Studies</b>		
Epstein-barr virus (EBV) and Cytomegalovirus (CMV) PCR		Indicates infection with the <b>virus</b>

## Other tests and procedures

### Liver biopsy

- A test done in radiology where a needle is used to take a very small piece of your child's liver to be examined further under a microscope
- This is done under sedation and your child will have to stay for 4-6 hours after the procedure for observation
- Helps the team monitor your child's liver and monitor for rejection

### Glomerular filtration rate (GFR)

- A test done in radiology in the nuclear medicine department. Two IV's are placed and the patient receives an injection of a radioactive tracer followed by blood sampling. The amount of radioactive material circulating in the blood is measured to check the filtering ability of the kidneys.
- Helps the team monitor your child's kidney function in addition to lab tests

### Liver ultrasound

- A test done in radiology that uses sound waves to look at the liver and its vessels
- Your child will not be able to eat or drink for a period of time before this test

### Ambulatory blood pressure monitor (ABPM)

- A test to monitor for hypertension, a long-term side effect of transplantation
- Monitors your child's blood pressure over a 24-hour period
- A blood pressure cuff will be placed on your child, and the monitor will automatically take a blood pressure every 20-30 minutes. After 24 hours, the blood pressure monitor can be returned to Children's Mercy for the reading.

## MEDICATIONS

After transplant, your child will take several medications. Each medication has a specific and important function to help prevent rejection and keep your child in the best possible health. Over time, the transplant team may decide to decrease or stop some medicines, but your child will require lifelong immunosuppressive therapy.

### Medication management

- Always take/give the medicine as directed
- Do not change the dose, frequency, or stop any medicine without talking with the transplant team. Notify the transplant team if your child experiences side effects.
- Do not try and make up missed doses unless instructed to do so by the transplant team
- Do not give over the counter medication unless you talk with your child's PCP or the transplant team
- Store medications away from heat, light, and moisture
- Call to refill prescriptions several days before you run out of medication
- Always keep the medication with you in a carry-on bag when traveling
- Keep an up-to-date list of your child's medications and dosing schedule (especially during the first 6 to 12 months as there can be frequent changes). A medication log is included at the end of the handbook. Bring a copy to every clinic appointment.

### Medication safety

- Do not give your child Aspirin (unless prescribed by your transplant team) or any medications that contain ibuprofen
- Check expiration dates on all medications
- Call the doctor if you notice any physical or mental changes in your child
- Talk with your pharmacist if any medication does not "look right"

In the following few pages, the most common medications that we use after transplant are discussed in more detail.

Medicine (Brand name)	What it does
<p><b><i>Immunosuppressants</i></b></p> <p>Tacrolimus (Prograf)</p> <p>Mycophenolate mofetil (CellCept)</p> <p>Sirolimus (Rapamune)</p> <p>Everolimus (Afinitor, Zortress)</p> <p>Prednisone, Prednisolone (Orapred)</p>	Helps prevent rejection
<p><b><i>Antacids</i></b></p> <p>Esomeprazole (Nexium)</p> <p>Lansoprazole (Prevacid)</p> <p>Ompeprazole (Prilosec)</p> <p>Ranitidine (Zantac)</p>	Decreases acid reflux
<p><b><i>Antibiotics</i></b></p> <p>Ciprofloxacin (Cetraxal, Ciloxan, Cipro)</p> <p>Sulfamethoxazole/Trimethoprim (Bactrim, Sulfatrim)</p>	Fights infections
<p><b><i>Antifungals</i></b></p> <p>Atovaquone (Mepron)</p> <p>Dapsone (Aczone)</p> <p>Nystatin (Nyamyc, Pedi-Dri, Nystop)</p>	Prevents and treats fungal infections
<p><b><i>Antihypertensives</i></b></p> <p>Amlodipine (Norvasc)</p> <p>Nifedipine (Procardia, Adalat)</p>	Helps control blood pressure
<p><b><i>Antivirals</i></b></p> <p>Acyclovir (Zovirax, Valtrex)</p> <p>Valganciclovir (Valcyte)</p> <p>Ganciclovir (Zirgan, Vitrasert, Valcyte)</p>	Fights viruses (e.g., CMV, chicken pox, HSV)
<p><b><i>Diuretics</i></b></p> <p>Fuorseamide (Lasix)</p> <p>Spironolactone (Aldactone)</p>	Treats fluid retention and high blood pressure

## IMMUNOSUPPRESSANTS

### Tacrolimus (Prograf)

When and how to give	<ul style="list-style-type: none"> <li>• Give at the same time every day, usually 12 hours apart</li> <li>• May give with or without food (give it the same way every day)</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• Increased blood sugar</li> <li>• Decreased magnesium</li> <li>• Increased potassium</li> <li>• Difficulty sleeping</li> <li>• Hand tremors</li> <li>• Diarrhea</li> <li>• Hair loss</li> <li>• Increased blood pressure</li> <li>• Kidney damage (if blood levels of Tacrolimus are too high, but long-term damage is also possible)</li> <li>• Increased risk of cancer</li> <li>• Seizures</li> </ul>
Additional instructions	<ul style="list-style-type: none"> <li>• Avoid grapefruit, grapefruit juice, pomelos and tangelos</li> <li>• Separate Tacrolimus and magnesium supplement by at least 2 hours</li> </ul>

