WELCOME

This handbook has been designed to help you learn about transplantation as well as assist you in caring for your child after transplant. It will give you a basic overview of the transplant team and how to contact them, tests and procedures associated with a transplant evaluation, what to expect during the transplant hospitalization and in the immediate post-operative recovery period, and the long term needs of your child's new organ. Additionally, there are pages in this handbook where you can record your child's lab results, make a list of your child's medications and dosages, and a place to write down questions you may want to ask. We hope you will find this handbook helpful as you go through transplantation and that it will answer many of your questions. If you think of new questions or concerns, feel free to ask the transplant nurse coordinator or your doctor.

“This booklet is provided through the generosity of contributors to the St. Louis Children’s Hospital Foundation.”

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St. Louis Children’s Hospital, St. Louis, MO 63110
**ST. LOUIS CHILDREN’S HOSPITAL**

**GENERAL INFORMATION**

During your child’s stay in our transplant unit, the liver transplant team will be your main contacts for the overall care and treatment of your child. Your child’s primary Gastroenterology physician will work closely with the liver transplant team and remain involved in the medical care of your child. You may need to call a team member during the transplant process. Following are some important numbers:

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<tr>
<th>IMPORTANT NAMES AND NUMBERS</th>
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<td>St. Louis Children’s Hospital (SLCH)</td>
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<th>PRIMARY NAMES AND NUMBERS</th>
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<td>Liver Transplant Medical Director</td>
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<td>Pediatric Nurse Practitioner</td>
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<td>Transplant Coordinators</td>
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<td>Chaplain</td>
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LODGING

Transplantation is a long and often complex process. Your child will be in the hospital for one to two weeks. If you live further than two hours away we may ask that you stay in St. Louis for one to two weeks post transplant for closer monitoring. Please plan on establishing a place to stay, whether with relatives, friends, local hotel, or if available, Ronald McDonald House or Haven House post transplant.

Ronald McDonald Houses: St. Louis currently has four Ronald McDonald Houses with four long-term apartments that serve as lodging for families. These accommodations cost $10 per night. First-time guests must work with the social worker to arrange for this lodging. Return guests may work directly with the local Ronald McDonald House.

Haven House: Located in West County, Haven House offers many of the same amenities as the Ronald McDonald House. These accommodations cost $25 per night and also require the social worker to arrange for this lodging for first time guests.

Your social worker can provide more detailed information about reserving a place in one of these houses. She will also suggest other lodging options. Please be aware that there is often a waiting list for families, so it may be helpful to plan ahead and anticipate lodging needs.

PARKING

Parking is available in the visitor’s garage across from the entrance to the hospital on Children’s Place. Only parents and grandparents may have their parking tickets validated at the information desk.

FOOD SERVICES

• Edison Center Atrium Café, the hospital’s cafeteria, located on the lower level, is open daily 24 hours a day. You may order guest trays through Dining On Call (call ext. 42752) that will be delivered directly to your room.

• Bookstore and Café, a service of Barnes and Noble, is just a short walk down the street on Children’s Place.

• Barnes-Jewish Hospital (BJH), North & South each have a cafeteria. BJH, North & South are both connected to our hospital via an enclosed walkway. Our hospital operator can provide the appropriate phone numbers to enable you to check hours of operation and selection.

• Special food needs or requests can be accommodated. If you have any dietary restrictions, please inform your child’s nurse or social worker. Please also tell them of any significant family dates such as birthdays or anniversaries, so we may try to assist you in celebrating them.

THE CENTRAL WEST END

Our hospital is within walking distance of a popular area of St. Louis called the Central West End. Within several blocks are many dining choices, including ice cream shops, sandwich shops and full-service restaurants. There are also art galleries, antique shops, novelty shops, a movie theatre and a bookstore.

OTHER SERVICES IN OR NEAR THE HOSPITAL

For information about available services in this hospital, please refer to the St. Louis Children’s Hospital Family & Patient Guide, that you will receive when your child is admitted to the hospital. You will find information about our Family Resource Center, banking, postal services, the hospital chapel, the Laundromat and other available services.
HISTORY

St. Louis Children’s Hospital performed its first pediatric liver transplant in 1985. Since then, more than 250 children ranging in age from 3 months to 18 years have received liver transplants. Today, the liver transplant program at St. Louis Children’s Hospital is among the most successful in the United States, with one-year survival rates of greater than 90%. Children who come to St. Louis Children’s Hospital for liver transplant have more options than ever before. To improve donor availability the liver transplant team has pioneered new surgical techniques, including:

- **Segmental liver transplants** – a portion of an adult cadaver liver can be transplanted into an infant or pre-teen.
- **Living donor transplant** – a portion of an adult’s liver (usually a parent or other family member) is transplanted into the child.
- **Split liver transplants** – an adult cadaver liver is split into two portions and either transplanted into an adult and infant or two children.

These techniques enable maximal use of donor resources in both adults and children. Multi-organ transplants are another option. St. Louis Children’s Hospital has performed combined liver-lung transplants as well as staged kidney-liver and heart-liver transplants.

CADAVERIC TRANSPLANT

Where Do Donor Organs Come From?

Organ donors are individuals in whom all brain function has ceased due to severe brain injury, (also known as “brain death”) and consent has been obtained for organ donation from family members. The evaluation of potential organ donors includes their medical history, blood tests, and studies looking at function of the specific organs (e.g. heart, lungs, kidneys, liver, pancreas). These tests are done by protocol at the site where the donor is located. In most cases, the tests are performed twice, with several hours in between to ensure an accurate result.

Brain death should not be confused with coma or vegetative state. A patient in a coma is medically and legally alive and may breathe on their own when the ventilator is removed. A patient in vegetative state retains motor reflexes, and has a natural sleep wake cycle, but is not aware of any activity.

LIVING DONOR TRANSPLANT

Livers can come from two sources: either a living donor or from an anonymous donor who has died and donated their organs. In the past, 20 percent of children awaiting liver transplant died due to the lack of a suitably sized cadaveric liver. New surgical procedures such as reduced size liver transplants (placing a part of a larger cadaveric donor liver in a small child, rather than the entire liver), reduced the number of children dying to one in 10. However, children and adults do continue to die due to a lack of suitable cadaveric donor livers. Additionally, many patients who can be transplanted become sicker while they wait for a donor liver.

The first living related liver transplant was done in 1989. Since then, hundreds of these transplants have been successfully performed around the world. A living donor liver transplant has several advantages. One of the most important is that it permits the surgeon the choice of optimal timing for transplantation. Potential living donors might be the recipient’s parents, adult siblings, grandparents, aunts, or uncles. Other unrelated donors such as close family friends may be accepted for donation after careful consideration and evaluation by the transplant team.

Regardless of the decision to do a living donor transplant, your child will be placed on the cadaveric liver transplant waiting list, and will remain listed until the day of the living donor liver transplant.

A potential living donor must be:

- Willing to donate
- Blood type compatible to the recipient
- Absolutely healthy

Ages of living donors may range from 18 to 60 years. It is a federal law that a person be at least
18 years old to donate. People nearing or over the age of 60 may be considered a potential donor on an individual basis depending on their health status. Two conditions that would exclude a person from donor consideration are liver disease and cardiovascular disease.

**WILLINGNESS TO DONATE**

Some donors decide to be considered for donation immediately while others need time to consider family, work, and financial circumstances. We encourage parents or significant others to participate in the transplant interview, and to learn as much as possible about the donation process. All living donors are evaluated by a separate living donor transplant team at Barnes-Jewish Hospital. Once your child’s evaluation has been completed and approved for transplant, then your transplant nurse coordinator will provide you with a phone number to give to those who are interested in being evaluated as a living donor. Of note, the living donor transplant team must hear from the donor directly and will not be able to speak or receive a referral from anyone other than the donor. Any information that the living donor transplant team receives from the potential donor will be confidential.

**COMPATIBILITY**

A person is one of four blood types: O, A, B, or AB. Type O is the most common followed by Types A, B, and AB. The donor’s blood type must be compatible with the recipient’s blood type. Type O is the universal donor and Type AB is universal recipient.

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<tr>
<th>Recipient Blood Type</th>
<th>Compatible Blood Type of Donor</th>
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<tr>
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<td>Type B</td>
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<td>Type AB</td>
<td>Type AB, A, B, O</td>
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**FINANCIAL**

**Who pays for an organ transplant?**

Many insurance companies now offer at least partial coverage for transplant costs, although the terms and extent of coverage vary widely. The transplant team includes staff that is able to assist with exploring your transplant medical coverage. Additionally, they can assist with exploring your options for fund-raising or other financial assistance programs. These individuals will meet with you and your family during the transplant evaluation to help you understand the financial aspects of transplantation. There are instances when we experience long delays with authorization from out-of-state Medicaid agencies to bring a child in for evaluation. We make every effort to work with those agencies on behalf of the patient; however there may be instances when it is not possible.

Your insurance coverage or financial situation may change over time. It is extremely important to notify the financial coordinator or social worker of these changes.

**TRANSPLANT TEAM MEMBERS**

**Transplant Surgeon** The transplant surgeon is a surgeon who has had additional specialized education and training in transplant surgery and medical management of transplant recipients. The transplant surgeon will provide information to you and your child about how the transplant is performed and the potential benefits and risks of transplant surgery. Additionally, the transplant surgeon participates in the immediate post-operative management of the transplant recipient, including performing any necessary re-operations.

**Transplant Medical Staff** We have a specialized team of physicians dedicated to caring for children undergoing liver transplantation. The medical director coordinates the overall functioning and policy making of the liver transplant program, including pre and post-operative care. You and your child will meet with the medical director during the evaluation process. Your child’s medical history will be reviewed and a physical exam will be performed. Information will be provided regarding the potential risks and benefits of transplantation, as well as long-term outcomes. Other transplant medical staff members may be caring for your child during their transplant hospitalization. These attending physicians have had extensive training in Gastroenterology and supervise fellows and house staff physicians. A fellow is a pediatrician who is specializing in Gastroenterology and is very important for your child’s care during the nights and on weekends.
Pediatric Nurse Practitioners are nurses who have an advanced level of education and experience. They have a master’s degree in nursing and are trained as nurse practitioners. They are licensed nationally both as registered nurses, and as nurses in advanced practice. They are board-certified by the state of Missouri to practice as pediatric nurse practitioners. Nurse practitioners work under the direction and supervision of your liver doctor.

Transplant Nurse Coordinators are nurses with experience in caring for transplant patients. They will teach you about your child’s disease, transplantation and how to care for your child after transplantation. Your transplant coordinator will be your main contact with the transplant team. They work under the direction and supervision of the doctors.

Some of the responsibilities of the transplant nurse coordinator:

- Educate children and families about their disease
- Coordinate the transplant evaluation including scheduling tests and consultations with members of the transplant team (surgeons, medical doctors, social work etc.)
- Add your child onto the national transplant waiting list
- Make necessary arrangements at time of transplant including contacting you about an organ being available, arranging for operating room time, contacting the hospital staff and transplant team members about your child’s admission, etc.
- Educate children and their families about post-transplant care including medications, signs and symptoms of rejection and infection, follow-up visits, etc.
- Conduct extensive discharge planning with local physicians, hospitals, and home health agencies
- Work closely with all other team members (surgeons, medical doctors, nurse practitioner, social work, etc.)
- Perform telephone triage of any illnesses your child may experience and refer to the appropriate team member (medical doctor, nurse practitioner, local physician)
- Participate in your child’s outpatient clinic visits (review medications, provide ongoing education, coordinate visits/referrals to other services)

Child Life Specialists help children and adolescents cope with the stress of the medical setting and treatment by providing developmentally appropriate social, emotional and educational support and activities. Services include:

- Providing materials and guidance for play and adapting activities according to a child’s strengths and limitations
- Preparing children for hospitalization, surgery, and medical procedures through hands-on activities and providing support during procedures
- Emotional support to children, siblings, and parents
- Advocating for an age-appropriate and child-focused environment and treatment experience

Psychologists Staff from the St. Louis Children’s Hospital Department of Psychology specializes in the psychological issues associated with chronic illnesses and disease. They work directly with children and families and provide consultation to the medical team. A psychologist sees new patients during the transplant evaluation. After this initial evaluation, follow-up services during hospitalization and/or on an outpatient basis may include:

- Emotional support and counseling
- Individual therapy with patients, siblings, and/or parents
- Family counseling
- Behavioral techniques to manage pain, anxiety, reactions to treatment side effects
- Interventions to assist with illness management.
- Medication compliance

Social Workers St. Louis Children’s Hospital Social Workers are members of the diverse team who serve as a liaison between families and medical staff. During the transplant evaluation, a psychosocial assessment is completed by the
social worker with the patients and their families
to help the medical team begin to understand your
family and any social concerns there may be. Social
workers also assist you and your child with stress
as well as the emotional and practical problems
associated with your child's illness. Assistance is
also available to connect you with community
resources that may be helpful to your family.
Other services they can help with are:

- Advice about resources potentially available
to families, including financial assistance
and lodging alternatives for families from
out-of-town
- Assistance with acquiring those resources
- Family support

Chaplain  St. Louis Children's Hospital is
committed to meeting the spiritual needs of all
our patients. We have two full time chaplains on
staff. Please notify your transplant team if you
wish to meet with the chaplain before or during
your transplant hospitalization. We can provide a
religious practitioner of your choice, i.e. Roman
Catholic Priest, Rabbi, Mormon Elder, etc. upon
request. Other services they provide:

- 24 hour on-call service. Call 314.360.1871
- Prayer service in St. Louis Children's Hospital
Chapel every Tuesday (1st floor next to Gift Shop).

