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INTRODUCTION

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

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

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

IMPORTANT PHONE NUMBERS

Children's Medical Center Dallas Main Number.....	214-456-7000
Kidney Transplant Clinic.....	214-456-8600
Kidney Transplant Office FAX.....	214-456-6467
Toll Free Number.....	800-846-6768

Transplant Clinic Location:

Solid Organ Transplant (SOT) B2300

Children's Medical Center of Dallas
1935 Medical District Drive
Dallas, Texas 75235
Phone 800-846-6768 or 214-456-8600
Main Fax 214-456-8405

Office Hours:

****Monday through Friday 8:30 a.m. until 4:30 p.m. ****

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

**IMPORTANT TIMES TO CONTACT THE KIDNEY
TRANSPLANT COORDINATOR**

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

- ◆ Fever above 100 F
- ◆ Continuous vomiting or diarrhea (more than 4 diarrhea stools in a 24-hr period)
- ◆ Cough that does not go away
- ◆ Decreased urine/pee
- ◆ Flu-like problems (weakness, tired, muscle aches, mucous or runny nose)
- ◆ Pain, tenderness or swelling over the surgery site
- ◆ Red or brown urine/pee
- ◆ Pain or burning during urinating/peeing
- ◆ Frequent urinating/peeing
- ◆ Severe headaches
- ◆ Rash (in one area or all over)
- ◆ Chicken pox or measles
- ◆ Exposure to people with chicken pox or measles (classmates or family member)
- ◆ Sudden weight gain or puffiness

The One for Children.....The One for Transplant

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

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

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

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

Kidney Transplant

More than 400 pediatric kidney transplants have been completed at Children's since the program started in 1980. Children's has constantly been a leader in the number of pediatric kidney transplants performed in Texas.

Liver Transplant

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

Intestinal Transplant

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

Heart Transplant

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

THE TRANSPLANT TEAM

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

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

Pediatric Nephrologists (Kidney Doctors)

The transplant nephrologists are pediatric kidney specialists with expert knowledge in kidney transplant. They will work with your child's primary pediatrician(s). After kidney transplant, the transplant nephrologists will become your child's kidney doctors. They will manage your child's kidney care, and will work closely with you and with your child's pediatrician to be sure all your child's medical needs are met.

Transplant Surgeons

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

Transplant Nurse Practitioners and Physician Assistants

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

Transplant Coordinators

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

Financial Coordinators

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

Social Workers

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

Psychologists

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

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

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

Dietitians

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

Transplant Pharmacist

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

Care Teams

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

Child Life/Child Development Specialists

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

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

Chaplains

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

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

Other Staff Members

Many other specialists trained in pediatrics will help care for your child. These specialists include pathologists (doctor that looks at body tissue under microscope), radiologists (x-ray doctor), infectious disease doctors (germ doctor), cardiologists (heart doctor), respiratory therapists (breathing specialist), and physical and occupational therapists (body movement specialist).

Other staff members, such as interns and residents (doctors in school), often are with your doctor on rounds. These are graduate, licensed doctors who are getting more training in specialized medical or surgical skills under the supervision and direction of the transplant team.

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

BASIC KIDNEY FUNCTION

Key Points:

- *How the kidney works*
- *What are the reasons the kidney stops working*
- *What happens when the kidney fails*
- *Treatment options for kidney failure*
- *Signs of high blood pressure*

Beginning with the Basics

Normally, a person has two kidneys. It is possible for just one kidney to do all of the basic functions for the body.

Your kidneys have many jobs:

- ◆ Controlling of the production of red blood cells. This is done by the kidneys releasing a hormone called erythropoietin.
- ◆ Helps control blood pressure
- ◆ Controls fluid balance by removing extra water as urine
- ◆ Filters waste products (toxins) such as BUN and creatinine by mixing them in excess water and getting rid of them in urine
- ◆ Controls balance of minerals like calcium, phosphorus, sodium and potassium
- ◆ Helps keep strong bones by converting vitamin D to a useable form
- ◆ Control of the amount and type of fluid in the body

Why the kidney stops working

Damage from:

- ◆ Congenital deformity (kidneys are not formed right before birth)
- ◆ Repeated bladder or kidney infections (Urinary Tract Infections)
- ◆ Blockage or Clog preventing kidneys from draining urine
- ◆ Inflammatory diseases that harm the immune system (i.e., Lupus, Focal Segmental Glomerular Sclerosis-FSGS)
- ◆ Injury to the kidney or urinary tract

What happens when the kidneys fail?

