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

**ST. LOUIS CHILDREN’S HOSPITAL**

**GENERAL INFORMATION**

<table>
<thead>
<tr>
<th>IMPORTANT NAMES AND NUMBERS</th>
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<tbody>
<tr>
<td>St. Louis Children’s Hospital (SLCH)</td>
<td>314.454.6000</td>
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<tr>
<td>SLCH Toll Free Number</td>
<td>888.503.2237</td>
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<thead>
<tr>
<th>PRIMARY NAMES AND NUMBERS</th>
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<tbody>
<tr>
<td>Kidney Transplant Medical Director</td>
<td>314.454.6043</td>
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<tr>
<td>Transplant Coordinators</td>
<td>314.454.6222</td>
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<tr>
<td>Transplant Coordinators</td>
<td>314.454.6216</td>
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<tr>
<td>Transplant Coordinators</td>
<td>314.454.2409</td>
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<td>Transplant Financial Coordinators</td>
<td>314.454.2091</td>
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<tr>
<td>Transplant Financial Coordinators</td>
<td>314.454.6191</td>
</tr>
<tr>
<td>To Make An Appointment</td>
<td>314.454.6289</td>
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<tr>
<td>Transplant Program Assistant</td>
<td>314.454.6289</td>
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<tr>
<th>ADDITIONAL HELPFUL NUMBERS</th>
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<tr>
<td>Ambulatory Procedure Center</td>
<td>314.454.2514</td>
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<tr>
<td>Chaplain</td>
<td>314.454.6211</td>
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<td>Child Life Services</td>
<td>314.454.6178</td>
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<td>Dialysis Unit</td>
<td>314.454.6065</td>
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<td>Family Resource Center</td>
<td>314.454.2350</td>
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<td>Information Desk</td>
<td>314.454.2615</td>
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<tr>
<td>Outpatient Lab</td>
<td>314.454.4130</td>
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<tr>
<td>Outpatient Pharmacy</td>
<td>314.454.6123</td>
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<tr>
<td>Patient Accounts</td>
<td>314.286.2384</td>
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<td>Psychologist</td>
<td>314.454.6069</td>
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<tr>
<td>Same Day Surgery</td>
<td>314.454.6174</td>
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<tr>
<td>School Liaison</td>
<td>314.454.2173</td>
</tr>
<tr>
<td>Security (escort to parking)</td>
<td>314.454.2660</td>
</tr>
<tr>
<td>Social Worker</td>
<td>314.454.6101</td>
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*If you are calling from within the hospital, dial only the last 5 digits of the number.
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.
St. Louis Children’s Hospital | KIDNEY TRANSPLANTATION HANDBOOK

UNDERSTANDING KIDNEY TRANSPLANTATION

HISTORY

An early pioneer in pediatric kidney transplant, St. Louis Children’s Hospital remains a leader in the field, achieving a graft and patient survival rate well above the national average over the past decade. Families from across the Midwest bring their children to St. Louis Children’s Hospital to benefit from its vast experience, outstanding success rates, and expertise in providing the latest innovations in kidney transplant. The outlook for pediatric kidney transplant has dramatically improved during the last two decades and continues to improve in part due to the surgical techniques developed and ongoing research at Washington University School of Medicine.

The hospital performed its first kidney transplant in 1964, and the program was formally established in 1970. Families with children who need kidney transplants have the opportunity to explore a number of donor options at St. Louis Children’s Hospital. In addition to the traditional wait for cadaveric organs, most children are candidates for living donor transplants, either from a relative (i.e. parent) or family acquaintance.

The kidney transplant program at St. Louis Children’s Hospital succeeds because of a strong team approach. Committed to providing patients with the best possible care during each stage of the transplant process, the transplant team works closely with the hospital’s other service areas when appropriate. The kidney transplant team provides continuity of care before, during, and after transplant.