### Mycophenolate (CellCept)

When and how to give	<ul style="list-style-type: none"> <li>• Give at the same time every day, usually 12 hours apart</li> <li>• May give with or without food (give it the same way every day)</li> <li>• Do not crush, break, or chew pills</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• High blood pressure</li> <li>• <b>Anemia</b>, low <b>white blood cell</b> count, low <b>platelet</b> count</li> <li>• Diarrhea</li> <li>• Belly pain or heart burn</li> <li>• Nausea</li> <li>• Risk of malformation in an unborn fetus</li> </ul>
Additional instructions	Separate Mycophenolate and magnesium supplements by at least 2 hours

### Sirolimus (Rapamune)

When and how to give	<ul style="list-style-type: none"> <li>• Give once a day, at the same time every day</li> <li>• May give with or without food (give it the same way every day)</li> <li>• Do not crush, break, or chew pills</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• Increased blood pressure</li> <li>• <b>Anemia</b>, low <b>platelet</b> count</li> <li>• Delayed wound healing</li> <li>• Mouth sores</li> <li>• Headache</li> <li>• Joint pain</li> <li>• Acne</li> <li>• Swelling in arms/legs</li> <li>• Kidney damage</li> <li>• Feeling tired/weak</li> <li>• High cholesterol level or triglyceride level</li> </ul>
Additional instructions	Avoid grapefruit, grapefruit juice, pomelos and tangelos

### Everolimus (Afinitor, Zortress)

When and how to give	<ul style="list-style-type: none"> <li>• Give at the same time every day, 12 hours apart</li> <li>• May give with or without food (give it the same way every day)</li> <li>• Do not crush, break, or chew pills</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• <b>Anemia</b>, low <b>white blood cell</b> count, low <b>platelet</b> count</li> <li>• Constipation</li> <li>• Diarrhea</li> <li>• Acne</li> <li>• Swelling</li> <li>• Feeling tired/weak</li> <li>• High cholesterol level or triglyceride level</li> <li>• Increased blood sugar</li> <li>• Rash</li> <li>• Mouth sores</li> </ul>
Additional instructions	Avoid grapefruit, grapefruit juice, pomelos and tangelos

**Prednisone, Prednisolone (Orapred)**

When and how to give	<ul style="list-style-type: none"><li>• If on daily dosing, give in the morning (can cause trouble sleeping)</li><li>• Take with food to lessen stomach upset</li><li>• May break pills if instructed</li></ul>
Common side effects	<ul style="list-style-type: none"><li>• Increased appetite</li><li>• Moon face</li><li>• May slow healing process</li><li>• Muscle weakness</li><li>• Acne</li><li>• Increased blood sugar</li><li>• Increased sun sensitivity</li><li>• Irritability</li><li>• Difficulty sleeping</li><li>• If on this medication for a long time, it can cause weaker bones, slow growth (height), and eye changes (cataracts/glaucoma)</li></ul>
Additional instructions	Always let medical providers and dentists know when your child is on steroids before any procedures or skin tests



## ANTIBIOTICS

### Sulfamethoxazole/Trimethoprim (Bactrim, Sulfatrim)

When and how to give	<ul style="list-style-type: none"> <li>• Can be given daily, every other day, or three times a week, as prescribed by the transplant doctor</li> <li>• May give with or without food</li> <li>• Give with plenty of fluids</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• Nausea/vomiting</li> <li>• Diarrhea</li> <li>• Sun sensitivity</li> </ul>
Additional instructions	Stop medication at the first sign of a rash and notify a physician

### Dapsone (Aczone)

When and how to give	<ul style="list-style-type: none"> <li>• Give as directed, usually daily</li> <li>• May give with or without food</li> <li>• Give with plenty of fluids</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• Mood changes</li> <li>• Diarrhea</li> <li>• Anemia</li> <li>• Headache</li> </ul>

### Atovaquone (Mepron)

When and how to give	<ul style="list-style-type: none"> <li>• Give as directed, usually daily</li> <li>• Give with high fat food (ice cream, milk) to help with absorption</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• Belly pain</li> <li>• Diarrhea</li> <li>• Headache</li> <li>• Muscle weakness</li> <li>• Difficulty sleeping</li> </ul>

## ANTIFUNGALS

### Nystatin (Mycostatin)

When and how to give	<ul style="list-style-type: none"> <li>• Give as directed; Always give nystatin last if you are giving other medications at the same time</li> <li>• Do <b>not</b> give with food or liquid</li> <li>• Swish liquid around in the mouth for one minute before swallowing</li> <li>• Do not eat or drink for 30 minutes after taking</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• Upset stomach</li> <li>• Diarrhea</li> <li>• Nausea/vomiting</li> <li>• Cavities (Nystatin contains sugar)</li> </ul>

## ANTIHYPERTENSIVES

### Amlodipine (Norvasc)

When and how to give	<ul style="list-style-type: none"> <li>• Give as directed, once or twice daily and at the same time every day</li> <li>• May give with or without food (give it the same way every day)</li> <li>• Do not crush, break, or chew pills</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• Cold hands and feet</li> <li>• Swelling of ankles and feet</li> <li>• Dizziness</li> <li>• Tiredness/weakness</li> <li>• Nausea</li> </ul>
Additional instructions	If a dose is missed, skip it and resume the next regularly scheduled dose

### Nifedipine (Procardia)

When and how to give	<ul style="list-style-type: none"> <li>• May give with or without food</li> <li>• Do not crush, break, or chew XL pills</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• Headache</li> <li>• Dizziness, light headedness</li> <li>• Flushing, heat sensation</li> <li>• Nausea/heartburn</li> <li>• Swelling of hands and feet</li> <li>• Tender or swollen gums</li> </ul>
Additional instructions	Regular brushing and flossing are very important