ADHERENCE/COMPLIANCE

Adherence, formerly known as compliance,
is defined as how a patient follows through
with medical advice given to them by their medical
team. Your 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. Different types of self-care and
self-monitoring are required depending on your
child's transplant. Your transplant team will outline
adherence guidelines they would like you to follow.
WHAT YOU CAN EXPECT FROM US

- We will treat you in a respectful manner
- We will make every effort to be on time for appointments with you
- We will return your calls within 24 hours
- We will be honest, upfront and keep you informed to the best of our abilities
- We will not discuss your child with other families
- We will treat your child and family as individuals and tailor a plan of care to address your needs

WHAT WE EXPECT FROM YOU

- We expect you to be on time for your appointments, biopsies, lab draws
- We expect you to get testing done when it is requested
- We expect you to call us with questions, and leave a message if we are not immediately available
- We expect at least 24 hours notice to refill prescriptions and 24 hour notification of cancelled appointment or tests
- We expect you to keep us updated on phone/address/insurance information
- We expect you to have a working phone with an answering machine
- We expect you to discuss questions/concerns about your child with the transplant team and not other families
- We expect you to respect the privacy of other families

REFERRAL PROCESS

In general, referrals are received by the transplant coordinators, transplant gastroenterologist from the patient’s primary physician/gastroenterologist, or insurance company case manager. Occasionally a parent calls the office indicating that their child is in need of a transplant and would like information on our program.

After receiving the referral, the patient’s medical records will need to be sent to the transplant office and reviewed by the medical team. The family is then notified and a meeting is arranged with the medical team to discuss the options available to the patient. The patient’s primary physician and insurance company are then notified of the family’s decision regarding a liver transplant. If the patient and medical team agree to move forward with the transplant process, an evaluation date is then arranged by the transplant coordinator.

If there is the option of a living liver donor then your child’s transplant nurse coordinator will give you the phone number for the living donor transplant program. It should be noted that the potential donor would need to contact the patient’s transplant coordinator for further information on becoming a potential donor. The above process with the donor would then be followed. A date for listing a patient on the UNOS cadaveric liver wait list or scheduling a date for a living donor transplant will not be made until the evaluation process is complete on both the recipient and donor.
The first step for your child is called the evaluation. Tests will be done to decide how severe your child’s liver disease is. After these tests, your doctor will decide if a liver transplant should be done. Your child will be evaluated over a two to three day period of time. Depending on the physical condition of your child, the evaluation can be done on an outpatient basis. During the evaluation, your child will be seen by many doctors and members of the transplant team. The following are tests that are completed during an evaluation:

- **Blood tests** – determines how well your child’s liver and kidneys work, your child’s blood type, and if your child has had prior exposure to certain viruses.

- **Electrocardiogram (EKG)** – records your child’s heart rate and rhythm.

- **Echocardiogram (ECHO)** – uses sound waves to look at the size of your child’s heart and how the heart muscle and valves are working.

- **Abdominal Ultrasound** – creates a picture of the liver, spleen, and kidneys, and shows the blood flowing through these organ’s blood vessels.

- **Chest x-ray** – will determine the size of your child’s heart and lungs as well as how well your child’s lungs inflate and if there is any fluid or infection in their lungs.

- **Neuropsychology and/or Developmental Testing** – for infants and toddlers, developmental testing is done by the psychology staff to determine if your child is at his/her age appropriate development level. For children and teenagers, school performance and emotional and social development are evaluated.

- **Visits** with the transplant surgeon, liver doctor (gastroenterologist), nurse practitioner, transplant nurse coordinator, psychologist, social worker and child life specialists.

- **Visits** with the lung, neurology (brain), kidney, and heart doctors, depending on your child’s medical condition.

- **Dental evaluation** with your child’s dentist.

**AFTER THE EVALUATION: NEXT STEPS**

Once your child’s evaluation has been completed, the transplant team will meet to discuss your child’s evaluation. If they decide a transplant is the best treatment choice, your child will be placed on a nationwide waiting list with UNOS, which stands for “United Network of Organ Sharing”, for a cadaver donor liver. If your family has identified someone who wishes to be a living donor, arrangements will be made for the liver donor to undergo a donor evaluation. Once the donor’s evaluation is completed and the donor has been accepted by the transplant team as a suitable donor, a transplant date will be scheduled by the transplant nurse coordinator.

**LISTING INFORMATION**

At the time your child is listed for a cadaver liver transplant with UNOS, they will be assigned a PELD score if under the age of 12 years or MELD Score if age 12 years or older. The PELD (Pediatric End Stage Liver Disease Model) and MELD (Model for End Stage Liver Disease) scores are numeric scales that give each individual patient a score based on how urgently he or she needs a liver transplant. The measures are based on certain lab values and growth. The normal wait time on the transplant list may be from several days to several months, depending on how urgently your child needs transplantation. Your child will be placed on the UNOS wait list regardless of whether or not a living donor is available. Should a suitable cadaver donor liver become available before the living donor transplant has taken place, the cadaver liver will be used in place of the living donor.

**WAITING FOR TRANSPLANT**

The normal waiting time on the transplant list may be from several weeks to months. The following is some general information while your child is waiting for their transplant to occur:

- While on the the transplant waiting list, your child will see the transplant hepatologist for regularly scheduled visits. Your child’s transplant coordinator will see you at these
visits as well to update the rest of the transplant team on your child’s health status.

- Should your child develop a fever, infection, or contagious illness (i.e. chickenpox, influenza, etc.) while on the waiting list, contact your transplant nurse coordinator, as your child’s transplant may be temporarily postponed until your child has recovered.

- Notify your transplant coordinator if you and/or your child are going out of town (i.e. family vacation, camp, etc.). Travel arrangements will need to be arranged if possible with the transplant coordinator in the event a donor liver is found while you are out of town.

- Call your transplant coordinator if your family or your child has any questions or concerns about proceeding with transplantation.

## PREPARING FOR THE CALL

There is no way to know when a new liver will become available; however, there are things you can do to help prepare your child and family:

- Make a list of things you and your child will need at the hospital: comfortable clothes, toiletries, your child’s favorite stuffed animal or toys, book/magazines to read, etc.

- If you have other children, arrange childcare for them ahead of time.

- Have cash available for gas money, cab fare, etc., so you will be able to leave at a moment’s notice.

- Each family is expected to have a cell phone to carry with them 24 hours a day so that they can be contacted when a donor becomes available.

## FLIGHT INFORMATION

If you and your child live more than four hours away from the hospital, flight arrangements will need to be made in advance to fly your child here at a moment’s notice when a liver becomes available. The flight company used is determined by your insurance company. Our transplant financial coordinators will check your insurance benefits regarding the flight. In the event your child is hospitalized at another center when a liver becomes available, the St. Louis Children’s Hospital Transport Team will make arrangements to bring your child to our hospital.
THE ACTUAL TRANSPLANT

THE DAY OF TRANSPLANT

Cadaveric Transplant

When your child is called in for the transplant, it is important for you to come to the hospital as soon as possible. Do not give your child anything to eat or drink. When the transplant nurse coordinator calls, please tell her when you will arrive at the hospital. When you get to the hospital, take your child directly to the transplant surgery floor. The charge nurse will direct your child where to go and which patient room is yours. You will meet the nurse who will be taking care of your child. One parent/guardian will then need to go to the Admitting Department to sign your child’s admission papers.

Once your child arrives, he/she will have blood drawn, x-rays taken, and a visit from the anesthesia doctor in order to prepare quickly for the upcoming transplant. Either the transplant surgeon or transplant nurse practitioner will perform a physical exam on your child to make sure he/she is without signs of infection or other illnesses and will write your child’s admitting orders. A member of the transplant surgery team will explain the operation to you and your child and ask a parent and/or guardian to sign surgery consent and blood administration forms.

Very rarely, your child could be called in for transplant, but before your child gets to the operating room, the transplant gets cancelled. The most common reason for canceling the transplant is related to problems with the donor liver which makes it unsuitable for transplant. If your child’s transplant were to be cancelled, your child would simply be sent back home. Their position on the transplant waiting list would not change as a result of the cancelled transplant.

HIGH RISK DONOR

Your transplant team may be offered an organ for your child that is considered CDC high risk. What does this mean to you? A Centers for Disease Control (CDC) high risk donor is one who falls under one of the following categories: a donor with a history of intravenous, intramuscular, or subcutaneous recreational drug use, hemophiliac, prostitution history, high risk sexual activity, exposure to HIV, and/or jail sentencing. In addition, persons who cannot be tested for HIV infection because of refusal, inadequate blood samples (e.g., hemodilution that could result in false-negative tests), or any other reasons are considered high risk donors. Even though the chance of transmitting a disease is low because the donor organ is tested and found to be negative for transmittable diseases, there is a small chance that it was not detectable at the time of testing.

Post-transplant care will include regular checking for hepatitis and HIV every few months. If you are offered an organ from a high social risk donor, the transplant team will explain the risks to you so that you can make a decision on whether to accept the offer. If you choose not to accept a high risk donor, this will not affect your care with the Transplant Program not will it change your position on the waiting list.

Living Donor Transplant

Preparing for a living donor is essentially the same as for a cadaver transplant except that the transplant recipient will be admitted the day before the scheduled transplant surgery to have their pre-operative tests performed in preparation for surgery. The donor will be admitted to Barnes-Jewish Hospital for their surgery and postoperative recovery. The donor will arrive the day prior to the scheduled surgery as well and spend the day having tests and preparing for surgery.

When your child goes to the operating room, you and your family should wait in the waiting room next to the OR on the sixth floor. It is normal for a liver transplant to take a very long time, possibly eight to 12 hours. During the operation, the nurses will call to let you know how your child is doing. After the operation, the surgeon will speak with you. Once the operation is over, your child will be taken to the pediatric intensive care unit (PICU) on the seventh floor. You will be able to see your child about one hour after his/her arrival in the PICU.
YOUR STAY IN THE PICU

Your child will go to the Pediatric Intensive Care Unit (PICU) immediately following surgery. The intensive care team will require an hour or more to stabilize your child before you will be allowed to visit. Your child may be on a respirator (also known as a ventilator, or breathing machine) and will have many monitoring lines and drainage tubes present. While on the respirator your child will have a tube in his throat (called an endotracheal tube) and will not be able to speak. There will be a tube in the nose that goes to the stomach (called a nasogastric or NG tube). This tube helps to keep air from accumulating in the stomach and helps to drain stomach acid. This tube is usually removed when the breathing tube comes out. Vital signs, such as blood pressure and heart rate will be monitored closely. Lab tests will be drawn frequently from an arterial line (A-line). This special line (a type of IV that is actually placed in an artery rather than a vein) is placed during the surgery. The A-line not only allows for blood draws, but also helps to monitor blood pressure. The ICU team will keep your child as comfortable as possible. As your child recovers, the tubes and monitoring lines will be removed. Again, each child is unique and the length of time your child is in the PICU will depend on many factors.

While your child is in the PICU, visiting will be limited to immediate family only (15 years of age or older) and only two visitors will be allowed at the bedside at a time. We realize there will be many concerned and relieved family members and friends, however your child is vulnerable to infection and we strongly discourage visiting by all but immediate family (parents, guardians or appropriate siblings) at this time. Please refer to the PICU booklet for further information.

The PICU staff can only give patient information over the phone to parents. It is suggested that you designate a friend or family member as a contact person to receive updates from you. Your transplant team will work together with the PICU team of doctors and nurses to provide your child with the best possible care. The transplant team will decide when to transfer your child out of the intensive care unit to the transplant surgery floor for continued recovery.

TRANSPLANT SURGERY FLOOR

Once your child is stable and does not need intensive care, your child will be moved to the transplant surgery floor. Your child’s nurse will have a lighter assignment that day to help them settle into their new room and to make sure that your child is doing well. Your child’s stay could be a week to several weeks depending upon their recovery. During this time, the Transplant Nurse Coordinator will be teaching you and your child how to best take care of your child’s new liver. Once the doctors have determined that the transplant liver is recovering and your child is stable, your child will be discharged from the hospital.
Our usual protocol the first month after discharge from the hospital is to draw your child's blood twice a week for lab work as well as see them in transplant clinic for a physical exam. For patients who live more than four hours from St. Louis, we may ask that you stay in St. Louis for an additional one to two weeks after discharge so we can continue to closely monitor your child. Once we are assured that your child's lab results are stable and they are not having complications from their surgery, we will allow you to return home. Labs can be done at a local lab or hospital near your home each week but you will still need to come to St. Louis once a week for transplant clinic. Please see the section SLCH Info (see page 3) for information concerning lodging available to our transplant families.

Once your child has stabilized after their transplant surgery, the transplant nurse coordinators will provide you with written instructions about how to care for your child after transplant. It will include the following information:

- Signs and symptoms of rejection
- Signs and symptoms of infection
- Information about medications your child will be taking post-transplant
- Reasons to call the transplant nurse coordinator or transplant physician
- General health information about immunizations, dental health, skin care, etc.

The transplant nurse coordinator will arrange times to meet with you and your child (if appropriate) to review all of these instructions. If there are other family members (i.e. grandparents, stepparents) who will be taking care of your child, you may want to have them included in the teaching sessions, especially if they will be administering medications to your child.

The staff nurses will also be working with you throughout your child's hospitalization to teach you any special skills you may need to take care of your child. Some of these skills include:

- How to take a blood pressure
- How to administer tube feedings (nasogastric or gastrostomy)
- How to administer TPN (Total Parenteral Nutrition)
- Wound care and dressing changes
- Central Line Care (see page 14)

If needed, arrangements will be made with a home health agency for any equipment or additional home nursing care that your child may need.

RETURN CLINIC VISITS

We ask that you respect the fact that we schedule many families after transplant for follow-up appointments, and flexibility in scheduling is not always available. We ask that you give special attention to keeping scheduled appointments. We realize that it is often hard for you and your child to miss work and school, however, this is unavoidable at times. When scheduling return clinic visits, please call two to three months in advance. Availability of appointment times depends upon physician availability, holidays, and if other testing is required to be done at the return visit. Appointments are subject to change if an emergency occurs.

To schedule or cancel your child’s appointments, please call the liver transplant program assistant at 314.454.6289.