CADAVERIC TRANSPLANT

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

Kidneys can come from two sources: either a living donor or from an anonymous donor who has died and donated their organs. Many people receive kidneys from anonymous donors, however, a kidney from a living donor offers the recipient a better chance for a long functioning kidney. Examples of potential related donors may be the recipient’s parents or siblings. These relatives will often share more inherited genetic characteristics with the recipient. It is also possible to have a non-related person, for instance a friend, step forward and be interested in donating their kidney. Whatever the case may be, all potential donors undergo careful evaluation and consideration by the transplant team.

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

Ages of donors may range from 18 to 60 years old. It is a federal law that a person be at least 18 years old to donate. People nearing or over 60 years of age may be considered a potential donor on an individual basis depending on their health status. Some conditions that would exclude someone as a donor would be high blood pressure, diabetes, or test positive for the AIDS virus.
**WILLINGNESS TO DONATE**

Some donors decide to be considered for donation immediately while others need time to consider such things as family, work, and financial circumstances. We encourage parents or significant others to participate in the transplant interviews and to learn as much as possible about the transplant/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 donor is 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.

<table>
<thead>
<tr>
<th>Recipient Blood Type</th>
<th>Compatible Blood Type of Donor</th>
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<tbody>
<tr>
<td>Type O</td>
<td>Type O</td>
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<tr>
<td>Type A</td>
<td>Type A, O</td>
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<tr>
<td>Type B</td>
<td>Type B, O</td>
</tr>
<tr>
<td>Type AB</td>
<td>Type AB, A, B, O</td>
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</tbody>
</table>

In addition to having a compatible blood type, recipients and donors (both cadaver and living donors) also undergo tissue typing and crossmatching. Tissue typing is a blood test that is done to determine the chromosomes that your child received from each parent. The tissue type of your child is then compared to the tissue type of the donor. It is helpful to have some identical chromosomes between recipients and donors but not essential to have this match for the transplant to be successful. Crossmatching is also a blood test that is done to determine whether your child’s immune system will react to their new kidney.

This test is done by mixing your child’s blood with blood taken from the donor to see if a reaction occurs. If no reaction occurs, this is called a negative crossmatch and means that your child will be able to accept a kidney from that donor. If a reaction occurs, this is called a positive crossmatch and means that if your child received a kidney from that donor, there would be an immediate reaction (in the operating room) causing the donor kidney to fail immediately. It is essential for the crossmatch between the recipient and the donor to be negative in order to have a successful transplant.

**FINANCIAL**

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 who are 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 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 kidney transplantation. The medical director coordinates the overall functioning and policy making of the kidney 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 will be discussed. Other transplant medical staff members may be caring for your child during their transplant hospitalization. These attending physicians have had extensive training in Nephrology and supervise fellows and house staff physicians. A fellow is a pediatrician who is specializing in Nephrology 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 kidney 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 the necessary arrangements at the time of transplant including contacting you about an organ being available, arranging for OR 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.
- Do 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 specialize in the psychological issues associated with chronic illnesses and disease. They work directly with children and families and provide consultation to the medical team. New patients are seen by a psychologist 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 your request. Other services they provide:

• 24 Hour On-Call Service by calling 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.

**REFERRAL PROCESS**

In general, referrals are received by the transplant coordinators or transplant nephrologist from the patient's primary physician/nephrologist or insurance 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 are 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 kidney 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 kidney 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 will 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 kidney wait list or scheduling a date for a living donor transplant will not be made until the evaluation process is completed on both the recipient and donor.
**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
THE TRANSPLANT EVALUATION

The evaluation process for a kidney transplant usually takes place over two days as an outpatient. During the evaluation, your child will be seen by several physicians and transplant team members. A schedule is mailed to your home listing your appointment dates, times and locations. The following tests are done during an evaluation to find and treat problems before transplant:

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

- **Tissue Typing and Crossmatching (special blood tests)** – determines your child’s genetic tissue type, whether or not your child has antibodies to certain tissue types, and compatibility of your child’s kidney to other kidneys – either a cadaver or living donor’s kidney.