## ANTIVIRALS

### Acyclovir (Zovirax, Valtrex)

When and how to give	<ul style="list-style-type: none"> <li>• May give with or without food</li> <li>• Give with plenty of fluids</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• Dizziness</li> <li>• Diarrhea</li> <li>• Low <b>white blood cell</b> count</li> <li>• Headache</li> </ul>
Additional instructions	Contact a physician and get seen as soon as possible if your child has a known exposure or at the first sign of a rash that is concerning

### Valganciclovir (Valcyte, Gancyclovir)

When and how to give	<ul style="list-style-type: none"> <li>• Give once or twice a day, as prescribed, and at the same time every day</li> <li>• Give with plenty of fluids</li> <li>• Give with food to help the medication pass into your child's bloodstream</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• Diarrhea</li> <li>• <b>Anemia, low white blood cell</b> or <b>platelet</b> count</li> <li>• Headache</li> <li>• Fever</li> <li>• Elevated blood pressure</li> <li>• Difficulty sleeping</li> </ul>

## ANTACIDS

### Esomeprazole (Nexium), Lansoprazole (Prevacid), Omeprazole (Prilosec), Ranitidine (Zantac)

When and how to give	<ul style="list-style-type: none"> <li>• Give prior to eating</li> <li>• Give with plenty of fluids</li> <li>• Do not crush, break, or chew pills</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• Headache</li> <li>• Constipation</li> <li>• Diarrhea</li> </ul>

## DIURETICS

### Spirolactone (Aldactone)

When and how to give	<ul style="list-style-type: none"> <li>• Give with food</li> <li>• Do not crush, break, or chew pills</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• Drowsiness</li> <li>• Increased potassium (symptoms - confusion, nervousness, heaviness/numbness in extremities)</li> <li>• Rash</li> <li>• Low blood pressure (symptoms - headache, dizziness)</li> <li>• Nausea/vomiting</li> <li>• Increased hair growth, breast tissue and/or tenderness, menstrual irregularities in females</li> </ul>

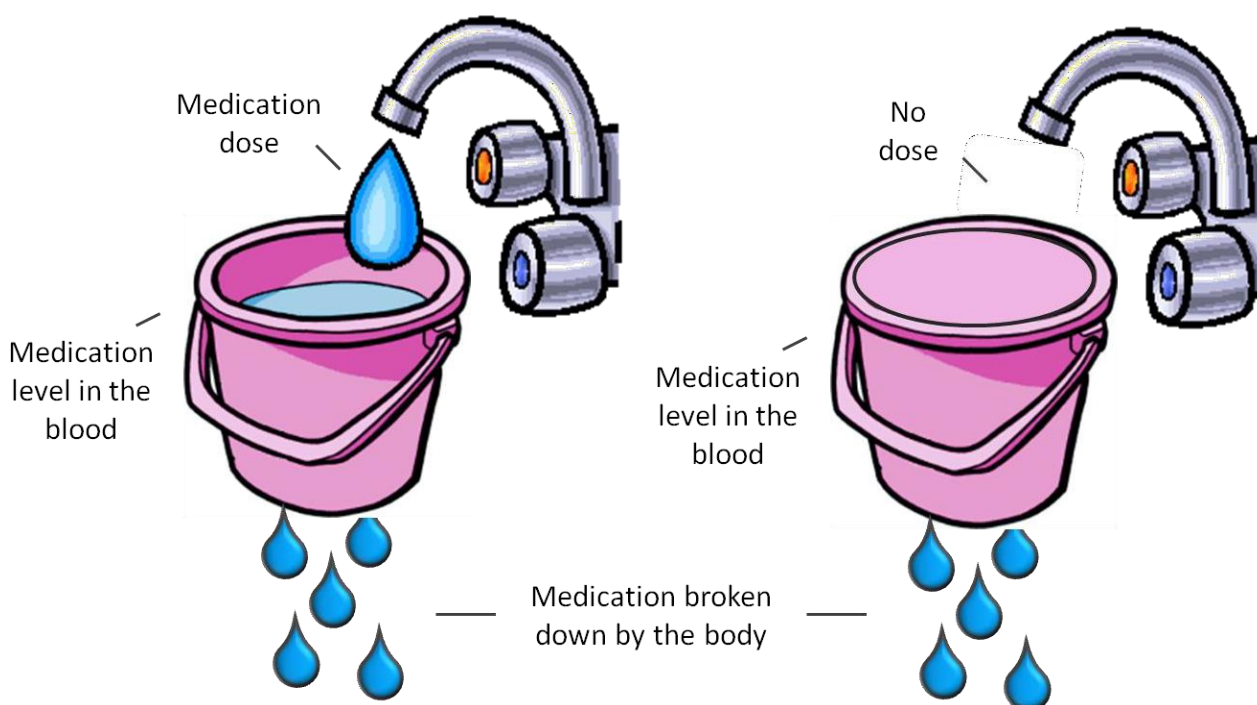
### Furosemide (Lasix)

When and how to give	<ul style="list-style-type: none"> <li>• May give with or without food</li> <li>• Do not crush, break, or chew pills</li> </ul>
Common side effects	<ul style="list-style-type: none"> <li>• Nausea/vomiting</li> <li>• Increased urine output</li> <li>• Anemia</li> <li>• Rash</li> <li>• Increased sun sensitivity</li> <li>• Decreased potassium (symptoms - weakness, muscle cramps)</li> <li>• Headache</li> <li>• Decreased hearing (rare)</li> </ul>
Additional instructions	Have your child get up slowly when they wake up or when they stand from a sitting position as they can experience dizziness