HIGHLY IMPORTANT: All patients need to call the prior authorization number and scheduler when any personal information has changed, such as name, address, phone number or insurance information. This information is needed to receive authorization from your insurance company. Without the proper information, approval for the visit will not occur and you will be responsible for the medical charges.
At the time of your child’s transplant, a central line (Broviac or Hickman) catheter will be placed. The central line is usually inserted into a large vein under the collarbone. This catheter will be used for giving all intravenous fluids, medications, blood, and nutrition (in the event your child is unable to eat) during your child’s hospitalization(s). It helps avoid the discomfort of multiple needle sticks during hospitalization. Occasionally, however, blood must still be taken directly from a vein or by finger-stick. If your child already has a central line, a decision will be made about the ability of this line to meet the needs of the transplant process.

The central line will require some special care. Before you go home, a nurse will make sure you know how to care for your child’s catheter. The care will include flushing the line with heparin to keep it from clotting with blood and a dressing change over the catheter site. The St. Louis Children’s Hospital Central Line Home Care Booklet will be provided to you during your child’s hospitalization. This booklet gives detailed, step-by-step instructions on how to care for your child’s central line.

PHONE NUMBERS FOR PRIOR AUTHORIZATION

Toll free number: 888.503.2237

Prior Authorization: 314.286.2600 or 877.906.2638 (toll free), or on the web at http://wuphysicians.org, click on “For Patients”, then on “Appointments and Registration”, then on “Patient Registration Services”.

GENERAL INFORMATION

BACK TO SCHOOL

We encourage our patients to get back to a normal life as soon as possible, including attending school. You will need to check with your child’s transplant coordinator as to when it will be best for your child to return to school. The following information should be given to their teacher and school nurse:

• Medications: may need a note from your child’s physician if your child must take medication while at school.

• Importance of reporting exposure to contagious illness (especially chickenpox) to which your child has been exposed.

• What to do if your child becomes ill at school, including how to reach your child’s transplant nurse coordinator.

• Basic instructions about your child’s broviac, i.e., what to do if there is a leak in the catheter.

• Frequency of blood drawing and transplant clinic visits so they are aware of days when your child will be late or absent from school.
**EXERCISE**

Daily exercise is strongly recommended post-transplant. Exercise helps to maintain weight, reduce loss of calcium from bones, improve the proportion of muscle to fat body stores, lower blood pressure and reduce stress. After transplant, however, your child may not participate in gym for three months after discharge. Please notify your child’s transplant nurse coordinator if this requires a doctor’s note. After three months time, your child may be integrated back into physical activities as he/she seems able. Physical activity should essentially be unrestricted with the exception of avoiding contact sports such as football and wrestling. Gymnastics, including trampolines, uneven parallel bars and the balance beam should also be avoided.

**DIET**

Diet recommendations will depend on your child’s disease process and nutritional status. Prednisone may increase your child’s appetite and thus your child’s weight. We will follow weight gain and weight loss in clinic. A nutritionist will be available for recommendations and concerns. Older children will benefit from drinking plenty of water or non-caffeine type drinks to keep their kidney function at an optimum. Remember, several of the medications your child will be taking post-transplant are hard on the kidneys. Dehydration can be harmful to the kidneys; drinking plenty of fluids will be beneficial.

**SKIN CARE**

Skin problems (usually minor) are very common in transplant patients. Patients who take immunosuppressant medication are at an increased risk for skin and lip cancers. There are things you can do to help decrease your child’s risk.

- Your child needs to apply lip balm and sunscreen lotion with a SPF (sun protection factor) of at least 30 **every day, rain or shine**, April through October. Apply the lotion to all exposed areas, especially the face, ears, neck and hands. Remember that sunscreen lotions wash off. Reapply the lotion as needed, especially after swimming.

  - Avoid midday (10 AM to 3 PM) sun when ultraviolet rays are the strongest.
  - Wear a hat and long sleeves when outdoors.

**Oily Skin or Acne:** Your child, especially in pubertal or post pubertal stages, may develop acne on the face, chest, shoulders, or back. Acne post-transplant is mostly due to the medication Prednisone. Primary measures used to control the acne are aimed at removing the excess oil and preventing formation of “white heads” or “black heads”. Wash the areas of acne three times a day, scrubbing gently with a soapy washcloth to remove the oil, dead skin and bacteria. Neutrogena soap works well, but any drying soap is fine. Rinse soap off the skin completely to leave pores open and clean. Use a clean wash cloth each time. Shampoo hair and scalp frequently and keep the hair away from areas of acne. Benzoyl peroxide cream or lotion (5-10%), can be purchased over the counter and is helpful in drying the acne. When acne is present, it is best not to use cosmetics, but if you must, use them sparingly. If the skin becomes dry, consider reducing the frequency of washing and application of medication. Remember that drying the skin is the objective of the treatment. Do not apply skin lotions to treat dry skin. If acne persists, we will refer you to a dermatologist. Please check with your transplant nurse or doctor.

**Dry Skin:** Use a mild soap like Dove for bathing and apply body lotion after bathing if your child has problems with dry skin without acne. Keri Lotion, Curel, and Moisturel are good over the counter lotions.

**Skin Lesions:** Warts may be particularly difficult to treat after transplant since they are caused by a viral infection. Moles that are changing, raised skin lesions, or sores that do not heal, should be brought to the attention of the transplant nurse or doctor. We will refer you to a dermatologist for these problems.

**Cuts and Scratches:** Prednisone can cause the skin to become thin, making it tear, scratch, or bruise easily. Keep the skin clean so such areas do not become infected. Keep minor cuts and scratches clean and dry by washing with soap and water. Cleanse with hydrogen peroxide if desired. For large cuts, animal bites, or cuts that appear
infected (redness, swelling, pus, tenderness), contact the transplant nurse. Antibiotic therapy may be indicated.

HAIR CARE

Prednisone and Cyclosporine will affect the condition of your child's hair. Older children may want to avoid tints, dyes, bleaches, and permanent wave solutions because they may make your child's hair break. We recommend that your child wait until their Prednisone dose is less than 20mg/day before they have a permanent wave or other hair treatment.

DENTAL

Dental visits are recommended every six months. Wait until six months after transplant to schedule the first visit. Good mouth care, including brushing teeth, tongue, palate, and flossing should be done regularly to prevent yeast infections in the mouth and painful swollen gums.

EYES

We recommend yearly eye exams by a pediatric ophthalmologist because your child is susceptible to cataracts and glaucoma from long term use of Prednisone.

VACCINATIONS

Your child may not have live virus vaccines. This includes MMR, Varivax (chicken pox vaccine) or Oral Polio. We recommend annual flu shots in the fall for our patients. All family members are encouraged to also receive an annual flu shot.

SMOKE

Your child must stay away from all forms of tobacco smoke. Smoke causes inflammation within the lungs whether first-hand or second-hand, making it easier to develop a lung infection. Your child should stay away from smoked filled areas as much as possible. If family members smoke they should smoke outside of the home and the family car.

MEDIC ALERT JEWELRY

We advise all transplant recipients to wear a medical identification bracelet or necklace. Information about Medic-Alert jewelry can be obtained by calling 800.ID.ALERT, or ask your transplant nurse for an application.

We suggest the following information:

- List the type of transplant your child received, “Immunosuppressed”, and any allergies. Include St. Louis Children’s Hospital, 314.454.6000 and your local primary physician in the emergency contact section.

PETS

If you have a pet, it is important that it visits the veterinarian on a regular basis. Your child should wash his hands after touching or playing with your pet. The child should never change kitty litter because of the potential infectious agent toxoplasmosis. We recommend against birds as pets because of the potential airborne infectious agents in their stool. Some reptiles carry salmonella in their stool, therefore if your child handles such animals they need to wash their hands thoroughly afterwards.

TRAVEL

When packing for your vacation, make sure you have an adequate supply of your child's medications, including some extra in the event you experience delays in your travel plans. If you are flying, carry the medications with you on the plane. Make sure you carry your child’s insurance card and the phone numbers to the hospital in the event your child becomes ill.

If you and your child are traveling outside of the U.S., you will need a letter from your child's transplant physician verifying all of your child's medications to show with their passport as they go through customs. Use caution in what your child eats and drinks. For instance, only water and ice from adequately chlorinated sources can be considered truly safe. If you are unsure, it’s best to have your child drink only bottled or canned water and soft drinks. Select food with care to avoid illness. Avoid unpasteurized milk and milk products and eat only what can be peeled or has been cooked and is still hot. If your child needs medical care while abroad, contact your travel agent, American Embassy or Consulate for names of physicians or hospitals.
TRANSITIONING TO AN ADULT CENTER

Once your child turns 18 years old and/or graduates from high school, we feel that they are best served in an adult transplant unit. We generally transfer them to the Barnes-Jewish Hospital Transplant Team, however, if you wish, your child could be followed by an adult transplant center near their home or college. We can help you identify a reputable transplant center if you wish. When your child is ready to transfer we will schedule a final appointment with us at St. Louis Children’s Hospital. We will have you sign a release of medical information form so we can forward your child’s medical records to the new transplant center. Once the adult center has received a copy of your child’s records, we will have you make your first appointment. We will continue to follow your child until they have been seen at the adult center so that there is no interruption in your child’s care.

As your child moves toward adulthood it is our responsibility as health care providers and your responsibility as parents to prepare them for transition into the adult medical system. We have outlined critical milestones for patients to achieve prior to transfer to adult care and will work with you and your child to meet these important goals. We realize this time of transition to independence is a complex process and will take several years. Starting at approximately age 14, we will ask that your child be seen alone for a portion of their clinic visit to help them develop skills in communicating with medical providers. We will then invite the parent back into the clinic room to review the plan of care. We realize maturity and developmental readiness is a better indicator of capabilities versus chronological age so we will work with each family individually.
Vaccines are developed to prevent certain illnesses and contain either live or killed organisms. Because your child’s body has been purposefully immunosuppressed to prevent rejection, your child is at risk for infection. The introduction of live organisms through immunizations/vaccines would result in developing the disease that the vaccine was designed to prevent. Following a transplant, NO LIVE VACCINES should be given.

It is important that we receive a list of vaccines that you or your child has had during the evaluation and listing process. The Immunization Action Coalition provides an updated handout on the internet detailing vaccines your child should have received and which ones MAY be due. This website is updated yearly or as new regulations occur. The website address for the Immunization Action Coalition is www.immunize.org. There is no copyright approval necessary; you may print directly from the website for updated schedules. This should be used as a guideline only. Your child’s immunization schedule may differ.

DO NOT GET THESE VACCINES POST-TRANSPLANT:
- Mumps, Measles, Rubella (MMR)
- Polio (oral) or OPV
- Varicella (Chickenpox)
- Yellow Fever
- Typhoid (oral)
- BCG
- Intranasal Influenza Vaccine (FluMist)

YOU MAY GET THESE VACCINES POST-TRANSPLANT:
- Tetanus
- Diphtheria, Pertussis, Tetanus (DPT)
- Polio (injectable) or IPV
- Hemophilus influenza B (HIB)
- Hepatitis A (Hep A · series of 2)
- Hepatitis B (Hep B · series of three)
- Influenza (Flu) vaccine (injectable)
- Typhoid (injectable)
- Pneumonia vaccine – Pneumovax or Prevnar

While not a vaccine, your child may receive the:
- Mantoux Tuberculin skin test
- Synagis

Keep in mind that if immunizations are given too soon after transplant (a month or so) the vaccinations may not take effect as they would later when your child’s immunosuppressive medicines are not as high. Your transplant nurse coordinator will notify you when your child may resume their immunizations.
After your child goes through transplant surgery, it is very important that he/she follows a healthy diet. Your child's body needs enough energy (calories & protein) to help after surgery. During surgery and recovery, your child may have also lost some weight or had a poor appetite.

A registered dietitian is available to you as part of your child's transplant team. Dietitians are there to help you plan your child's diet to meet his/her specific needs and tastes. Just a few simple changes in your child's diet can help keep your child and your child's transplant healthy for a long time.

Follow the simple food guide pyramid to ensure good nutrition:

- Depending on your age and weight, eat enough servings from each of the five basic food groups everyday.

**For Meat and Protein Foods, Choose More Of:**
- fresh fish, chicken and turkey without skin
- ground turkey
- lean, well-trimmed beef, veal, lamb, pork
- meatless protein-dried beans, lentils, peas, tofu
- egg whites
- water-packed tuna

**LIMIT:**
- fried meats
- fatty cuts of meat
- bacon, sausage, lunch meats, frankfurters
- liver and organ meats
- cured and smoked meats, fish
- egg yolks (3 per week)
- canned meats and fish

**For Breads and Cereals, Choose More Of:**
- plain breads, English muffins, bagels
- plain pasta and rice
- hot or cold cereals
- popcorn, rice cakes
- low-fat baked goods—angel food cake, graham crackers, fruit cookies, gingersnaps, fortune cookies

**LIMIT:**
- high-fat, high-sugar baked goods – Danish pastry, croissants

**For Milk, Cheese and Dairy Products, Choose More Of:**
- skim or 1% milk
- evaporated skim milk, or nonfat dry milk powder
- yogurt
- cheeses

**LIMIT:**
- creams, half & half, non-dairy creamers
- whipped cream, non-dairy whipped toppings
- whole-milk yogurt, sour cream and cheeses

**For Fruits and Vegetables, Choose More Of:**
- several servings a day, with plenty of variety
- all fresh and sundried fruits
- all fruit juices (preferably unsweetened)
- raw or frozen vegetables

**LIMIT:**
- coconut
- deep-fat fried vegetables

**For Fat, Choose More Of:**
- unsalted margarine
- vegetable oils
- low-fat diet salad dressings
- reduced calorie mayonnaise
• cook with oils, which are low in saturated fats, such as olive oil and canola oil

LIMIT:
• foods containing salt pork, lard, meat fat, and hydrogenated or partially hydrogenated solid vegetable shortening; products made with coconut or palm oil
• regular salad dressings and those made with sour cream
• saturated and trans fat

For Sweets, Choose a Minimal Amount:
• fruit ices, gelatin, sherbets low-fat frozen yogurt ice milk

LIMIT:
• doughnuts, pastries, cakes, cookies, and pies unless prepared with low-fat ingredients

FIBER
It is very important to eat a diet that is high in fiber. High fiber foods help to lower cholesterol, maintain bowel regularity, and may help reduce your blood sugars. There are two different types of fiber:

1. INSOLUBLE FIBER

Insoluble fiber is found in foods such as wheat bran, whole grain breads, bran cereals and vegetables. These foods help prevent constipation. They can also help fight against colon cancer.