When kidney function (working) stops or decreases, there is a buildup of waste products (toxins) and extra fluid in the body. This can be harmful to the body. Your child can have heart rhythm problems, blood pressure problems, and get puffy looking. After a loss of about 85% of kidney function, other ways to get rid of the waste products and fluids is needed. Dialysis and kidney transplant are two treatment options for chronic kidney failure. Dialysis is a machine that is connected to your child and cleans their blood. It filters (cleans) the blood of waste products and extra fluid. Your child may have to have a graft (surgical connection of two vessels under the skin that is used for dialysis) or catheter (large IV tube) placed in their body to attach the dialysis machine. Your child maybe on dialysis now and may need dialysis after transplant.

KIDNEY TRANSPLANT EXPLAINED

Key Points:

- *What is a Kidney Transplant?*
- *Where do kidneys come from?*
- *How long have kidney transplants been performed?*
- *The Good and Bad of getting a Kidney Transplant*
- *The decision of transplant*
- *Who pays for a Transplant?*

What is a Kidney Transplant?

Transplant is the surgical placement of a healthy kidney from a human donor into your child's body. If successful, the donor kidney should take over the functions (job) of the diseased (sick) kidneys. A successful transplant may improve your child's energy level and get rid of the need for fluid limitations and dialysis.

Where do kidneys for transplant come from?

A kidney for transplant can come from two sources:

1. A living donor can be either a person who is closely related to your child (living related or LRD), or a person who is not related by blood (living unrelated or LURD), but who has a strong emotional bond with the recipient.
2. A deceased donor is a person who has recently died, and the family has agreed to donate the organs for transplant.

How long have kidney transplants been performed?

The first successful living donor kidney transplant was performed in the United States in 1954 between identical twins. The first successful deceased donor kidney transplant was done in 1962 which was also the first transplant to use immunosuppressive medications to prevent rejection.

What are the advantages of kidney transplant?

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

- ◆ Likely to have freedom from dialysis
- ◆ Corrected symptoms of uremia (general feeling of tiredness, nausea, vomiting)
- ◆ Improved quality of life
- ◆ Fewer diet and fluid restrictions
- ◆ Improved growth (when on low dose steroids)

What are the disadvantages of kidney transplant?

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

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

Who can qualify for a transplant?

At Children's Medical Center Dallas, we believe that kidney transplant is the treatment of choice for children with end stage renal disease. Here are some *guidelines* we use:

- ◆ Any child who has chronic kidney disease, that is not reversible or changeable, is able to be *considered* for kidney transplant.
- ◆ Your child must weigh *at least* 10 kg which is around 20 pounds.
- ◆ Children under the age of 2 do not do well with deceased-donor transplants. Children under 18 months of age are not considered to be good candidates for live donor transplant.
- ◆ You should talk about transplant with your doctor. For some children, transplant may not be the best treatment option. There may be other medical conditions that put transplant on hold until a later time. Waiting a few extra months may offer a better outcome in some cases. Timing is everything. **The first transplant your child receives usually has the best overall outcome.**

Is dialysis necessary/needed before the transplant?

Each child is different. If there are signs that kidney disease will worsen and your child is close to dialysis, it is possible for your child to be evaluated for transplant before beginning dialysis. There are some situations where transplant is possible without dialysis. Your transplant team will work with you to decide the best plan of care for your child.

What starts the transplant process?

- ◆ Talk with the doctor caring for you.
- ◆ If it is decided that transplant is the treatment of choice, the transplant office will be notified by your doctor.
- ◆ Financial and insurance approval

This process can take a short time or many weeks. You will be kept informed of the progress of your application by the transplant office.

Who pays for transplant?

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

Each child is different. In general, Medicare, Medicaid, and most insurance plans cover the cost of transplantation for the recipient. The coverage for the cost of a living donor and/or the kidney from a deceased donor depends on the individual insurance policy. If the child is eligible for Medicare through his/her parent, the donor evaluation will be covered as long as the correct premiums are paid. A Financial Counselor or your Social Worker is available to help you through this involved process.