## Maintaining a dosing schedule

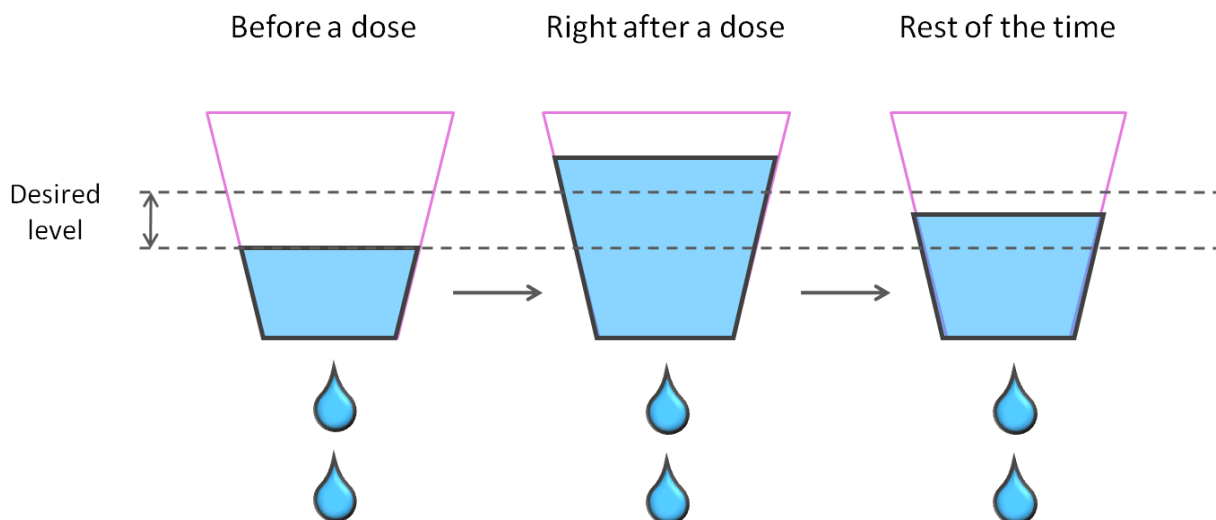
The key to preventing rejection is making sure there is the right amount of medicine in the bloodstream. Because some medicines get broken down and removed from the bloodstream more quickly than others, taking more than one dose every day may be needed. This is why it's important to take each dose of medicine on time.

When a dose of anti-rejection medicine is taken, the bloodstream fills up with medicine. It's like turning on the faucet to fill up a bucket with water, except there is a leak in the bucket that is similar to the body breaking down the medicine and getting rid of it.



If the correct dose is taken on time, the right amount of medicine is kept in the bloodstream. But, if a dose is missed, taken late, or not the right amount each time, there won't be enough medicine in the bloodstream. It is like the leak is still there, but the faucet is off.

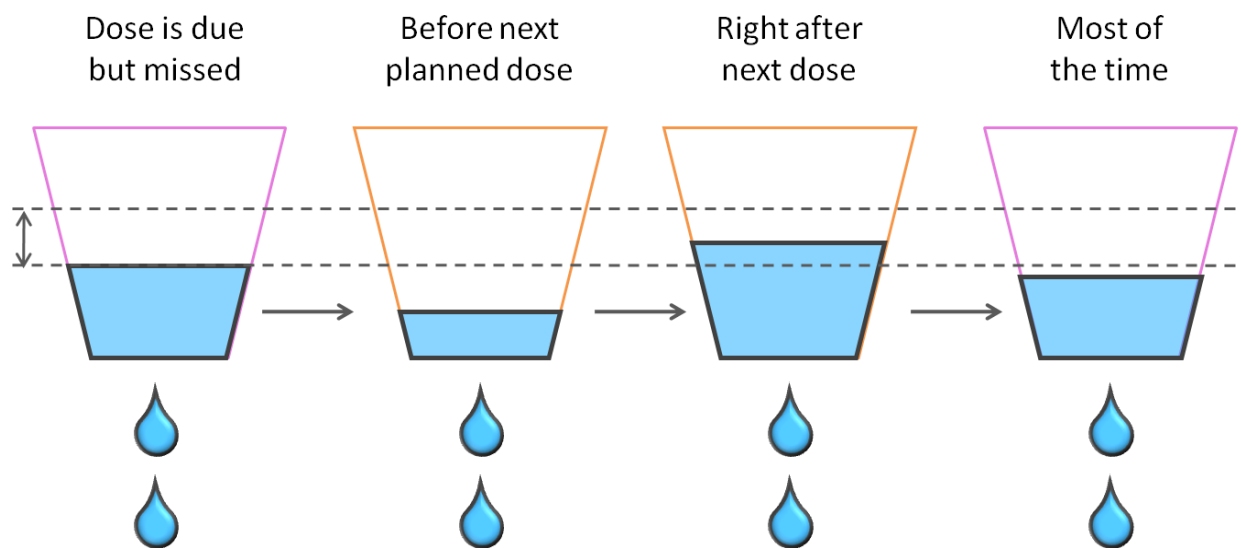
The doctor prescribes a certain amount of anti-rejection medicine to be taken every day. The level of medicine in the bloodstream is checked to make sure there is enough that stays within the range needed to prevent a rejection.



Blood levels are checked right before a dose is due. At this time, the amount of medicine in the blood will be at the lowest safe level to prevent a rejection. Right after a dose of medicine is taken, the level in the blood goes up.

Over time, the body works to break down the medicine and get rid of it—like the constant leak in the bucket. All the time between doses, the level of medicine in the bloodstream will be high enough to prevent a rejection...until it's time to take the next dose.