2. SOLUBLE FIBER

Soluble fiber is found in foods such as oat bran, oatmeal, citrus fruits, apples, strawberries, beans and barley. They help lower your blood cholesterol, too.

Can I keep my weight under control?

Weight gain after transplantation is commonly due to steroid treatment, which greatly increases your child's appetite. You can successfully control your child's weight by:

1. Limiting the amount of high calorie foods your child eats.

2. Gradually increasing your child's physical activity to burn off calories.

If you are not sure if your child's weight is healthy, ask your child's doctor. He/she can determine which weight is good for your child's height and body size.

My doctor said I need to lose weight…what is considered safe weight loss?

• Set out to lose weight slowly. A weight loss of one half to one pound per week is generally considered a safe goal.

• Avoid yo-yo dieting (losing and gaining weight over and over) that can permanently slow down your metabolism and increase the fat stores in your body, making it even more difficult to lose weight.

• Eat regularly. Skipping meals may increase your appetite further.

• Include exercise in your program. Regular exercise helps you lose pounds and control weight. Regular physical activity may help to better control your blood pressure and reduce your risk of many other diseases.

OTHER TIPS...

• Limit fats such as margarine, gravy, cream, oil, mayonnaise, salad dressing, and fried foods.

• Limit sugar intake of high-sugar sweets such as candy, cookies, cakes and regular sodas. Try fruits or popsicles for dessert.

• Limit portions. Select only one entrée at mealtimes. Add a salad or vegetable if you are hungry.

• Eat slowly and eat a variety of foods.

• Drink plenty of water and low-calorie beverages. Limit high-calorie beverages between meals (soda, Kool-Aid, sweetened juices).

• Trim all visible fat from meat including skin from poultry.

• Avoid frying meat. Instead, roast, bake or broil meats.

• Steam or stir-fry vegetables in acceptable oils.

• Avoid using whole eggs in recipes. Instead,
replace with two egg whites for one egg, or use 1/4 cup of egg substitute for one egg.

- Use applesauce in baked goods instead of oil or butter. One cup of applesauce equals 1 cup oil/butter.
- Replace low-fat for whole versions of yogurt, ice cream, sour cream, cheese and milk.

**CALCIUM**

Steroids (Prednisone, Solumedrol) may cause bones to lose calcium particularly if dietary calcium is inadequate. Osteoporosis is a common consequence of long-term steroid use. Dairy products are the main sources of calcium and should be included in the diet to help keep bones strong.

Your daily calcium needs change as you age.

- Birth – 6 mos: 400mg/day
- 6 mos – 1 year: 600mg/day
- 1 – 5 years: 800mg/day
- 6 – 10 years: 800-1200mg/day
- 11 – 24 years: 1200-1500mg/day

Ways to increase calcium in your diet:

- Choose at least 2 servings of low-fat dairy products per day, such as 2 eight-ounce glasses of 1% low-fat or skim milk. An 8-ounce glass of milk contains 300mg of calcium
- Eat a healthy, balanced diet. Salt, excess protein and phosphorus increase the loss of calcium in urine. Too many fibers reduce the amount of calcium that can be absorbed.
- Don’t drink caffeine. This causes calcium to be secreted into the urine.
- Don’t smoke! (Enough said!)
- Exercise to work your bones and help to build bone mass. Regular activity is vital to preventing bone loss.

**FOOD SAFETY**

Because of your child’s medicines, he/she is more susceptible to germs in the foods they eat and bacteria from improper food handling and storage. Use the following tips to improve food safety.

**Keep A Clean Kitchen**

- Clean work surfaces often, and remove all food particles. Sanitize cutting boards after each use with a bleach and water solution and let them air dry. Also clean sinks, counters, kitchen tables with a bleach solution or with anti-bacterial soaps or sprays. The recipe for a homemade bleach solution is to mix one teaspoon of bleach with one quart of water.
- Change towels and dish cloths often. Toss sponges and scrub brushes into the dishwasher each night. Boil them with a small amount of bleach if you don’t use a dishwasher. Replace sponges often.
- Wipe up spills in the refrigerator right away and keep shelves, sides and doors sanitized.
- Don’t let dishes soak in the sink. The mixture of food, warm water and soap provides the perfect conditions for bacterial growth.

**Proper Food Handling**

- Wash your hands in warm, soapy water before and after every step in the food preparation process. Be especially vigilant immediately after preparing meat or poultry.
- If you have a cut or open sore on your hand, use plastic gloves or a plastic-sealing bandage. Wounds are easy areas for bacteria to enter the body.
- Be sure to wash all fresh fruits and vegetables with soap and water and peel before eating.
- Thaw meat, poultry or fish in the refrigerator. Never thaw on the counter. Bacteria thrive in food at room temperature.
- Use one cutting board for raw meat and poultry, another for chopping food that won’t be cooked. Plastic boards that can be tossed in the dishwasher after each use are best.
- If you use a wooden cutting board, be sure to wash and scrub it after each use with soap and hot water, then sanitize with bleach solution or anti-bacterial spray designed for this purpose.
- Beware of cross-contamination. For example, don’t carry the cooked meat to the table in the same dish used to carry the raw meat to the grill.
• Avoid raw or under-cooked meat, poultry or seafood. Cook beef and lamb to at least 140 degrees F, pork to at least 150 degrees F and poultry to at least 165 degrees F. Use a meat thermometer to ensure complete cooking.

• Cook eggs thoroughly until both the yolk and white are firm, but not runny. Consider using pasteurized eggs instead of shell eggs whenever possible.

• Avoid sushi, raw oysters, and raw eggs in any form (cookie dough, eggnog, Caesar salad dressing).

• Stuff chicken or turkey just before roasting. This keeps the bacteria in raw poultry from invading the starchy stuffing. Once cooked, poultry and stuffing should be stored separately in the refrigerator.

• Treat cracked eggs carefully. If you find a cracked egg in a carton, don’t use it. Cracked eggs can harbor disease-carrying organisms.

Proper Food Storage

• Keep foods out of the temperature zone: 40 – 140 degrees F. Foods left out for more than 2 hours (even in heated serving units) invite bacteria to grow. Keep refrigerator temperatures between 40 – 45 degrees F and freezer at zero degrees.

• Put raw seafood, poultry and meat in plastic bags so drippings can’t contaminate other foods.

• Put eggs in their original carton in the main section of the refrigerator. Don’t put them in the egg section of the door because the temperature there is higher.

• Keep the cupboard or pantry clean, dry, dark and cool. The ideal temperature is 50-70 degrees F. Temperatures over 100 degrees F are harmful to canned goods.
OVERVIEW

This next section includes an overview of your child’s medications, plus specific information about the medicines he or she will likely be taking. Please read this section carefully and ask any questions you may have. Following is a list of dosage forms and abbreviations that you may see. This is for informational purposes only and need not be memorized.

Your child’s medications are prescribed in grams, milligrams or micrograms:

• One gram (g) = 1000 milligrams (mg)
• One milligram (mg) = 1000 micrograms (µg)
• 1 cubic centimeter (cc) = 1 milliliter (mL)

Your child’s medications are administered according to a preset schedule:

• qd (one a day)
• bid (twice a day)
• tid (three times a day)
• qid (four times a day)

Your child may take his/her medications via different routes:

• po (by mouth)
• ng (by nasogastric tube)
• sl (sublingually—under the tongue)
• IV (intravenously)
• inhaled

IMMUNOSUPPRESSIVE THERAPY

Immunosuppressive therapy is necessary to prevent or decrease the body’s ability to reject the new organ. The goal of therapy is to induce the body’s tolerance of the new organ while leaving the immune system intact to provide protection against infection. A combination of drugs is utilized to most effectively meet this goal. The type, dosage, and frequency of these medications are prescribed on an individual basis. Each person’s medications are prescribed according to his or her blood levels, body size, absorption, and tolerance of the drug.

These are powerful medications that have side effects. Therefore, they must be taken EXACTLY as prescribed to maintain the delicate balance in your child’s body. Taking too little of the drugs may allow the immune system to destroy the new organ. However, too much of these drugs may alter the body’s ability to fight off infections. Any alteration in medications that is not prescribed by your doctor may lead to serious consequences!

If you are concerned about any medication side effects please contact your transplant nurse coordinator. There are several medication “rules” which you and your child must follow:

1. Never stop taking medication unless your doctor tells you to do so.
2. Do not skip a dose of medicine. If your child misses a dose, do not double the following dose. Please call your transplant coordinator for further instructions.
3. Do not take medicine that the doctor has not prescribed. Tylenol is acceptable in moderation.
4. Do not take medications at times other than what has been written on the schedule unless you have discussed this with your child’s doctor. Make a schedule and get into the habit of taking medications at the proper times.
5. If your child becomes ill and cannot take medication or if he/she is throwing up or having diarrhea, please call your transplant coordinator for further instructions. If your child throws up within 20 minutes of taking medications, please repeat dose. If it has been greater than 20 minutes, DO NOT REPEAT DOSE.
6. Do not allow your child’s medicine to run out. Refill your child’s medication before the bottle is empty. It is important to not miss a dose. Allow 7 days for your pharmacy to refill prescription.
7. Please check the expiration date on all medications. Do not take expired medications.

8. Please check liquid medication concentrations when refilled at the pharmacy. Liquid medications come in many different concentrations so check carefully for proper dosage.

9. Please learn medications by brand and generic name. It is also very important that you know medication doses by concentration or strength (gram, milligram, microgram, or units) as well as form (capsule, tablets, liquid).

For children too young to take pills, we will prescribe a liquid form of the medication. All doses of the liquid medication will be measured by a syringe. The nurses will teach you how to use different size syringes and draw up the correct dose of medicine.

It is best to get in the practice of giving your child the medications directly out of the syringe so it is not spilled or wasted. We will send you home with a large supply of syringes. You may wash and reuse the syringes as long as the numbers are visible. When you need more, you can refill the prescription at the hospital or your local pharmacy.

Never stop any medication unless instructed by your child’s doctor.

Store all medications out of the reach of young children. If accidental swallowing of any medication occurs, take the child and the medication to the nearest Emergency Center immediately.

**DRUG INTERACTIONS**

Many medications (both prescription and over the counter) can interact with your child’s immunosuppression (anti-rejection) in an undesirable way. For instance, some antibiotics affect the absorption of these medicines, either causing the drug levels to become too high or too low. The following is a brief list of medications that are known to interact with your child’s transplant medications. Prior to starting your child on any of the following medications, you **must** notify the transplant team:

<table>
<thead>
<tr>
<th>Actifed</th>
<th>Biaxin</th>
<th>Ciprofloxacin</th>
<th>Dilantin</th>
<th>Erythromycin</th>
<th>Flucconazole</th>
<th>Ibuprofen</th>
<th>Itraconazole</th>
<th>Ketoconazole</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Pepto Bismol</td>
<td></td>
<td>Pseudoephedrine</td>
<td>(Sudafed)</td>
<td>Reglan</td>
<td>Rifampin</td>
<td>Tegretol</td>
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<td></td>
<td></td>
<td>Pediazole</td>
<td></td>
<td>Phenobarbital</td>
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</tbody>
</table>

This is just a small list of medications known to interact with your child’s transplant medicines; there are many others that interact as well. Therefore, **do not give your child any over-the-counter medications or medications prescribed by a physician who is unfamiliar with your child’s medical history, without first consulting the transplant team.**

Medications are essential to the success of your child’s transplant. Your child will be on many different medications early after his/her transplant. Two or three of these will be immunosuppression (anti-rejection) medications. Without these medications, the body will reject the new organ. Each medication is prescribed for your child’s individual needs and is adjusted according to the body’s response. The medications must be taken as directed; **DO NOT** change or quit giving your child’s medications unless instructed by a member of the transplant team. We expect parents, and eventually the child, to understand the actions of each medication; so please be sure to ask questions to clarify any information given to you. Understanding the medications enables you to better identify the side effects when they occur.

Prior to discharge, your family will begin to administer medications to your child, with the assistance of your nurse. Before discharge from the hospital, we will teach you:

- the generic and brand names of each medication;
- what each looks like;
- the purpose and action of each drug;
- how to determine the correct dosage;
- precautions required for each one;
• how and when to take the drugs; and
• the common and uncommon side effects for each drug.

Before discharge, your transplant nurse coordinator will give you a medication schedule for your child listing the names of the drugs, dose, any special instructions, and times to administer the medications. Each time you or your child is getting ready to take their medications, you should have the medication schedule in front of you as you get the medications ready.

Each time a change is made in medication (either the dose or the frequency), you should make the change on the schedule. Medications should be given by your schedule, not according to the instructions written on the medication bottle. If you have any questions, please contact your transplant nurse coordinator.

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

Always carry your child's medication schedule with you so changes may be made if necessary. You may also wish to provide your child a copy of medications for his/her wallet. Should your child require hospital admission, please bring all your medications.

IMMUNOSUPPRESSANT MEDICATIONS

PROGRAF® (Tacrolimus)

Action:
Tacrolimus is an immunosuppressant drug that decreases the number of specific white blood cells to help prevent rejection. Should not be given with Cyclosporine.

Preparation:
Available in 5 mg, 1 mg, and 0.5 mg capsules. Also available as a liquid preparation.

Frequency:
Twice a day (bid) at 12 hour intervals.

Possible Side Effects:
• Infection: Because this drug suppresses the immune system, infection is one of the leading potential risks.
• High blood sugar: Tacrolimus may cause high blood sugar and progress to diabetes.
• Kidney Impairment: Kidney function is carefully monitored in patients on this drug because kidney damage can occur.
• Tremor: Fine shaking of the hands may occur during the first month of using this medicine. If it worsens and/or interferes with the child's daily activities, contact your child's doctor. Seizures are a rare complication seen in the first several months.
• High Blood Pressure: This may be a common early side effect and can be controlled with blood pressure medicine.
• Hair Loss: Sometimes occurs but usually not permanent. Hair will grow back.