- **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.

- **Chest and Bone X-rays** – 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. The bone x-ray shows how well your child is growing.

- **Voiding Cystourethrogram (VCUG)** – A x-ray to look at how the urine flows through your child’s kidneys and how well your child’s bladder expands and then empties the urine.

- **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 developmental level. For children and teenagers, school performance, emotional, and social development are evaluated.

- **Visits** with the transplant surgeon, kidney doctor (nephrologists), transplant nurse coordinator, psychologist, social worker, financial coordinator, dietician and child life specialists.

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

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

**LISTING INFORMATION**

If a living donor is not available then your child will be placed on a nationwide waiting list with UNOS, which stands for “United Network for Organ Sharing”, for a cadaver donor kidney. The normal wait time on the transplant list may be from several days to several months. Your transplant coordinator will notify you when the team is ready to list your child.

**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 transplant waiting list, your child will continue to see their nephrologist as usual for regularly scheduled visits. Your child’s transplant coordinator may 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 nephrologist regarding treatment. Also contact your transplant 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, etc., will need to be arranged if possible with the transplant coordinator in the event a donor kidney 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 kidney 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 kidney 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 kidney 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 kidney becomes available, the St. Louis Children’s Hospital Transport Team will make arrangements to bring your child to our hospital.
THE ACTUAL TRANSPLANT

Transplant can occur two ways. If a living donor is available, the transplant is scheduled and the date is known. If you are waiting on the waitlist, the kidney will come from a cadaver donor. Depending on which type of transplant you are having, living donor or cadaver, the transplant instructions may differ.

If you have a living donor available and both evaluations are completed, you will have a date scheduled for the transplant. The day prior to the scheduled date, both the donor and recipient will be admitted. The donor will be admitted to Barnes-Jewish Hospital for their surgery and postoperative recovery. The recipient will be admitted to the transplant surgery floor at St. Louis Children’s Hospital for their surgery and recovery. Once on the floor, final labs are sent and testing is done to make sure that neither person is currently ill. The donor and recipient will begin a clear liquid diet starting at lunchtime and will then have nothing to eat or drink after midnight. The transplant will be the first case in the morning and will go to the OR around 7:00 a.m.

If you are on the UNOS waiting list, and no living donor is available, the date of the surgery is unknown. The transplant depends upon an available organ. 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 (bold). 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, including a crossmatch, x-rays taken, and a visit from the anesthesia doctor in order to prepare quickly for the upcoming transplant. The transplant surgery physician 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. They will also explain the operation to you and your child and ask a parent and/or guardian to sign surgery consent and blood administration forms.

Rarely, your child could be called in for transplant but then have the blood crossmatch between the recipient and the donor be positive, meaning that the organ is not compatible with the recipient. Or possibly, upon retrieval of the organ, the surgeon determined that the organ was not suitable. If the decision is made not to proceed, the recipient is sent home to continue waiting. When this occurs, this is referred to as a “dry run”. Your child’s position on the transplant waiting list will not change as a result of the cancelled transplant.

TRANSPLANT SURGERY FLOOR

Kidney transplant patients will be admitted to the transplant surgery floor following their transplant. This floor specializes in caring for kidney and liver transplant patients as well as general surgery patients.

When surgery is completed, your child will return to the transplant surgery floor and receive one-to-one nursing care. This means that one nurse will take care of your child for an entire shift and only have your child as a patient. After approximately two days, your child will no longer need this intensive nursing care and your child’s nurse will have additional patients to care for.

Very rarely, some children, especially younger children ages 2-5 years, may be required to stay in the Pediatric Intensive Care Unit (PICU) for a few days following their transplant instead of going to the transplant surgery floor. This is due to the large amount of IV fluids that are being given and the need for closer monitoring in this age group.
Our usual protocol the first three months 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)
- Wound care and dressing changes
- Central Line Care (see page 13)

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 kidney 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.

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”.