But, if a dose is missed or late, the level of medicine keeps falling (the bucket keeps leaking) so the level drops lower than it needs to be to prevent rejection. Even if the next dose is taken on time, it may take a while before the level gets back up to where it should be. And, the level will only get back up if doses aren't missed or late.



## Talking with the Transplant Team about your child's regimen

It's important to learn as much as you can about each aspect of your child's treatment regimen. The Liver Transplant Team is available to answer any questions you may have, and they acknowledge that it is a lot of information so repetition helps improve understanding. Possible questions to ask:

- How do I take this medicine?
- Do I need any laboratory tests done while I take this medicine?
- How long will I take this medicine?
- How can I tell if the medication is working?
- What should I do if I miss a dose?
- What will happen if I do not take this medicine at all?
- What are the side effects of this medicine?
- What do you recommend for managing various side effects?
- Does this medication need to be taken with food or after a meal?
- Do I need to avoid any food or drinks while taking this medicine?
- Do I need to avoid any over-the-counter and prescription medicines, vitamins, or dietary supplements while taking this medicine?

## COMPLICATIONS AFTER TRANSPLANT

### Rejection

#### Immune System

- The body's natural defense against disease - recognizes and tries to destroy any foreign substances in the body
- Foreign substances include viruses, bacteria, fungi, and foreign tissue (such as a transplanted liver)
- This means that your child's immune system recognizes their new liver as a
- foreign substance and tries to destroy it. This attack is called rejection.

#### Preventing Rejection

- To help prevent these "attacks", your child is prescribed medications that suppress the immune system
  - Prograf (Tacrolimus)
  - Cellcept (Mycophenolate Mofetil)
  - Prednisone, Prednisolone, Methylprednisolone
- Even with these medications, however, there is a strong possibility that your child will experience one or more episodes of rejection
- Give your child's medications exactly as directed by the liver transplant team
- Do not miss any doses of medications
- Bring your child to all clinic appointments, follow-up tests, and blood tests
- Check with the transplant team before giving your child any over-the-counter medications, including herbal (natural) medications because these medications can sometimes interfere with the immunosuppressant medications.

#### Timing of Rejection

- Rejection is most common in the first year after transplant, but can occur at any time

#### Signs and Symptoms of Rejection

**\*\*Notify the transplant team IMMEDIATELY if any of these symptoms occur\*\***

- Fever greater than 100F (38C)
- Clay-colored stools
- Yellow eyes
- Tea-colored urine
- Fatigue
- Feeling ill



- Other reasons to notify your local physician immediately
  - Vomiting/diarrhea
    - Vomiting where your child can not keep medication down
    - More than 4 loose, watery stools in 24 hours
  - If this occurs your child may need IV medication, as severe vomiting/diarrhea can cause medication drug levels to drop quickly

#### Elevated liver function tests may require further testing to confirm rejection

- Abdominal Ultrasound to check your bile ducts and blood vessels
- Blood tests that look for viruses
- Liver biopsy to look at your child's liver tissue

#### Treatment for Rejection

- Most commonly treated with high dose IV steroid (90% successful)
- Adjustment of baseline immunosuppression medicines

## Infection

Your child is immunosuppressed (decreased immune system or ability to fight off infections). They will get illnesses just like other children; however, more serious infections that initially appear routine can occur. If your child is getting ill, it is important to consult your PCP to have them evaluated.

#### Have your child seen by their PCP within 24 hours for the following conditions:

- Temperature greater than 101F (38.3C) for more than 24 hours
- A cough that lasts more than 24 hours or becomes productive
- Nasal drainage that is green or yellow
- A sore throat or headache (especially with fever for more than 24 hours)
- Vomiting or diarrhea lasting more than 24 hours, or if severe and would affect medication administration or absorption
- Persistent skin rash (especially with fever for more than 24 hours)

#### Common Infections

##### *Cytomegalovirus (CMV)*

- CMV is a member of the herpes virus family
- Most commonly diagnosed through blood tests or by tissue samples
- Treated with antiviral medications that may require hospitalization

### *Epstein-Barr virus (EBV)*

- EBV is a member of the herpes virus family
- In most people, EBV causes a viral illness with minor or no symptoms
- EBV infection increases the chances of developing post-transplant lymphoproliferative disorder (PTLD) (see next section on cancer)
- EBV is routinely checked in the blood
- If there is evidence of EBV in the blood, the dose of immunosuppression medicine may be lowered to allow the body to clear the virus on its own.
- Drugs to treat EBV are available, but may be ineffective or have side effects

### *Chicken Pox*

- If your child develops a rash that is concerning for chicken pox, notify the transplant team and your PCP immediately and get seen.
- If your child has chicken pox, they will be admitted to the hospital and treated with an IV drug called Acyclovir. The sooner it is started after the diagnosis the better.
- Your child should avoid contact with persons infected with chicken pox or who have shingles (a painful rash also caused by the varicella virus).
- If your child is exposed to a person with chicken pox or shingles (herpes zoster) they also may need IV medicine. Call the transplant team to discuss whether this is necessary.

### Avoiding Infections

- Practice good hand-washing for everyone who lives at home
- Ask friends/relatives who are sick to avoid visiting until they are better
- Maintain general well-being by getting enough rest, eating healthy food, drinking enough fluids, and keeping active

## **Cancer**

As discussed in the next section, your child is at higher risk for developing skin cancer, so close observation of changes in any lesions or lesions that do not heal is important to get seen.