Special Instructions:
• There are a number of medications that interact in various ways with Tacrolimus either increasing or decreasing Tacrolimus levels in the bloodstream. Your child should not take any other medications (over-the-counter or prescription) without checking with the transplant team first.
• Do not take Tacrolimus with grapefruit or grapefruit juice.
• While taking this medicine, lab work will be obtained to monitor the drug level. It is important to have this done as scheduled so dosages can be correctly adjusted according to your child's needs.
• Capsules should not be opened or crushed.
• For liquid preparations, shake the bottle well before drawing up the dose.
**PREDNISONE – Steroid**

**Action:**

*Prednisone* decreases the body’s response to foreign cells by altering the immune system, to help prevent rejection.

**Preparation:**

Available in liquid preparation and various pill strengths.

**Frequency:**

Usually given once or twice (BID) per day.

**Possible Side Effects:**

- **Infection:** Because this drug suppresses the immune system, infection is one of the leading potential risks.
- **Increased appetite and weight gain:** Transplant patients taking Prednisone often have an increased appetite leading to weight gain.
- **Acne:** Most often occurs on the face but can also occur on the chest and back. Keep affected areas clean and dry. Refer to section on Acne (see page 15).
- **Increased sensitivity to the sun:** Always apply sunscreen to exposed skin when in direct sunlight. A minimum SPF (sun protection factor) of 30 is recommended.
- **Delayed growth:** Slows down growth and delays puberty.
- **Muscle weakness or cramps:** These can be decreased by walking, biking, or doing exercises that strengthen muscles.
- **High blood sugar:** Prednisone may cause high blood sugar and progress to diabetes.
- **Change in Vision:** Cataracts may occur in some patients who receive Prednisone in high doses for a long time.
- **Mood Changes:** Very “up” or very “down”. Children may cry easily, be giggly, or have increased irritability. This usually improves as the child adjusts to the medication and the dose is decreased.
- **Decreased bone density:** Thinning of the bones.
- **Insomnia:** May cause sleep disturbance.

**Special Instructions:**

- **Never stop** this medication unless instructed by your child’s doctor.
- **Take** this medication in the morning if possible. This may help alleviate sleep disturbances.

**CELLCEPT® (Mycophenolate mofetil)**

**Action:**

*CellCept* is an immunosuppressant drug which decreases the number of specific white blood cells which are responsible for rejection.

**Preparation:**

Available in 250 mg and 500 mg capsules. Liquid preparation is also available.

**Frequency:**

Twice a day (bid) at 12 hour intervals.

**Possible Side Effects:**

- **Infection:** Because this drug suppresses the immune system, infection is one of the leading potential risks.
- **Bone Marrow Suppression:** May decrease white blood cell counts leading to increased risk of infection and decreased platelets, causing bruising. Dosage adjustment is required if this occurs.
- **GI Distress:** Signs and symptoms include nausea/vomiting/diarrhea/cramping. Generally this resolves in time.

**Special Instructions:**

- Capsules should not be opened or crushed.

**IMURAN® (Azathioprine)**

**Action:**

*Imuran* is an immunosuppressant drug which decreases the number of specific white blood cells which are responsible for rejection.

**Preparation:**

Available in 50 mg tablets; can be prepared as liquid.

**Frequency:**

Once per day, usually at bedtime; need to take consistently at the same time every day.
Possible Side Effects:
- **Infection:** Because this drug suppresses the immune system, infection is one of the leading potential risks.
- **Bone Marrow Suppression:** May decrease white blood cell counts leading to increased risk of infection and decreased platelets, causing bruising. Dosage adjustment is required if this occurs.
- **Hair Loss:** Sometimes occurs, but usually not permanent. Hair will grow back.

**RAPAMUNE® (Sirolimus)**

**Action:**
Rapamune is an immunosuppressant used to prevent transplant rejection.

**Preparation:**
Available in tablet and liquid form.

**Special Instructions:**
- The liquid form of Rapamune must be mixed in 2 ounces (60 ml) of water or orange juice in a plastic or glass cup. Stir the solution well and drink immediately. The cup should then be refilled with 4 ounces (120 ml) of water or orange juice, stirred, and the patient should drink this as well.
- **DO NOT** use Rapamune with apple juice, grapefruit juice or milk products. Patients who have taken Rapamune undiluted have developed mouth ulcers.

**Possible Side Effects:**
- High cholesterol and high triglycerides.
- High blood pressure, edema (swelling), fever, headache, acne, upset stomach, decrease in white blood cell and platelet counts, and joint pain.

**Special Instructions:**
- While taking this medicine, lab work will be obtained to monitor the drug level. It is important to have this done as scheduled so dosages can be correctly adjusted according to your child's needs.

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**ANTI-VIRAL MEDICATIONS**

**ZOVIRAX® (Acyclovir)**

**Action:**
Acyclovir is an antiviral drug that fights or helps prevent viruses of the Herpes family i.e. Herpes Simplex (virus that causes “cold sores”), Varicella (chickenpox), etc.

**Preparation:**
Available in 200mg/5 ml liquid preparation. Available in 200mg, 400mg, and 800mg capsules/tablets. Also available as a topical ointment and as an IV preparation.

**Frequency:**
Variable, depending on if it’s being used for prevention or for treatment.

**Possible Side Effects:**
- **Bone Marrow Suppression:** May decrease white blood cell counts leading to increased risk of infection and decreased platelets, causing bruising. Dosage adjustments are required if this occurs.

**Special Instructions:**
- Important to increase oral fluid intake while on this medicine.

**CYTOVENE® (Gancyclovir)**

**Action:**
This medication is an antiviral agent that is used to prevent or treat Cytomegalovirus (CMV) and other viral infections.

**Preparation:**
Available in 250 mg capsules. Liquid preparation is also available. An IV form of Gancyclovir may also be used.

**Frequency:**
Variable; depends on if being used for prevention or treatment.

**Possible Side Effects:**
- **Bone Marrow Suppression:** May decrease white blood cell counts leading to increased risk of infection and decreased platelets, causing bruising.
Dosage adjustment is required if this occurs.

- **Headache, Confusion**

- **GI Distress:** Signs and symptoms include nausea/vomiting/diarrhea/loss of appetite. Generally this resolves in time.

- **Kidney Impairment:** Because this drug is cleared through the kidneys, possible damage may occur. Kidney function is carefully monitored in patients on this drug.

**Special Instructions:**
- Capsules should not be opened or crushed.
- Wash hands thoroughly after handling this medication.

**VALCYTE® (Valgancyclovir)**

**Action:**
Valgancyclovir is an anti-viral drug used to prevent and/or treat Cytomegalovirus (CMV).

**Preparation:**
Available in 450mg scored tablets. Liquid preparation is also available.

**Frequency:**
Usually once or twice a day (BID).

**Possible Side Effects:**
- **GI Distress:** Signs and symptoms include nausea/vomiting/diarrhea/cramping. Generally this resolves in time.
- **Headaches**
- **Bone Marrow Suppression:** May decrease white blood cell counts leading to increased risk of infection and decreased platelets, causing bruising. Dosage adjustment is required if this occurs.

**Special Instructions:**
- Wash hands thoroughly after handling this medication.

### PROPHYLACTIC MEDICATIONS

#### BACTRIM/SEPTRA (Sulfamethoxazole/trimethoprim – (SMZ-TMP))

**Action:**
Bactrim is given to children for the treatment and/or prevention of urinary tract infections (kidney/bladder infections). In the case of transplant patients, it is given to prevent a specific type of pneumonia called pneumocystis pneumonia.

**Preparation:**
Bactrim is supplied in both liquid and tablet form.

- The strength of the liquid is: Sulfamethoxazole 200 mg and Trimethoprim 40 mg per 5 ml (1 teaspoon).
- A single strength tablet contains Sulfamethoxazole 400 mg and Trimethoprim 80 mg.
- A double strength tablet contains Sulfamethoxazole 800 mg and Trimethoprim 160 mg.

**Possible Side Effects:**
- **Rash**
- **Bone Marrow Suppression:** May decrease white blood cell counts leading to increased risk of infection and decreased platelets, causing bruising. Dosage adjustment is required if this occurs.
- **Sun sensitivity**

**Special Instructions:**
- Please notify your physician if your child has sulfa allergy

#### DIFLUCAN (Fluconazole)

**Action:**
An antifungal used to treat or prevent yeast infections (thrush) of the mouth and throat. It can also treat yeast infections in the bloodstream.

**Preparation:**
Supplied in IV, liquid, and tablet forms.

**Possible Side Effects:**
- Side effects are rare
- Prograf (Tacrolimus) levels may run higher when taking Fluconazole. Increased monitoring of Tacrolimus levels may be necessary when taking this drug.

**Special Instructions:**
- Always tell your child’s doctor that he/she is taking Fluconazole
ANTI-HYPTERTENSION/DIURETIC

PROCARDIA/ADALAT® (Nifedipine)

Action:
Nifedipine is given for the treatment of high blood pressure. It helps lower blood pressure by relaxing the blood vessels in the body.

Preparation:
This medication is available in tablet or liquid form.

Possible Side Effects:
• Dizziness, fainting, flushing, headache
• Swelling of hands and feet
• Gum Swelling: Good dental care is important to keep gums healthy. Daily brushing, flossing, and routine dental check-ups (every six months) are recommended. If there is gum overgrowth, this can be surgically removed.

Special Instructions:
• Always tell your child’s doctors that he/she is taking Nifedipine.
• High blood pressure should improve within 15 minutes after a dose of Nifedipine is given. If there is no improvement when the blood pressure is re-measured, call the child’s doctor.
• Children on Nifedipine XL may see the tablet in their stool. This is only the shell of the medication and does not mean that their body is not absorbing the medication.

NORVASC® (Amlodipine)

Action:
Norvasc is given for the treatment of high blood pressure.

Preparation:
Available in 2.5 mg, 5 mg and 10 mg tablets. Liquid preparation also available.

Possible Side Effects:
• Headache, dizziness
• Swelling of hands and feet

Special Instructions:
• Always tell your child’s doctor that he/she is taking Norvasc.

LASIX® (Furosemide)

Action:
Stimulates the kidney to remove excess water from the body. There is usually an increase in urine output starting about one hour after the dose and lasting from four to eight hours.

Preparation:
Lasix Oral Solution is supplied as 10 mg/ml liquid.
Lasix is also supplied in 20 mg, 40 mg, and 80 mg tablets.

Possible Side Effects:
• Weakness or unusual tiredness
• Irritability or listlessness
• Sudden weight change
• GI Distress: Signs and symptoms include nausea/vomiting/diarrhea/loss of appetite. Generally this resolves in time.
• Dizziness, headaches, blurred vision
• Ringing in the ears or hearing loss
• Light-headedness upon standing
• Signs of dehydration: May include inability to make tears, dry mouth, decreased urine output, and sunken eyes.

Special Instructions:
• Once opened, Lasix liquid is good for 90 days.
• When Lasix stimulates the kidneys to release the excessive water in the body, an important body element, potassium, is also washed out of the body. To help replace the potassium you need to include foods from this list in your child’s diet to replace the potassium.

<table>
<thead>
<tr>
<th>All Baby Formulas</th>
<th>Milk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bananas</td>
<td>Orange Juice</td>
</tr>
<tr>
<td>Beans, pinto or kidney</td>
<td>Peaches</td>
</tr>
<tr>
<td>Citrus fruits</td>
<td>Potatoes</td>
</tr>
<tr>
<td>Dried dates</td>
<td>Prunes</td>
</tr>
<tr>
<td></td>
<td>Prune Juice</td>
</tr>
</tbody>
</table>

• Contact the dietitian for further nutritional information.
ALDACTONE® (Spironolactone)

**Action:**
Stimulates the kidney to remove excess “water” from the body without losing potassium.

**Preparation:**
Available as 25 mg, 50 mg, and 100 mg tablets. Liquid preparation is also available.

**Possible Side Effects:**
- Weakness, unusual tiredness
- Irritability or listlessness
- Sudden weight change
- Abdominal cramping and diarrhea
- Dizziness, headaches, mental confusion
- Irregular menstrual cycle, or swelling of breast tissue
- Deepening of the voice
- Signs of dehydration: May include inability to make tears, dry mouth, decreased urine output, and sunken eyes.

**Special Instructions:**
- Shake the bottle well before measuring.
- Store medication in the refrigerator.
- Liquid preparation is only good for one month.

MEDICATIONS GIVEN FOR TREATMENT OF REJECTION

THYMoglobulin® (Antithymocyte Globulin – Rabbit)

Thymoglobulin is used in the hospital for prevention or treatment of transplant rejection. Thymoglobulin is a very potent immunosuppressant with many side effects and is only given in the hospital. The most frequent adverse reaction is fever and chills. Other adverse reactions include decrease in white blood cell count, decreased platelet count, pain, headache, diarrhea and increased blood pressure. In rare instances, severe allergic reaction can occur. Patients are pre-treated with acetaminophen, antihistamines, and steroids to reduce the severity of adverse reactions. Vital signs and blood work will be used to monitor for adverse effects.

OTHER IMPORTANT MEDICATIONS

MAGNESIUM

**Action:**
Magnesium is an important element used by the body to complete many enzyme reactions. It is vital for muscle function including heart function. Several immunosuppressant drugs can decrease magnesium levels.

**Preparation:**
Many forms of magnesium are available. Please check with your physician for recommendations.

**Possible Side Effects:**
- GI Distress: Signs and symptoms include nausea/vomiting/diarrhea/loss of appetite. Generally this resolves in time.
- Muscle weakness

**Special Instructions:**
- Do not take magnesium or other antacids at the same time as Mycophenolate Mofetil (Cellcept). Allow at least two hours between these medications.