CENTRAL LINE PLACEMENT

At the time of your child’s transplant, a central line (Broviac or Hickman) catheter may 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.
GENERAL POST-TRANSPLANT 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. Generally, we allow our patients to return to school one month post hospitalization, however, every child has different medical situations so please check with your child’s nurse coordinator. When your child does 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 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 Consult for names of physicians or hospitals.

TRANSITIONING TO AN ADULT CENTER

Once your child turns eighteen 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 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](http://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 two)
- 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.
Diet and Nutrition

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 OR AVOID:

- 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
- low fat, low-salt snack foods—unsalted pretzels, air-popped popcorn, rice cakes
- low-fat, low-salt baked goods—angel food cake, graham crackers, fruit cookies, gingersnaps, fortune cookies

LIMIT:

- high-fat, high-sugar baked goods – Danish pastry, croissants
- salted chips, cheeses or butter crackers
- seasoned pasta and rice mixes

For Milk, Cheese and Dairy Products, Choose more of:

- skim or 1% milk
- evaporated skim milk, or nonfat dry milk powder
- yogurt
- low-fat, low-salt 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
• homemade or low-sodium canned soups, bouillons and broths
• low-sodium vegetable juices

**LIMIT:**
• coconut
• deep-fat fried vegetables
• pickles and olives

**For Fat, Choose:**
• 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
• salted nut snacks

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

**LIMIT:**
• ice cream
• chocolate
• doughnuts, pastries, cakes, cookies, and pies unless prepared with low-fat and low-salt 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 meal-times. 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.
• 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.
• 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.

LOW SODIUM DIETS

Sodium helps with nerve activity, muscle contraction and fluid balance. Everyone needs some sodium, but since sodium is found naturally in foods, most people consume more sodium than they need. This means that you may need to make some dietary changes such as:

1. Restrict your use of table salt.
   • Do not add salt to your food.
   • Do not add salt to your food while cooking.

2. Avoid high-sodium foods. Some of these foods are:
   • ham, bacon, sausage, cold cuts, cheese
   • potato chips, pretzels, corn chips, salted nuts and pickles
   • soups, ketchup, mustard, relishes, steak sauces, canned/packaged foods

3. Read food labels carefully (watch for the words “sodium”, “salt” and “soda”).
   • If the label says a certain food has more than 200 mg sodium per serving, you need to limit your intake of this food.
   • If the label says a certain food has less than 100 – 150 mg sodium per serving, this is considered a “low-sodium” food.
• Avoid regular canned soups or soups made from dry mixes. Buy low-sodium or make your own at home without salt. Use low-sodium broth, bouillon or consommé instead of the high-sodium kinds.

• Many stores now have low sodium breads, canned vegetables, canned fish, cheeses, crackers, salad dressings, soups and snacks.

• Only buy frozen dinner meals that have less than 400 mg on the nutrition facts label.

• Regular cheese contains a medium to high amount of salt. If you eat cheese buy low-sodium kinds as often as possible. Add only 1/3 – 1/2 the amount listed in the recipe.

• Check labels of medicine for sodium content. Ask your doctor or caregiver if you are not sure before taking a medicine.

• Buy fresh or frozen vegetables to use in cooking instead of canned vegetables. Buy only low sodium canned tomato products.

• Avoid or use only small amounts of cooking wines or sherries made with salt.

**Why do I need to cut down on salt?**

Although a small amount of sodium (about 500 mg) is essential to normal body functions, it is estimated that the average person consumes 4,000 to 5,000 mg a day. It is widely believed that a large amount of dietary sodium could result in high blood pressure (also called hypertension) and may lead to heart attack, stroke or kidney failure.

Because we get most of our dietary sodium from salt, health professionals are advising us to eat less salt.

**Salt In Our Food**

• Saltiness is an acquired taste. It’s estimated that about 1/4 of our sodium in-take comes from salt we add to food in the kitchen. We sprinkle it from the shaker at the table, add it to cooking water, and add to other dishes while preparing them.