## **PTLD**

After transplant, your child is at risk for developing another cancer-like problem called lymphoproliferative disease (PTLD) syndrome. It is related to taking Prograf and developing an Epstein Barr virus (EBV) infection.

- The virus can make a person's lymph glands/nodes larger

- In immunosuppressed patients, the medications can prevent the immune system from clearing them
- Over time, there is a risk that the enlarged lymph glands/nodes will turn into lymphoma (a malignant tumor, or cancer)

### Signs and Symptoms of PTLD

- Classic signs of Mono/Mononucleosis (caused by the EBV virus)
  - Sore throat
  - Enlarge lymph nodes in the neck
  - Fever
  - Lethargy (feeling tired)
- If you suspect mono, contact your PCP immediately and get seen so that we can start treatment with a medication
- If your child has enlarged lymph glands/nodes (and no other symptoms) that persist for more than a month, a biopsy may be needed to rule out PTLD

### **Ear/nose/throat problems**

- Recurrent sinus and/or ear infections
- Snoring due to enlarged tonsils and/or adenoids
  - Causes sleep apnea that may lead to more serious issues
- May need consult by a ear, nose, and throat physician

### **Headaches**

- Some children develop persistent headaches following transplantation
- Give Tylenol according to the instructions - **Do NOT give ibuprofen**
- Contact your PCP if Tylenol does not relieve the pain
- If your child develops migraine headaches after transplantation, further evaluation by a neurologist may be needed

### **Kidney problems**

- Some transplant medications can cause kidney damage, usually over many years
- Closely monitored with blood tests as well as radiology studies (GFR or glomerular filtration rate test)
- Can have high blood pressure and may need medication to prevent any further kidney or heart damage
- In rare cases, a kidney transplant may be needed if kidney damage is severe

## GUIDELINES POST-TRANSPLANT

### Activity

Your child will return to their previous activity level almost immediately. While we encourage everyday play activity (riding a bike, going on walks), your child should not participate in competitive sports, vigorous exercise, or physical education until cleared by the transplant team (usually 3 months after surgery).

It is not unusual for children to have weak muscles prior to transplant due to their liver disease; however, after transplant you will likely notice improvements but do keep in mind they will be gradual.

Steroids post-transplant surgery can also cause muscle weakness. Physical therapy may be started while your child is in the hospital and may be continued after discharge.

### Adjusting after transplant

Readjusting to life after a liver transplant takes time. Feeling worried or unprepared to cope without the support of medical staff is common and usually gets better with time, support, and resources provided by the medical team to make the transition home easier. After leaving the hospital, you may notice or experience the following:

#### Younger children

- Being clingy to parents or siblings
- Bed wetting or thumb sucking
- Difficulty sleeping alone or nightmares

#### Older children and teens

- Complaining of headaches or stomachaches
- Changes in sleeping and eating patterns
- Being easily startled or overly concerned about things

#### Parents

- Being over protective even when things are going well
- Worrying about being able to manage their child's medical care on their own

If things don't improve within a few weeks, get worse, or begin to interfere with daily activities, talk with the transplant team about getting some extra help.

## Tips for coping after transplant

Allow everyone some time to adjust. The road to transplant can be a long one, in which new patterns of behavior may have developed. Be patient and reassure family members including siblings that things are returning to normal.

Gradually get back to daily routines. Children feel safe when things are predictable. As your child recovers from transplant, encourage participation in previously enjoyable activities (with your doctor's approval). This also includes gradually giving your child more responsibility in things, such as chores.

Set normal limits. Your child has been through a lot and it is easy to be lax on the rules or expectations. However, maintaining normal expectations and being consistent with rewards and discipline promotes better adjustment over time.

Encourage time with friends. When children are away from school or their friends for an extended period of time, they may feel "different" or worry about what their friends will say. Remind your child that friends ask questions because they care about him or her. Work with your child on having answers to questions that friends may ask to avoid feeling caught off guard.

Give yourself time to heal. Helping your child manage the post-transplant treatment regimen and providing emotional support will be challenging if you are feeling overwhelmed, worried, or angry. Talk with others about your feelings, don't be afraid to ask for help, and make time again for things you enjoy.

## Dental care

Your child should visit a dentist a minimum of every 6 months. Reasons:

- Some transplant medications can cause gum overgrowth that is aggravated by plaque. Routine dental hygiene is effective in decreasing the severity.
- Medications that lower your child's immune system can potentially cause complications from a cavity, such as a tooth abscess.

Remember when your child gets their checkups or treatments they may need antibiotic prophylaxis according to the guidelines established by the American Heart Association. Your local dentist or PCP will be familiar with the guidelines. However, if you have any questions you can always call the transplant team.

## Eye care

Your child should have routine eye exams every year and as your PCP recommends.

## Immunizations

To prevent infection after transplant, it is very important that your child get their immunizations (vaccines).

In general, your child CANNOT receive any live virus vaccinations:

- MMR (mumps, measles, or rubella)
- Varicella (chicken pox vaccine)
- Rotavirus
- Inhaled influenza (FluMist)
- OPV (oral polio vaccine, this is only used in other countries)
- Yellow fever (used for foreign travel to some locations)
- Oral typhoid (used for foreign travel to some locations)

In general, your child CAN receive the following vaccinations:

- Dtap/Tdap (tetanus, diphtheria, pertussis)
- Hepatitis B series
- IPV (injectable polio vaccine)
- Hepatitis A series
- Hib (H. influenza vaccine)
- Pneumococcal 13 and 23 vaccines
- Meningococcal vaccines
- HPV (Gardasil)
- Influenza (Flu) Shot

Other family members CAN receive the varicella, MMR, rotavirus, FluMist, yellow fever, or oral typhoid vaccines, but not OPV. Vaccinating family members helps to protect the patient. When a sibling receives one of these vaccines, we recommend good handwashing, no sharing of cups/utensils, and no sleeping together for 1 week following vaccination.