PHOSPHORUS (NEUTRAPHOS)

**Action:**
Phosphorus is an important electrolyte in the body. It works together with calcium to keep bones strong and healthy. In patients who are urinating large amounts (i.e. new kidney transplant recipient), too much phosphorus is lost in the urine so it needs to be replaced.

**Preparation:**
Available as a capsule or individual packets containing 250 mg of phosphorus each.

**Possible Side Effects:**
- GI Distress: Signs and symptoms include diarrhea and nausea. Generally resolves in time.

**Special Instructions:**
- Neutraphos capsules and packets must be mixed with fluid. Open capsule or packet and dissolve in at least 2 1/2 ounces of fluid of choice (i.e.}
water, juice, punch, etc) and drink. **DO NOT SWALLOW CAPSULES WHOLE – MUST BE DILUTED.**

- Do not take magnesium or other antacids at the same time as Neutraphos. Allow at least 2 hours between these medications.

Many medications will affect the absorption of the immunosuppressive drugs or may interact with them in an undesirable way. Therefore, do not give your child any over-the-counter medications or medications prescribed by a physician who is unfamiliar with your child’s medical history without first consulting the transplant team.
READMISSION TO THE HOSPITAL

READMISSION

Readmission to the hospital may occur for several reasons:

- **Fever** – especially if your child has a Broviac (central line)
- **Infections** – such as pneumonia, CMV, UTI, etc. as your child may need antibiotics.
- **Vomiting and Diarrhea** – especially if your child is unable to keep down fluids and/or their medications
- **Observation after a procedure** – i.e. after a biopsy
- **Treatment for organ rejection**

In the event your child is to be admitted to the hospital after transplant, please bring the following with you:

- All current medications
- Medical records (including x-ray films) – if your child was initially seen at an outside physician office or hospital for this current illness or problem
- Current insurance card

In most cases, your child will be admitted on the same floor as they were on post-transplant. However, if your child has an infectious illness such as chickenpox or influenza, they may be on the general medicine or infectious disease floor so as not to expose other children who have been transplanted.

WHAT TO REPORT

If you have any questions after you leave the hospital or if your child experiences any of the following, you should call your transplant coordinator or the GI physician-on-call at 314.454.6000 if after normal business hours.

Some things to call the transplant nurse coordinators about are:

1. **Fever**: Temperature at or above 38.5°C or 100.0°F
2. **Rejection**: Signs and symptoms of rejection include: fever, rapid weight gain, jaundice, swelling and tenderness over transplant site, light colored stools, dark orange urine
3. **Wound infection**: Redness and/or drainage from incision site
4. **Medication questions**: Any questions regarding dose, how to give, if started on new medication, missed dose
5. **Exposure to contagious disease**: Especially chicken pox
6. **Cold or flu symptoms**: Fever, diarrhea, vomiting, congestion, nasal drainage, mouth sores or skin rashes
7. **Urinary tract infection**: Symptoms include pain or burning with urination, cloudy and/or foul smelling urine, blood in urine, frequency and/or urgency
8. **Diarrhea**: loose, watery stools and/or more than six stools per day

Often you will be directed to the primary care doctor if the issue is not directly transplant related, but the transplant team is always willing to help you get the best care for your child.

If your concern cannot wait until normal business hours, call the GI physician-on-call at 314.454.6000.
TRANSPORT COMPLICATIONS

There are many complications that are associated with transplantation. Complications may be a result of the surgical procedure itself or due to side effects from the many medications your child will be taking after transplant. There is no way to predict if your child will develop any of these problems or how severe they may be. Some complications are more severe than others; some are temporary and some are long term. Most complications are treatable, however, some complications may result in permanent conditions. If complications do occur, the transplant team will take the necessary steps to treat and/or minimize the problem.

SURGICAL COMPLICATIONS

PRIMARY GRAFT NON-FUNCTION

Primary graft non-function is a very rare but life threatening complication. For unknown reasons, the new liver simply does not work and fails within the first 24-48 hours following transplantation. There is no known cause, no way to predict it will occur, and no way to prevent it from happening. If your child should develop primary graft non-function, the only treatment is to undergo another liver transplant emergently.

POST-OPERATIVE BLEEDING

If your child is going to develop post-operative bleeding, this will most likely occur within the first 48 hours following transplantation. Bleeding can occur at the site where the new blood vessels are sewn together or, if your child had a reduced size (“cut down”) liver transplant, bleeding can occur from the cut surface of the liver. Slow blood clotting (elevated Prothrombin time) and low platelet count can also make the bleeding worse. Signs of bleeding include a rapid or ongoing drop in hemoglobin and hematocrit, increased heart rate, low blood pressure, and increased bloody drainage from JP drains. If there is a large amount of bleeding, your child will need to be taken back for a second operation by the transplant surgeon so he can find the source of the bleeding and stop it. Your child will also need additional blood transfusions to help replace the blood that is being lost.

BLOOD VESSEL THROMBOSIS

Thrombosis or development of a blood clot within the major blood vessels connected to the liver is a very serious complication if it occurs within the first few days after transplant. Infants and children are more at risk for this than adolescents due to the small size of their blood vessels, but it can happen in any patient. If a blood clot develops in the blood vessels carrying blood to the liver (portal vein and/or hepatic artery), the liver cannot get the blood it needs which will cause it to fail. Signs of blood vessel thrombosis include sudden increase in liver transaminases, unstable vital signs, and signs of liver failure. An ultrasound may be performed which would show lack of blood flow in the affected vessel. In some cases, the transplant surgeon can try to re-operate and remove the blood clot from the vessel but this is usually not successful. In most cases, your child will need another liver transplant emergently and will be relisted at the highest status on the UNOS waiting list. The transplant team tries to prevent thrombosis from developing by allowing clotting times to remain prolonged immediately after transplant and by giving your child medications to keep their blood from clotting normally.

BILE DUCT COMPLICATIONS

There are 2 types of bile duct complications that can occur as a result of the transplant surgery. The first is a bile leak. Bile leaks can occur at the area where the new bile duct is connected to the existing bile duct or intestine or can occur from the cut surface of the liver in those patients who have a reduced size liver. If your child is going to develop a bile leak, it will most likely happen within the first 1-2 weeks after transplant. Signs and symptoms of a bile leak include fever, abdominal pain, and abdominal distention. Sometimes, bile is seen in the JP drain as well. Radiology tests (HIDA scan, abdominal CT scan) may be performed to determine how severe the leak is. In many cases, if the leak is small, it will stop leaking on its own and not cause further problems. If it is a large leak, however, a biliary stent may need to be placed in
the bile duct where the leak has occurred until it heals. In some cases, the transplant surgeon may elect to re-operate to repair the leak.

The second type of bile duct complications are **biliary strictures**. A biliary stricture is a narrowing of the bile duct at the site where it is connected to the existing bile duct or intestine. Biliary strictures generally do not occur until 2-6 months after transplant. Signs and symptoms of biliary strictures include fever, abdominal pain, jaundice, itching, increased bilirubin, alkaline phosphatase and Gamma GT blood levels, and clay colored stools. These symptoms occur because the bile is unable to flow out of the liver through the narrowed bile duct. If a biliary stricture is suspected, an ultrasound will be performed to see if the bile ducts within the liver are dilated (or enlarged) suggesting bile is “backing up” within the liver. If there is a stricture present, a biliary stent will need to be placed to stretch and open up the narrowed bile duct. Most biliary strictures are successfully treated with stents but it may take as long as 6 months to 1 year to resolve.

**POST-TRANSPLANT INFECTIONS**

The immunosuppressant medications that your child will be taking after transplant to prevent rejection will also interfere with your child’s ability to fight off infections. Your child will not necessarily be more prone to catching colds or other illnesses but when they are ill, it may take them longer to get over the illness. Additionally, your child is more prone to “opportunistic” infections; these are infections that your child has already been exposed to either prior to transplant or from the transplant itself, that reactivate when your child’s immune system is suppressed.

It’s very important for you to re-establish your child with their pediatrician once they return home from the hospital. We recommend that you take your child in for a well visit appointment within the first month after returning home. This will give your pediatrician the opportunity to see your child when they are healthy as well as review your child’s transplant course with you.

**BACTERIAL INFECTIONS**

Bacteria can be found everywhere. We all have bacteria on our skin, in our mouth, and in our intestine. When we are healthy, this bacteria does not hurt us or make us sick. However, children who have had surgery, such as a transplant, or who are on immunosuppressant medications, can develop infections from their normal body bacteria. Bacterial infections are usually treated with oral or IV antibiotics, depending on the severity of the infection. The following are signs that your child may have a bacterial infection:

- Fever – temperature greater than 101°F or 38.5°C
- Sore throat – may be a strep throat infection
- Redness around your child’s incision and/or pus draining from incision, drainage tubes, or central line site
- Pain or burning with urination – may be a urinary tract (bladder) infection
- Difficulty breathing or shortness of breath.

If your child develops any of these symptoms, you need to call your child’s transplant nurse coordinator or transplant physician on call for further instructions. For minor illnesses such as earache, we will most likely have you take your child to their pediatrician for exam and treatment. However, before starting your child on any new medications, contact your transplant nurse coordinator to make sure these medications are compatible with your transplant medications.

If your child has been transplanted for less than three months, has a central line (broviac), and develops any of the above symptoms, we may ask you to come to the transplant clinic for further evaluation. You should bring extra clothes, as your child may need to be admitted to the hospital for evaluation and treatment.

**VIRAL INFECTIONS**

Viruses most often cause illnesses such as the common cold, stomach flu, and influenza. In most cases, these illnesses are caught from other people in the community who are currently sick. There is no “cure” for these types of viral illnesses – it just takes time for the virus to go away. There are things you and your child can do however, to
help prevent them from getting these infections:

- Practice good handwashing! Most cold germs are passed from your hands to the mucous membranes in your nose and eyes.

- Avoid friends and relatives you know to be ill. If an immediate family member is ill, use common sense: have them use separate drinking glasses, cover their mouth when coughing and sneezing, etc.

- Instruct your child to not share drinking glasses or eating utensils with others, at home and at school.

Should your child develop any of the following symptoms, please contact your child’s transplant nurse coordinator or physician on call:

- Fever – temperature greater than 101°F or 38.5°C
- Vomiting and diarrhea – especially if your child is unable to keep fluids and medication down or is having persistent diarrhea (watery and/or more than six stools per day) for more than two days
- Cold symptoms such as cough, earache, sore throat, or runny nose
- Low grade fever, muscle aches, excessive fatigue

There are a few other viruses of which transplant patients need to be aware. The viruses described below can come from different sources:

- For a first time infection, the virus could have been transmitted from the donor organ or from a blood transfusion.
- Reactivation of a person’s own virus – in other words, the patient had been exposed to the virus prior to transplant and the virus “reactivated” when the patient was immunosuppressed with medication.

Blood tests are performed on your child and the organ donor prior to transplant to see if they have been exposed to these viruses. Exposure to these viruses does not exclude either the patient or the donor from transplant; it merely helps the transplant team to plan for surveillance of developing infection and treatment after transplant.

CYTOMEGALOVIRUS (CMV)

CMV is a type of virus in the Herpes Virus Family. It causes flu-like symptoms such as fever (usually spike a fever at the same time every day), muscle ache, and fatigue. CMV can also affect different organs in the body as well. For instance, the virus can settle in the retina of the eye, cause pneumonia, or cause hepatitis (inflammation of the liver). A medicine called Ganciclovir is used to try to prevent an active CMV infection immediately after transplant; this same medicine is also used to treat patients who develop active CMV. Unfortunately, it does not get rid of the virus completely; it merely returns it to an inactive state. Some transplant recipients have multiple CMV infections.

EPSTEIN-BARR VIRUS (EBV)

EBV is also a member of the Herpes Virus Family. It is the same virus that causes mononucleosis (“mono”). It is transmitted the same as the CMV virus – either reactivation of the virus or transmission from the donor organ. Signs and symptoms of an EBV infection include low grade fever, extreme fatigue, sore throat, and swollen lymph glands in the neck. Treatment of EBV infections consists of supportive care and often, a reduction in your child’s immunosuppressant medications. Reducing your child’s anti-rejection medicines will allow your child’s natural defenses to combat the EBV infection. In some cases, the EBV virus continues to grow or proliferate within your child’s lymph system causing swollen lymph nodes throughout your child’s body. This condition is called Post-Transplant Lymphoproliferative Disease (PTLD). PTLD can be pre-cancerous but it can also develop into a lymphoma, which is a type of cancer. In some cases, chemotherapy is given to treat this condition.

HERPES SIMPLEX VIRUS (HSV)

There are 2 types of HSV – Type I and Type II. HSV Type I is more commonly known as the virus that causes fever blisters or cold sores on the lips and in the mouth. HSV Type II is more commonly known as the virus that causes genital herpes and is spread through sexual intercourse. In both cases, the virus initially causes a tingling sensation followed by redness then small blisters. The fluid in the blisters is very contagious, and if broken open, can spread to other areas. HSV can be treated with a medication called Acyclovir. Should your child develop cold sores, please contact your transplant nurse coordinator.
VARICELLA ZOSTER (VZV, CHICKENPOX, SHINGLES)

Chickenpox is a very common childhood illness that most children tolerate well. For children who get chickenpox after they’ve received a transplant however, it can be very serious, even fatal. During your child's transplant evaluation, if it's determined that your child has not had chickenpox, we will ask you to have your child be vaccinated with the Varivax, which is the vaccine that prevents chickenpox. If your child is too young to receive the vaccine and/or is transplanted prior to receiving the vaccine, you must notify the transplant office in the event your child is exposed to chickenpox for further instructions. If your child should develop active chickenpox, contact your transplant nurse coordinator immediately so treatment with Acyclovir can begin. In some cases, your child may need to be admitted to the hospital.