• Salt is added, often in large amounts, to processed or prepared convenience foods such as soups and salad dressings, canned or dry dinner mixes, packaged cookies and crackers, bouillon, sauces, condiments and dessert mixes. Many canned vegetables are also seasoned with salt.

• Pickled foods such as sauerkraut, olives, relishes, dills and gherkins are packed in vinegar and/or brine (heavily salted water), making them exceptionally high in sodium.

• Cheeses contain salt for preserving as well as for flavor.

• Smoked or canned meat and fish products as tuna, ham, bacon, cold cuts, corned beef and sausage are well seasoned with salt. Deli roast beef and turkey breast are often cooked with salt.

**Sodium Is Also Found Naturally In Foods**

Nearly all foods contain some natural sodium. A few foods may be limited on a medically prescribed diet because of their relatively high levels of natural sodium. As a rule, however, the amount of sodium contained in unseasoned, non-processed foods is low.

Sodium is a part of many other ingredients added to prepare foods that often have no salty taste. Some are used in amounts that add a significant amount of sodium to the final product.

• Monosodium glutamate (MSG)…a flavor enhancer

• Baking soda (sodium bicarbonate)…used to make quick breads and cakes rise.

• Sodium nitrate…a curing agent for meat.

• Sodium saccharin…an artificial sweetener

• Sodium propionate…a mold inhibitor found in baked foods

• Sodium citrate…an acidity controller found in soft drinks, fruit drinks, jams and jellies.

**What do food labels tell about sodium content?**

If a nutrition label is not available, you can check the ingredient statement for the presence of salt or other sodium compounds. Ingredients are listed in descending order by weight, but since the specific weights aren’t listed, it only gives you a rough idea of the amount of sodium. Your best bet is to buy only those items with a nutrition label. The Food and Drug Administration has also established the following guidelines for sodium claims.
**Sodium Free** food contains less than 5 mg sodium per serving.

**Very Low Sodium** food contains 35 mg sodium or less per serving.

**Low sodium** food contains 140 mg sodium or less per serving.

**Reduced Sodium** food contains 25% less sodium than original item.

**Light in Sodium** food has 50% less sodium than original item.

**Unsalted, No Salt Added** or **Without Added Salt** is used only if no salt is added to a food that is normally processed with salt.

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**Sodium Watch**

The following is a list of foods that tend to be high in sodium. Check labels to be sure; some may be sodium-reduced.

- Anchovies
- Bacon
- Baking Soda
- Bouillon Cubes (Chicken, Beef or Vegetable)
- Canned Soups
- Canned Tuna
- Canned Vegetables (unless they’re “no salt”)
- Cheese
- Cold Cuts (unless low salt)
- Condiments
- Cooking Sauces
- Cottage Cheese
- Croutons
- Gravy
- Ham
- Hot Dogs
- Olives
- Pickles
- Salad Dressings
- Salsa
- Sausage
- Sea Salt (same amount of sodium as table salt)
- Soy Sauce
- Spaghetti Sauce
- Tomato or Vegetable Juice
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 to give 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:

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.

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

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. Refer to sections on Diet and Nutrition.
• 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 14).
• 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.

**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, 400 mg, and 800 mg 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.
- **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:**
- 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 450 mg 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.

**DIFFUCAN (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 blood stream.

**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-HYPERTENSION/ 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.
- High blood pressure should improve within 15 minutes after a dose of Norvasc is given. If there is no improvement when the blood pressure is re-measured, call the child’s doctor.
- Children on Norvasc 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.

**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 two months.
- 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>
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</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 90 days.

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.

MEDICATIONS GIVEN FOR TREATMENT OF REJECTION

THYMoglobulin® (Antithymocyte Globulin – Rabbit)

Thymoglobulin is similar to ATGAM. It 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, deceased 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.

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.
If you have any questions about your child’s care after you leave the hospital, please contact one of the transplant nurse coordinators during daytime hours (8 a.m. – 5 p.m., Monday through Friday). After hours, weekends, or holidays, then please call the hospital operator at 314.454.6000 and ask to speak to the kidney doctor on call.