Some schools or activity programs may need a letter explaining why your child has not had live virus vaccines. The transplant team can provide this letter to you.

It is recommended for transplant patients and their families to receive the influenza vaccine every year.

If your family is planning international travel, you may need additional immunizations. Please contact the transplant team for more information.

## Medical alert identification

It is very important that your child wear a medical alert bracelet/necklace at all times. A brochure on how to order this will be given to you.

## Nutrition

It is important for your child to eat a well-balanced diet. A dietician will meet with you frequently to discuss recommendations and address any questions or concerns.

- While on steroids your child needs to be on a no added salt diet (the same diet they were on in the hospital)
- Steroids can increase your child's appetite and cause weight gain
  - Be mindful of overeating as your child will feel hungry and eating will not necessarily satisfy this hunger
  - Establish good eating habits. Limit junk food and high fat foods.
- Include high protein foods (meat, poultry, milk, cheese) in your child's diet
  - Protein is necessary to build muscle

## Skin care

No special skin care is necessary. Notify your child's PCP of any new raised areas or sores that won't heal or any wart or moles that have changed.

- Acne is often a side effect of steroids. Encourage your child to wash their face regularly with an over-the-counter acne wash. If acne becomes a problem, you may need to see a dermatologist. Contact the transplant team before beginning any dermatologic treatments or prescription medications.
- Warts are viral infections of the skin. In a child that is immunosuppressed, warts can spread easily, so it is important to seek treatment from your PCP or a dermatologist as soon as a wart is noticed to try and prevent spreading of the infection.

## Sun exposure

Because of your child's medications, their skin is more sensitive to the sun and they are at greater risk of developing skin cancer.

- Limit sun exposure between 10 a.m. and 2 p.m.
- Always use sunscreen with a minimum SPF of 30 and broad-spectrum coverage
- Apply sunscreen frequently throughout the day as water and perspiration can decrease effectiveness
- Encourage your child to wear light, protective clothing, as well as hats

## RESOURCES



## Helpful Websites and Resources

NOTE: All website information and links were up-to-date at the time of printing

### Transplant-Related Organizations and Websites

#### **American Liver Foundation**

An organization that facilitates, advocates and promotes education, support and research for the prevention, treatment and cure of liver disease.

1 (800) 465-4837 | [www.liverfoundation.org](http://www.liverfoundation.org)

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#### **Children's Organ Transplant Association**

An organization that works to make life-saving organ transplants accessible to all ages to arrange the necessary funding for transplant expenses.

1 (800) 366-2682 | [www.cota.org](http://www.cota.org)

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#### **Donate Life America**

Donate Life America is a not-for-profit alliance of national organizations and state teams across the United States committed to increasing the number of donated organs, eyes and tissue available for transplant to save and heal lives.

[www.donatelife.net](http://www.donatelife.net)

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#### **Midwest Transplant Network (MTN)**

MTN's mission is saving lives by honoring the gift of organ and tissue donation with dignity and compassion. As part of their mission, MTN facilitates written correspondence between transplant recipients and donor families.

(913) 262-1668 | [www.mwtn.org/recipients](http://www.mwtn.org/recipients)

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#### **National Foundation for Transplants**

National, non-profit organization that offers a program of health care and financial support services and patient advocacy for transplant candidates and recipients.

1 (800) 489-3863 | [www.transplants.org](http://www.transplants.org)

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#### **Transplant Living**

Developed by UNOS and designed to support the patient-physician relationship. To help ensure the website is accurate, unbiased, and understandable, the content is reviewed by a team of transplant candidates, recipients, and medical professionals.

[www.transplantliving.org](http://www.transplantliving.org)

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### **United Network for Organ Sharing (UNOS)**

A non-profit membership organization that manages the National Organ Procurement and Transplant Network (OPTN) and U.S. Scientific Registry under contracts with the U.S. Department of Health and Human Services.

1 (800) TXINFO-1 | [www.unos.org](http://www.unos.org)

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## **Adjustment and Coping**

### **Band Aids and Blackboards**

Designed for children with medical challenges of all types, this site is highly interactive, with information for kids, teens, and adults.

[www.lehman.cuny.edu/faculty/jfleitas/bandaides/](http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/)

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### **Food Safety for Transplant Recipients**

Food safety is important for everyone, but it's especially important for children who have had liver transplants. This booklet, prepared by the U.S. Department of Agriculture's Food Safety and Inspection Service and the U.S. Department of Health and Human Services Food and Drug Administration, is designed to provide practical guidance on how to reduce your risk of food borne illness.

[www.fda.gov/downloads/Food/FoodbornellnessContaminants/UCM312793.pdf](http://www.fda.gov/downloads/Food/FoodbornellnessContaminants/UCM312793.pdf)

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### **Mind Your Mind**

Award-winning site for youth by youth, offering information, resources and tools to help manage stress, crisis, and mental health.

[www.mindyourmind.ca](http://www.mindyourmind.ca)

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### **MyMedSchedule**

A free medication reminder system for your child and family. A medication chart clearly shows when to take each medication and how much to take. The schedule can be printed and/or you can download an application for your smart phone.