In some people who have had chickenpox, the virus stays in the body and settles along nerves. When patients are stressed or immunosuppressed with medications, the virus can “wake up” and cause what’s known as shingles. When shingles occurs, the patient will develop pain, itching, or tingling followed by the development of small blisters. It usually if found on the chest, back, or hip but can occur on the face, arm or leg. It is usually only present on one side of the body. The fluid in blisters is contagious to people who have not had chickenpox. Treatment for shingles is the same for chickenpox; Acyclovir until the lesions crust over. Your child may also need pain medicine until the shingles resolve.

FUNGAL INFECTIONS

The most common type of fungal infection that affects transplant recipients is candida albicans, which is a type of yeast. Most often this presents as oral thrush. Thrush is thick, white patches that are present on the tongue and inside cheeks. It can also be present in the throat and esophagus. Oral thrush is most often treated with a medication called Nystatin; in severe cases, it may be treated with another medication called Diflucan. Girls can also get vaginal yeast (candida) infections. This presents as white or yellow vaginal discharge as well as they may complain of itching and burning in the genital area. In most cases, vaginal yeast infections are treated with Diflucan. There are many other types of fungus and molds that are in the environment that can be dangerous to transplant recipients if inhaled. These types of fungus and molds are most often found in construction areas (in the dust), compost piles, and in bird droppings. If you are remodeling your home, check with your transplant nurse coordinator to determine if your child needs to stay elsewhere while the construction is being done. If your child has a pet bird, they should not clean out the birdcage.

OTHER COMPLICATIONS

ACUTE REJECTION

Acute Rejection is the most common complication in the post-transplant period. It occurs when the immune system of the recipient recognizes, becomes sensitized against, and tries to destroy the transplanted organ. All patients who have received transplants have some degree of rejection, however, the severity of the rejection is individualized. The chance of your child developing rejection will likely decrease over time, however, it can occur many years after transplant, especially if your child quits taking their medications. Signs and symptoms of acute rejection vary: your child may feel ill or feel perfectly fine. Rejection can be determined by lab tests, x-rays and by biopsy of the transplanted organ. Acute rejection is usually treatable by adjusting your child’s current immunosuppressant medications or by adding additional medications.

BIOPSIES

A liver biopsy is a procedure in which a small piece of liver tissue is taken through a needle puncture in your child’s side or abdomen to determine how well the liver is working. Liver biopsies are done prior to transplant to diagnose liver disease and after transplant to determine whether or not your child has rejection. The decision to perform a liver biopsy after transplant is determined by your child’s lab results – if your child’s liver labs are very elevated, a biopsy can help determine the cause. Biopsies are usually done in the OR procedure room. If your child does not have an IV, one will be started by the OR nurse. Your child will be sedated and a local anesthetic is used at the biopsy site to decrease pain. Biopsy results are
usually available within 24 hours. Once the results are reviewed by the doctors, a decision will be made as to whether or not treatment is needed. After the biopsy, your child will be admitted to the hospital for observation. If your child has rejection and needs treatment, they may need to be admitted for several days.

**SEIZURES**

A frequent and often worrisome side effect of some immunosuppressants is tremor. Tremors are an uncontrollable trembling or shaking of the limbs that are sometimes accompanied by numbness.

Seizures, however, are a less common but more serious side effect of Cyclosporine and Prograf. Seizures may be tonic/clonic in nature (jerking of arms or legs or whole body) or focal in nature (staring, eye deviation, or unable to speak). These medicines can lower the “seizure threshold” in the brain and then allow the seizures to happen. These seizures are not usually life threatening, however, if they occur outside of the hospital, call 911 for emergency medical assistance. If seizures occur, your child would have to be admitted to the hospital for medical treatment including observation and anti-seizure medications, if needed. Often the anti-seizure medicines can be stopped after several months.

**HYPERTENSION**

Hypertension, also known as high blood pressure, can be very common after solid organ transplant. Most often this is due to the amount of IV fluids needed during and after surgery but may also be due to medications that are needed after transplant. Sometimes your child's blood pressure will return to normal before discharge. If not, there are many different medications available to treat hypertension. It is important to remember that diet and exercise are important factors in helping to keep blood pressure in good control.

**RENAL INSUFFICIENCY**

A common post-transplant complication is renal insufficiency, or decreased function of the kidneys. Decreased kidney function is a known side effect of the anti-rejection medicine Prograf. Chronic antibiotic therapy (especially aminoglycosides) and post-operative complications such as bleeding and hypotension (blood pressure that is too low) can also contribute to decreased kidney function. Signs and symptoms of renal insufficiency include hypertension and elevated kidney function tests (i.e. elevated creatinine and BUN). Most transplant recipients have some degree of renal insufficiency, especially in the first few months post-transplant when their anti-rejection drug levels are at their highest. In many cases, once these drug levels decrease, the kidney function improves. Some patients, however, have more significant and progressive renal insufficiency requiring ongoing monitoring by a kidney doctor (nephrologist). In rare cases, these patients may have such severe renal insufficiency that they will need dialysis. There isn't any way to determine how much renal insufficiency your child will experience after transplant; your transplant team will continually monitor your child's kidney function post-transplant for evidence of decreasing kidney function.

**PTLD – POST-TRANSPLANT LYMPHOPROLIFERATIVE DISEASE (PTLD)**

Post-transplant Lymphoproliferative Disease (PTLD) is a possible but rare complication (approximately 5% of patients) of immunosuppression. It most commonly occurs six to 18 months following transplantation but may occur many years after transplant. PTLD occurs when the EBV (Epstein-Barr Virus) continues to grow or proliferate within your child's lymph system, causing swollen lymph nodes throughout your child's body. PTLD can be pre-cancerous, but it can also develop into a lymphoma, which is a type of cancer.

Signs and symptoms of PTLD vary. Some patients have flu-like symptoms (low-grade fever, malaise, etc.), while others have no symptoms at all. If the PTLD involves the transplanted organ, there may be symptoms related to organ impairment. The prognosis of the disease depends on the amount and location of the enlarged lymph nodes and whether or not they are cancerous. In a small number of cases, PTLD may be fatal. There are a number of treatment options for PTLD. Decreasing the dose of immunosuppression drugs may cause the lymph nodes to shrink or disappear. However, this may increase the risk for organ rejection. Your transplant team will follow your child closely for signs of rejection. In some cases, decreasing the dose of immunosuppression does not effectively
treat the PTLD, and it progresses the lymphoma. In this case, a Hematology/Oncology Specialist will be consulted as surgery and/or chemotherapy may be necessary.

**OBESITY**

A large number of patients gain weight during the first six to twelve months after transplant. Your child’s medications do not cause the weight gain. Medications such as Prednisone cause an increased appetite so your child is tempted to eat more calories than needed. It is important to begin (with permission from the transplant team) an exercise program after transplant. We encourage exercise and have never “lost” an organ due to activity. The transplant team includes a dietician who may guide you with a healthy eating and exercise plan.

**DIABETES (Diabetes Mellitus)**

A condition characterized by high blood sugar resulting from the body’s inability to use sugar (glucose) efficiently. In Type 1 diabetes, the pancreas is not able to make enough insulin; in Type 2 diabetes, the body is resistant to the effects of available insulin. Diabetes is one of the leading causes of kidney disease.

**DIABETES POST-TRANSPLANT**

Post-Transplant Diabetes Mellitus (PTDM) is seen in approximately 5-40% of post-transplant patients. The leading cause is medication. Steroids increase glucose levels and cause the body to resist insulin. Tacrolimus inhibits the release of insulin and add to the effect of the steroids by causing elevated blood sugar. Certain factors predispose patients to developing PTDM: increase in age, family history of diabetes, and African Americans are at higher risk.

The treatment of PTDM may depend on the severity of the hyperglycemia. A change in diet, decrease in steroids, and or insulin may be used to treat elevated blood sugar.

**GROWTH AND DEVELOPMENT**

**GROWTH**

Optimizing normal growth for your child is important both pre and post transplant. Many things impact your child’s normal growth: the severity of your child’s illness prior to transplant, nutritional status, and the medications they take after transplant, especially steroids. Prior to transplant, and at each clinic visit thereafter, your child’s height and weight will be measured to ensure your child is growing as normally as possible. If your child is not gaining weight appropriately, dietary supplements such as special formulas or nutrition additives, may be added to your child’s daily diet. In some cases, it may be necessary to give extra nutrition to your child through a nasogastric or gastrostomy tube or intravenously using Total Parenteral Nutrition (TPN). After transplant, some patients will experience “catch-up” growth and can actually get to a more normal height and weight pattern. In many cases, this catch-up growth does not occur until they are more than 6 months out of transplant and/or are on a lower dose of steroids. If you have concerns about your child’s growth, please talk to your transplant nurse coordinator or physician.

**DEVELOPMENT**

Delay in meeting developmental milestones such as sitting independently, walking, talking, etc. is common in infants and children who have chronic illness. Older children may have regression of behaviors as a way to cope with their illness. Prior to transplant, your child will undergo testing (neuropsychological testing) to determine if they are at the appropriate developmental stage for their age. Referrals may be made to programs such as Parents As Teachers, to help with your child’s development. After transplant, most children catch up quickly and continue to meet their milestones appropriately. If there are continued concerns about your child’s development, testing may be repeated.
COMMUNICATIONS AND MEDIA RELATIONS

CONTACTING THE DONOR FAMILY

Following your child’s transplant, we will provide you with a packet from Mid-America Transplant Services (MTS) called The Gift of Life. This packet includes the brochure, Writing to the Donor Families. The decision to write to the donor family is a very personal one; we urge you to write a letter when you feel the time is right for you.

MEDIA RELATIONS

The overall purpose of media relations is to increase and manage the public awareness of St. Louis Children’s Hospital (SLCH) and its role in the community. This requires a delicate balance between the needs of reporters, patients, parents, physicians, and SLCH employees while maintaining high level of privacy and adherence to our mission to “Do what’s right for kids”.

In addition to protecting the health and general welfare of its patients, a hospital’s responsibilities include protecting the patient’s legal rights as well. That includes the legal right to privacy concerning medical information. To ensure patient privacy and confidentiality, we require a media relation staff escort anytime the media come into SLCH or interview a patient. We also require a signed consent form from each patient and/or parent.

When working with transplant patients and their families, the most common theme is the need for organ donations and creating awareness of the need for organ donations. When a child is listed for a transplant at St. Louis Children’s Hospital, there are several reasons why the family might want to contact the media relations department:

- If the family is working with COTA or another fundraising group, and would like to contact the local media in their hometown, or the media in St. Louis.
- If the family has already had some media attention in their hometown, and their local media would like to interview the patient at St. Louis Children’s Hospital.
- If a reporter calls the family and would like to set up an interview with their transplant physician.
- If a reporter would like to know the patient’s current condition.

If you would like further information, please contact the Media Relations Department at 314.286.0416 or 314.286.0304.
St. Louis Children’s Hospital and Washington University are committed to making transplant outcomes better. We can only do so with your help. You/your child will join a team that also includes your physicians and scientists here at Washington University and around the world. As a member of that team, you/your child will be asked to participate in both clinical and basic research studies. As with all research studies, participation is entirely voluntary and will not impact your ability to receive standard care.

Each research project you/your child is asked to participate in will have been reviewed and approved by an institutional review board (IRB). At Washington University, this board is called the Human Studies Committee (HSC). The function of the HSC is to review and monitor research to ensure protection of any person thinking about participating in research studies. Before enrolling in any study, you/your child will be asked to review and sign a consent form that outlines the potential benefits of the study as well as the potential risks to you/your child. Minor children will be asked for their assent as well.

AUTOPSIES

When a transplant recipient dies, sometimes there are questions that remain unanswered for family members and physicians. The goal of an autopsy is to understand the reasons that lead to death. For these reasons, we seek permission to perform an autopsy on all transplant patients who die. An autopsy is a special type of surgical operation performed by an autopsy assistant and a pathologist (a specially trained physician). It may be performed on the whole body or on specific body parts. It is performed with respect and compassion as well as in accordance to religious beliefs. When completed, it allows for any type of funeral ceremony, including an open casket. It generally takes eight to twelve weeks for the complete autopsy report to become available. When it is available, the results will be discussed with you by your child’s physician.
ABO compatibility There are four blood types: O, A, B, and AB. Type O is the universal donor and type AB is the universal recipient. Type O can receive only type O blood, Type A can receive type A or O. Type B can receive type B or O. Type AB can receive A, B, AB or O.

Acquired Not caused by hereditary or developmental factors but by a reaction to environmental influences outside of the organism.

Acute Beginning abruptly.

Acute Rejection Attempt of body to destroy transplanted organ usually within the first year after transplant.

Adverse Reaction An unintended response from a drug.

Allocation System of ensuring that organs/tissues are distributed fairly to patients in need of transplant.

Allograft A graft between 2 individuals who are of the same species but have genetic differences, i.e. Human – Human.

Anaphylaxis A severe allergic reaction that can be fatal.

Anastomosis A surgical joining of two ducts, blood vessels, or bowel segments to allow flow from one to the other.

Anesthesia The absence of normal sensation, especially sensitivity to pain. Topical, local, regional, or general.

Antibody A substance that is produced by the immune system in response to specific antigens, helps the body fight infection and foreign substances.

Antigen Substances that trigger an immune response.

Antihypertensives Substance or procedure that lowers high blood pressure.

Antiviral Destructive to viruses.

Arterial Line A catheter inserted into an artery which allows for continuous direct blood pressure readings as well as access to the blood supply for monitoring labs.

Arteriogram An x-ray of the arteries taken with the aid of a dye.

Ascites An abnormal accumulation of fluid in the abdomen.

ATN — Acute Tubular Necrosis Reversible kidney damage resulting in delayed kidney function.

B

B-Cell A specialized white blood cell responsible for the body's immunity. B-cells function in antibody production.

Bacteria Tiny organisms (germs) that cause infection.

Bile A greenish-yellow fluid produced by the liver which is needed to help your body use fats and vitamins.

Biopsy The removal and examination of tissue to determine how well the organ is working or if it is rejecting.

Bladder Part of the urinary tract that receives and stores urine from the kidneys until you urinate.

Bronchoscopy Procedure used to diagnose infection and/or rejection of the lungs.