Some things to call the transplant nurse coordinators about are:

1. **Unexplained fever:** temperature above 38.5°C or 100.0°F
2. **Rejection:** Signs and symptoms of rejection include: fever, rapid weight gain, swelling and tenderness over kidney, swelling of eyelids, hands or feet, decreased urine output, general ill feeling
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
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. **Mouth sores or skin rashes**
9. **Diarrhea:** loose, watery stools and/or more than six stools per day
10. **Vomiting:** Including not being able to keep down medications

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 daytime hours, call the renal MD on call at 314.454.6000.

**WHAT TO REPORT**

**READMISSION TO THE HOSPITAL**

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.

**READMISSION**

- **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**

**To The Hospital**
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**

Surgical complications after kidney transplant include but are not limited to graft non-function, and post-operative bleeding/hemorrhage.

**PRIMARY GRAFT NON-FUNCTION**

Primary graft non-function is a very rare but life threatening complication. For unknown reasons, the new kidney 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 start dialysis.

**POST-OPERATIVE BLEEDING**

If your child is going to develop post-operative bleeding, this would most likely occur within the first 48 hours following transplantation. Signs of bleeding include a rapid or ongoing drop in hemoglobin and hematocrit, increased heart rate and low blood pressure. If there is a large amount of bleeding, your child will need to be taken back to the operating room so the surgeon can find the cause of bleeding and stop it. Your child may require 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 kidney is a very serious complication if it occurs. Infants and small 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. Signs of blood vessel thrombosis include severely decreased or no urine output and an increased creatinine and BUN. If these symptoms occur, 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, resulting in loss of the kidney.

**UROLOGIC COMPLICATIONS**

There are 2 types of urologic (urinary tract) complications that can occur with kidney transplantation. First, are urine leaks. A urine leak can occur from either the bladder (due to rupture from over distention) or at the site where the new kidney ureter is connected to the bladder. Leaks resulting from bladder rupture are very rare as your child will have a Foley (urinary) catheter in place which continuously drains urine from the bladder, preventing over distention. Urine leaks that occur at the site of the ureteral anastamosis must be surgically repaired. Signs of a urine leak include decreased urine output, lower abdominal tenderness, abdominal distention, elevated creatinine and BUN, and fever.

The second urologic complication that can occur is an obstruction or stenosis of the ureter. This most often occurs at the site where the new kidney ureter is sewn onto the bladder. It may also be due to compression from a lymphocele (see section on Lymphocele). It can occur early or late in the post-transplant period. Signs of a ureter obstruction are decreased or no urine output and an elevation in the creatinine and BUN. If obstruction is suspected, an ultrasound may be performed which would show a dilated ureter and swollen kidney...
(from urine backing-up in the kidney) above the stenosis with marked narrowing at the site of stenosis. A cystogram may be performed in order to place a stent across the narrowed area; sometimes surgery needs to be performed.

**LYMPHOCELE**

Throughout the abdomen, there are small drainage systems called lymphatics which drain lymph fluid. During kidney transplantation, these lymphatics get severed but are usually sewn over or cauterized. In some cases, the lymphatics begin leaking, causing a pooling of lymph called a lymphocele. Small lymphoceles usually do not cause a problem and are reabsorbed with time. Large lymphoceles, however, can cause the following problems: obstruction of the ureter due to compression of the ureter by the lymphocele, abdominal distention, swelling of the lower extremity on the same side the kidney was placed, or obstruction of the kidney blood vessels. If a lymphocele is suspected, an ultrasound may be obtained which would show the fluid collection. If the lymphocele is large enough to obstruct the ureter or blood vessels, the lymphocele will need to be drained.

**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 he/she is 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 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. 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 is 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 always treatable by adjusting your child’s current immunosuppressant medications or by adding additional medications.