[www.MyMedSchedule.com](http://www.MyMedSchedule.com)

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### **MyHealth Passport**

A customizable, wallet-size card that gives patients instant access to their medical information and can be used when patients go to a new doctor and/or visit the emergency room. MyHealth Passport is a project of SickKids Good 2 Go Transition Program.

[www.sickkids.on.ca/myhealthpassport](http://www.sickkids.on.ca/myhealthpassport)

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### **National Transplantation Pregnancy Registry (NTPR)**

The information collected by the NTPR has helped countless recipients make family planning decisions. NTPR is available to speak to anyone interested in parenthood after transplantation. Patients are encouraged to participate in the registry if they have a solid organ transplant and are currently pregnant, have had a post-transplant pregnancy, or have fathered a pregnancy after their transplant.

1 (877) 955-6877 | [www.transplantpregnancyregistry.org](http://www.transplantpregnancyregistry.org)

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### **Parents Offering Parent Support (POPS) – Children’s Mercy Kansas City**

A network of parent volunteers who mentor other parents through the challenges of their child’s health condition. POPS offers guidance and encouragement by connecting parents with compassionate mentors who have been through the same experiences with their own children.

[www.childrensmercy.org/Patients and Families/Support and Services/](http://www.childrensmercy.org/Patients%20and%20Families/Support%20and%20Services/)

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### **Sibling Support Project**

Support for individuals who have siblings with special needs.

[www.siblingsupport.org](http://www.siblingsupport.org)

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*All resources are provided to you for informational purposes only. Children’s Mercy Kansas City is not associated with any of these organizations and does not make any representations regarding their services. We make no claim regarding the content or accuracy of websites listed above, and we do not recommend or endorse any particular products, services, or organizations or make any determination that they are appropriate for your child. Children’s Mercy assumes no liability or responsibility for acts or omissions of these organizations.*

## GLOSSARY

**Ammonia** – results from the digestion of protein and is cleared from the blood by the liver

**Anastomosis** – a connection made surgically between adjacent blood vessels, parts of the intestine, or other channels of the body such as the bile ducts

**Anemia** – is a condition in which you don't have enough healthy red blood cells to carry adequate oxygen to your tissues

**Anesthesiologist** – a medical doctor who monitors the patient during surgery and gives medications that allow the patient to be in a deep sleep so that he cannot see, hear, or feel anything during the surgery (including pain)

**Ascites** – excess fluid in the abdomen

**Bile** – a fluid made by the liver and stored in the gallbladder which helps to remove waste products and is released to help with digestion and absorption of fats and vitamins

**Bile Ducts** – the tubes that carry bile

**Bile Salts** – components of bile that play a crucial role in the digestion and absorption of nutrients

**Bilirubin** – produced when red blood cells are broken down

**Cardiologist** – a medical doctor that cares for patients with heart problems

**CMV (cytomegalovirus)** – a viral infection that can sometimes affect the lungs, liver, and other organs

**Coagulation** – a process in which liquid blood is changed into a semisolid mass called a blood clot

**EBV (Epstein-Barr Virus)** – a viral infection that causes mononucleosis (mono)

**Esophagus** – a muscular tube-like structure that allows the passage of food/liquid from your mouth to your stomach

**Hematocrit** – the portion of blood that consists of packed red blood cells

**Hemoglobin** – The oxygen-carrying pigment and predominant protein in the red blood cells

**Hematologist** – a medical doctor that is an expert on bleeding disorders

**Hepatic Encephalopathy** – a brain disorder caused by the buildup of ammonia in the blood which causes irritability, confusion, sleepiness, coma, etc.

**Hepatitis** – inflammation of the liver

**Hepatoblastoma** – a malignant tumor of the liver

**HIV (Human Immunodeficiency Virus)** – a virus that damages the immune system and can cause AIDS

**HSV (Herpes Simplex Virus)** – a virus that affects the skin and mucous membranes and causes sores (cold sores); it can also affect the nervous system

**Immune System** – a system that protects the body from foreign substances and organisms (viruses, bacteria, etc.)

**Immunocompromised** – a state in which a person's immune system is weakened

**Intravenous** – into a vein

**Intestines** – a tubular structure that goes from the stomach to the rectum where digestion and nutritional absorption (turning food into energy) occurs

**Jaundice** – yellowing of the eyes and skin as a result of increased bilirubin levels in the blood

**Malignancy** – cancer

**MELD Score (Model for End Stage Liver Disease)** – a scoring system used to determine the urgency of the need for liver transplant used in patients 12 years of age and older

**Multi-disciplinary Team** – members of different professions (surgeons, physicians, nurses, social workers, etc.) with each providing specific services to the patient

**Nasogastric tube** – a flexible tube that is placed through the nose and into the stomach

**Neonatal** – an infant that is younger than 4 weeks of age

**Nephrologist** – a medical doctor that cares for patients with kidney problems

**PELD Score (Pediatric End Stage Liver Disease)** – a scoring system used to determine the urgency of the need for liver transplant used in patients less than 12 years of age

**Platelets** – disk shaped cell fragments that are involved in clotting

**Portal Hypertension** – an increase in blood pressure of the veins of the liver

**Potassium** – a mineral needed for the body to function

**Red Blood Cells** – the blood cells that carry oxygen

**Rickets** – a softening of the bones associated with low vitamin D levels

**Stent** – a tubular support placed inside a blood vessel, canal, or duct to aid or relieve an obstruction

**Sodium** – a mineral needed for the body to function

**Varicella** – a virus that causes the chicken pox

**Varices** – enlarged, swollen veins

**Virus** – a pathogen (germ) that causes infection

**White Blood Cells** – the blood cells that help fight infection