Broviac A type of IV that is placed through a large vein in the chest that allows for delivery of medicine and drawing of blood for labwork.

BUN – Blood, Urea, and Nitrogen A waste product normally excreted by the kidneys. The BUN, along with creatinine, will represent how well the kidney functions.

C

Cdavover A donor that has recently expired for reasons that do not affect the function of an organ to be transplanted.

Candida A type of yeast.

CAPD – Continuous Ambulatory Peritoneal Dialysis A cleansing fluid that fills a person's abdomen and then is drained to filter out wastes and excess fluid from the body.

Cardiologist A doctor who specializes in treating heart disorders and diseases.

Catheter A hollow, flexible tube that can be inserted into a vessel or cavity of the body to withdraw or instill fluids.

Central Line A type of IV that goes directly to the heart through a large vein in the shoulder or neck.

Chest X-ray A picture of the lungs and upper body
taken by an x-ray machine.

**Cholangiogram**  Dye is injected into the bile ducts of the liver to show leaking or blockage within the bile duct.

**Cholangitis**  Inflammation of the bile ducts caused by bacteria from the bowel.

**Cholestasis**  Stoppage or suppression of bile flow.

**Cholesterol**  A fatty substance that comes partially from foods eaten.

**Chronic**  Developing slowly and persisting for a long period of time.

**Chronic Rejection**  Slow failure of the transplanted organ/tissue.

**Cirrhosis**  A disease of the liver in which normal, healthy tissue is replaced with nonfunctioning tissue and healthy cells are lost.

**CMV/Cytomegalovirus**  A viral infection common to immunosuppressed patients

**Coagulation**  Blood clotting.

**Compatible**  The degree to which the body’s immune system will tolerate the presence of foreign material (organ, blood) without an immune reaction.

**Compliance**  The degree to which someone follows medical instructions and protocols.

**Congenital**  Present at birth.

**Contraindication**  Prohibited.

**Corticosteroids**  Hormones secreted by the adrenal gland. Can be man-made and given for immunosuppression.

**Creatinine**  A substance found in blood and urine monitored to determine kidney function.

**Cross Match**  A test which mixes a potential donor’s blood with the recipient’s blood and after several hours is examined under a microscope to determine compatibility. If there is cell death, the result is positive which means that the recipient has cells that attack the donor’s blood. If there is no cell death, the result is negative and the recipient and donor are compatible.

**D**

**Dexascans**  A type of x-ray that measures the density of the bones.

**Diabetes**  A disease in which patients have abnormally high sugar levels in their blood.

**Dialysis**  Cleaning the body of waste by artificial means.

**Diastole**  The bottom number of the 2 blood pressure numbers which measures blood pressure when the heart is at rest.

**Discharge**  To release from the hospital or from care.

**Discontinue or D/C**  To stop.

**Distention**  Visible increase in abdomen.

**Diuretic**  A drug given to promote the formation and excretion of urine.

**Dormant**  An infection that is currently not active.

**Drean**  A type of tube that may be attached to a collection device that allows an accumulation of fluid to be removed.

**Dressing change**  To remove an old covering of a wound or incision and replace, with clean or sterile technique.

**E**

**Echocardiogram**  Sound waves that are bounced off the heart to look at size and function.

**Edema**  A build-up of too much fluid in the body tissue resulting in swelling.

**EKG/Electrocardiogram**  A measurement of the current through the heart that tells us how the heart is working.

**Electrolytes**  Refers to the dissolved form of a mineral in the body, sodium, potassium, magnesium, etc.

**Encephalopathy**  When the liver can no longer clear the wastes in the blood. Wastes build up and cause lethargy and coma.

**Endocrinologist**  A doctor who specializes in treating diseases of the endocrine system (pancreas, thyroid, etc). These physicians manage the care of patients with diabetes.

**Endotracheal Tube**  A breathing tube that is connected to a ventilator that helps you breathe.

**Epstein-Barr Virus (EBV) – Mononucleosis**  A type of virus that causes fever, sore throat and swollen lymph nodes.

**ERCP – Endoscopic Retrograde Cholangiopancreateography**  An x-ray procedure that helps evaluate the liver and the bile ducts. Dye is injected into your biliary tree and x-rays are taken. A tube with a small light attached (endoscope) will look down your throat to examine the bile ducts.
Erythropoietin  A hormone that helps make new red blood cells.

Evaluation   A series of tests and meetings with the members of the transplant team to make sure that each candidate is ready for transplantation.

Extubate  To remove a breathing tube.

F

Fibrosis  Scarring caused by healing response to injury, infection or inflammation.

Foley Catheter  A tube is inserted into the bladder via the ureter which is connected to a pouch for the collection and measurement of urine.

Fulminant Hepatic Failure  A rapid, sudden and severe insult to the liver which can cause liver failure.

Fungal infection  An infection caused by a type of fungus. Can be life threatening in an immunosuppressed patient.

G

Gastroenterologist  A physician who specializes in the treatment of disorders of the digestive tract.

Generic  A drug’s chemical name.

Genetic  Referring to hereditary, birth.

Gingival hypertrophy  Enlargement of the gums. A common side effect of Cyclosporine.

Glucose  A type of sugar found in the blood.

Graft  A transplanted tissue or organ (kidney, heart, bone marrow or liver).

Graft survival  A transplanted organ or tissue that is accepted by the body and functions properly.

H

HCT – Hematocrit  A measure of the amount of red blood cells in the blood.

Helper T-Cell  A white blood cell that tells other parts of the immune system to fight infection or foreign material.

Hemodialysis  A method of dialysis in which blood is cleaned of waste by circulating through a machine outside of the body.

Hemoglobin – Hgb  A compound in the blood that carries oxygen to the cells.

Hemorrhage  A rapid loss of blood/excessive bleeding.

Hepatic  Having to do with the liver.

Hepatologist  A physician who specializes in treating liver disease.

Hereditary  A condition, characteristic or disease that is passed from parents to offspring.

HIDA Scan  Dye is given through an IV and flows through the liver. An x-ray is taken to show the flow and possible blockages in the bile ducts that drain the liver.

Hirsutism  An excessive increase in hair growth. A common side effect of Cyclosporine and steroids.

Histocompatibility  The compatibility of the antigens of donor and recipient transplanted tissue.

HLA – Human Leukocyte Antigen  Genetically determined series of antigens that are present on white blood cells and tissues.

Hyperacute Rejection  Very rare rejection that occurs very suddenly and unexpectedly. Usually occurs within the first few hours after surgery.

Hypertension  High blood pressure.

I

Immune response  A defensive reaction to foreign material by the immune system.

Immunity  Being able to resist a particular infectious disease.

Immunization  Resistance to an infectious disease is induced by giving a vaccination.

Immunosuppression  Prevention or suppression of the immune response either by drug therapy or by disease.

Intravenous (IV)  Into or within a vein. Also refers to fluids or medications that are infused through a needle or catheter that is inserted into a vein.

Intubated  A breathing tube inserted into the mouth or nose to the throat. The tube is connected to a breathing machine that will help them breathe until they are strong enough to breathe on their own.

Invasive  A diagnostic or therapeutic technique that requires entering the body.

IVP – Intravenous Pyelogram  Dye is injected into a vein. The dye concentrates in the kidneys and makes them show up on an x-ray. The doctor looks at the x-ray to see if there are two functioning kidneys with normal internal structure. Used in evaluating potential kidney donors.
Jackson-Pratt A small drain that is sometimes placed near an incision to drain any blood or fluid that may accumulate.

Jaundice Yellowing of the eyes and skin caused by an increased amount of bilirubin.

K

Kangaroo Pump A type of feeding pump used to deliver tube feedings.

Kidney Rids body of waste materials and maintains fluid balance through the production of urine.

L

LRD – Living Related Donor A blood relative that donates an organ.

Lymphocyte A white blood cell.

M

Mononucleosis – (EBV – Epstein-Barr Virus) A type of virus that causes fever, sore throat and swollen lymph nodes.

MRI – Magnetic Resonance Imaging A type of x-ray that uses magnetic waves to take pictures of tissues.

Myalgia Muscle aches and pains.

Myopathy Muscle disorder that causes severe weakness.

N

Nasogastric Tube A tube inserted through the nose that drains the stomach of excess bile to prevent nausea.

Nephrologist A doctor that specializes in treating problems involving the kidney.

Neuropathy A breakdown of the peripheral nerves; symptoms are numbness and tingling in extremities.

Neutropenic Severe decrease in the amount of white blood cells.

Noncompliance Failure of the patient to cooperate by doing what is necessary or required for his/her medical care.

Noninvasive Does not require skin to be broken or body entered.

NPO – Nothing By Mouth Term used when someone is without food/drink prior to exam/procedure.

O

Oncologist A doctor who specializes in treating patients with cancer.

OPO – Organ Procurement Organization Link between the potential recipient and donor. Responsible for retrieval, preservation and transportation of organs for transplantation.

Opportunistic Infection Infections that in healthy persons would not pose a threat but in immunocompromised persons can be very harmful.

Organ Part of body made of tissues specialized to perform a certain function.

Osteoporosis Weakening of the bones.

OTC – Over the Counter A type of medicine or product that does not require a prescription.

P

PACU Post Anesthesia Care Unit

Papilloma Virus Viruses that cause warts on hands, face and fingers.

PCP – Pneumocystis Carinii Pneumonia A type of pneumonia that is seen primarily in immunocompromised patients.

PELD – Pediatric End-Stage Liver Disease A scoring system for pediatric liver patients. Based on certain lab values and growth failure; assigned a number 0-40 based on need.

Percutaneous Through the skin.

Peripheral IV A small IV that is placed in the arm, hand or foot for delivery of IV fluids or medicines. Usually placed during surgery.

PFT – Pulmonary Function Test A test used to determine the ability of the lungs to exchange oxygen and carbon dioxide.

PICU Pediatric Intensive Care Unit

Platelet A small blood cell needed for blood clotting.

P.O. By mouth.

Primary Care Physician Pediatrician or doctor that follows patient for primary illness.

PRN As needed.

Prophylactic An agent or regimen used to prevent an infection or disease.

PTLD (Post-Transplant Lymphoproliferative Disorder) A type of cancer that attacks the lymphatic system of some immunocompromised patients.
**Pulmonologist** A doctor who specializes in treating lung disease.

**R**

**Recurrence** Reappearance or a sign or symptom of a disease after a period of remission.

**Rejection** An immune response against the transplanted tissue which if not successfully treated will result in graft failure.

**Renal** Having to do with the kidneys.

**Resistance** Ability of a virus to fight the effects of a treatment because the information in the virus changed. Can be caused from a person’s noncompliance with certain medicines.

**S**

**Sensitized** Being immunized or able to mount an immune response against an antigen by previous exposure to that antigen.

**Shingles** A type of varicella zoster, characterized by a painful, blistering rash on one side of the body.

**Stent** A tube used to support openings and vessels during and after surgical procedures.

**Stricture or Stenosis** A narrowing or passage in the body.

**Systolic** The top number of the blood pressure, measures the maximum blood pressure as the blood is pumped out of the heart.

**T**

**T-Cell** White blood cell responsible for the body’s immunity. Can destroy cells infected by viruses, graft cells and other altered cells.

**T-Tube** A tube placed in the bile duct to drain bile externally into a small bag.

**Thrush** A fungal infection in the mouth.

**Tissue Typing** A blood test that evaluates the closeness of tissue match between the donor’s organ and the recipient’s HLA antigens.

**Total Parenteral Nutrition (TPN) – Parenteral (Intravenous) Nutrition** A method of supplying nourishment to children unable to eat.

**Transplant** to transfer an organ or tissue from one person to another or from one body part to another to replace a diseased structure, restore function, or to change appearance.

**U**

**Ultrasound** Sound waves are bounced off the organs to check size and function.

**UNOS – United Network for Organ Sharing** Governing body that oversees organ transplantation in the U.S.

**Ureter** A tube that carries urine from kidney to the bladder.

**URI** Upper respiratory infection.

**UTI** Urinary tract infection.

**V**

**Vaccine** Protects a person against infection and/or disease. Made from killed or weakened forms of the disease and given to cause an immune response to create resistance to a certain disease.

**Varicella Zoster** Virus that causes chicken-pox and shingles.

**VCUG – Voiding cystourethrogram** A bladder and kidney x-ray.

**Ventilator** Breathing machine.

**Virus** Small disease causing germs that can only multiply when inside the cell of another organism.

**Vital Signs** Pulse, temperature, blood pressure, respiration.

**V/Q Scans** Ventilation perfusion scan of the lungs. Indicates air exchange and blood flow in the lungs.

**W**

**Waiting List** A nationwide computerized network called UNOS. All transplant centers in the U.S. belong. Supervised by the federal government to ensure that patients throughout the country receive organs as soon as they become available.

**WBC – White blood cell** Composed of several different types that all work to fight infection.
**WEIGHT (MASS)**

Pounds to Kilograms (1 pound = 0.4536 kilograms)

**Example:** To obtain pounds equivalent to 33.2 kilograms, find 33.11 and 33.57 in table, read “70” on side scale and “3” or “4” on top scale. Equivalent is between 73 and 74 pounds, closer to 73 pounds.

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## TEMPERATURE

Fahrenheit (°F) to Centigrade (°C): \( C = (°F - 32) \times \frac{5}{9} \)

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DAILY LOG

These pages are for you to record questions that arise, supplies needed, vital signs (blood pressure, temperature, etc.), medications and other information that is helpful for you to have at hand.

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LABORATORY

RESULTS

These pages are for you to record specific laboratory results for specific dates. This information will be helpful for you to have available for your child’s physician or transplant nurse coordinator.

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<th>BUN</th>
<th>Calcium (Ca)</th>
<th>Magnesium (Mg)</th>
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<th>Direct/Con Bilirubin</th>
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<th>ALT (SGPT)</th>
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Weight

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ST. LOUIS CHILDREN’S HOSPITAL
Liver Transplant Program
One Children’s Place
St. Louis, Missouri 63110
314.454.6254

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