BIOPSIES

A kidney biopsy is a procedure that is performed after transplant to determine if your child has rejection. The procedure is performed in the Ambulatory Procedure Center with IV sedation so your child does not remember the procedure. Your child will be admitted to the hospital overnight after the procedure for observation. Biopsy results are usually available within 24 hours. Once the
pathologist (which is a physician that specializes in looking at cells and tissue samples under a microscope) determines the level of rejection your transplant team will determine what type of treatment is necessary. Treatment can range from switching the medicines you take by mouth to spending several days in the hospital requiring strong IV medications. There are two types of rejection, acute and chronic. Both types can be determined by a biopsy. Chronic rejection is usually seen years after receiving your transplant but may occur earlier. It is a slow, progressive deterioration (scarring) in the kidney. There is no treatment for chronic rejection and it may persist for a long period of time.

SEIZURES

A frequent and often worrisome side effect of some immunosuppressants is tremor. Tremors are an uncontrollable trembling or shaking of the limbs which is 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 usual 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. Often the anti-seizure medicines can be stopped after several months.

GENERAL RENAL COMPLICATIONS

Your child will be in the hospital between five and nine days after his/her kidney transplant. A number of complications are possible after surgery that may make your child’s stay longer. There is no way to predict which patients will have which problems. The most common complications are rejection and infection. Your child’s transplant team will do their best to reduce your child’s chance of having complications and to treat them right away. Some of these problems may include but are not limited to:

- **Delayed graft function or ATN** (acute tubular necrosis): In this case the new kidney does not immediately “wake up”, and it shuts down its ability to clear waste products. You may temporarily need dialysis. This acute renal failure is different from chronic renal failure in that the kidney is not scarred and will recover. This recovery may take days to weeks.

- **Hypertension or high blood pressure** This is very common after kidney 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 your child needs to take after the transplant. Sometimes blood pressure will return to normal before going home, but if not, there are many different medications that are available to treat hypertension.

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 6 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 drugs 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 6 – 12 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 an exercise program after transplant, with permission from your child’s transplant team. We encourage exercise and have never “lost” an organ due to activity. Your child’s transplant team is comprised of a dietician who is available to 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. Cyclosporine and Tacrolimus inhibit 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

COMMUNICATING WITH 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 the public awareness of St. Louis Children’s Hospital (SLCH) and its role in the community. In order to manage pediatric media relations successfully, there is a delicate balance between coordinating interviews and information from patients, parents, physicians, and SLCH employees while maintaining a high level of privacy and adhering to our mission to “Do what’s right for kids”.

One of the concerns of the hospital is to protect the health, legal rights and general welfare of its patients. Patients have specific legal rights to privacy concerning medical information. To ensure patient privacy and confidentiality, we require a media relation’s staff escort anytime the media come into SLCH to film 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 station(s) would like to film/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.
RESEARCH AND
PATHWAYS TO THE FUTURE

St. Louis Children’s Hospital and Washington University School of Medicine 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 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 consent 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 8 to 12 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.
GLOSSARY

A

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.

Anastamosis 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

Cadaver 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.

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**

**Dexascan** 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.

**Drain** 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.
**J**

**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/also obtain necessary referrals for insurance from PCP office.

**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.

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.


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.
**CONVERSION TABLES**

**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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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

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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.

<table>
<thead>
<tr>
<th>Date</th>
<th>WBC</th>
<th>Hemoglobin (HGB)</th>
<th>Hematocrit (HCT)</th>
<th>PLT (Platelets)</th>
<th>Sodium (Na)</th>
<th>Potassium (K)</th>
<th>Chloride (Cl)</th>
<th>CO₂</th>
<th>Glucose</th>
<th>Creatinine</th>
<th>BUN</th>
<th>Calcium (Ca)</th>
<th>Phosphorus (Phos)</th>
<th>Magnesium (Mg)</th>
<th>Tacro Level</th>
<th>Sirolimus Level</th>
<th>Weight</th>
<th>Height</th>
<th>Blood Pressure</th>
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