It is important to know that it is illegal to buy or sell kidneys or any other organs. The donor receives coverage for the medical expenses of the donation. However, the donor is not given money for time off work, lodging/housing, meals, travel or other expenses of daily living. We will work with the living donor's employer to be sure that all available benefits are used. Most employers understand when employees need time off to donate a kidney.

Will my child be involved in research?

Children's Medical Center Dallas is one of the leading pediatric kidney transplant research centers in the United States. Clinical research is the reason that there has been improvement in patient and graft (transplanted organ) survivals.

You may be asked to participate in a research. This is voluntary. Whether or not you choose to participate will not affect your child's medical or nursing care.

THE TRANSPLANT EVALUATION

Key Points:

- *The steps of the transplant evaluation process*
- *There are many tests that are a part of the transplant evaluation*
- *What happens to your child's kidneys during the transplant process*
- *A committee reviews the test results to see if transplant will be an option for your child*
- *The tests that help match your child to a donor*

What are the steps of the transplant evaluation?

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

1. *Medical, Surgical, Psychologist and Social Work Evaluation:* The child will have a complete medical, surgical and psychological evaluation including medical history, physical exam and a series of tests to decide if your child is healthy enough both physically and mentally to receive a kidney transplant. The time it takes to complete this evaluation depends on the child's dialysis schedule and when testing can be scheduled. If other medical problems are found, then more tests or meetings with other doctors may be needed.
2. *Tissue Typing / ABO Blood Type:*
 - ◆ *Tissue Typing* is a *blood* test, (not a sample of tissue). Blood is taken from the child; these special blood tests are used to find out the child's HLA antigens (genetic make-up).
 - ◆ *ABO Blood Type* determines blood group compatibility. The child and the donor must have *compatible* blood groups. Compatible means able to work together well.

These are important tests used in both living related and deceased donor. This information is put into a computer database (UNOS) and is used to match your child with the best possible donor.

3. *Presentation to the Transplant Selection Committee:* After your child's evaluation is complete, the evaluation and consult results are presented to the Transplant Selection Committee for final approval. After approval, the patient will be registered or "listed" with the United Network for Organ Sharing (UNOS), the national wait list for all patients awaiting organ transplant.
4. If a living-related donor is found, their work up will begin once the patient has been listed.

What tests are done as part of the evaluation?

- ◆ Blood tests to look for viruses. A virus test may come back positive because the child has been exposed to the virus.
- ◆ A chest x-ray to see if your child has any lung problems. This is a black and white picture that shows the shape and size of the heart and lungs. This test only takes a few minutes and it is not painful.
- ◆ A heart evaluation including EKG, echocardiogram and a visit with a cardiologist (heart doctor) is done to see if there are any problems in the way your child's heart works. EKG looks at the electricity that is happening in your child's heart. Echocardiogram is an ultrasound that shows a picture of the heart pumping blood. This procedure does not hurt and takes 20-40 minutes. Your child must be still during the test. If your child cannot lay still, then medication to help them relax or sleep maybe given.
- ◆ A voiding cystourethrogram (VCUG) is a special x-ray done to look at the urinary drainage or "pee" system including the bladder (organ that holds urine) and ureters (the tubes that carry the urine from the kidney to the bladder). During this test, a small catheter (tube) will be inserted into the bladder and a special dye will be put into the bladder. The test will evaluate the bladder (size, shape and how much it can hold) and show if urine backs up into the kidney during peeing, this is called reflux. If a problem is discovered, further tests may be needed.
- ◆ A sonogram of the kidneys is an imaging study where a transducer (similar to a microphone) is moved across your child's skin to the determine size, and physical structure of the kidneys.
- ◆ An exam by an urologist (a doctor that specializes in the care of the urinary or "pee" system). He will also look at the results of the VCUG and sonogram.
- ◆ Urine tests include a culture (looking for infection/germs) and a 24-hour urine collection (to measure remaining kidney function). The urine will be sent to the lab to see if there is any infection. A 24-hour urine means to collect your child's pee over a 24 hour timeframe at home.
- ◆ An eye exam by an ophthalmologist (eye doctor).
- ◆ A dental exam to look for any possible dental problems that would need to be fixed before to transplant.
- ◆ Immunization and your child's past disease history are important for the transplant team to know. Immunization records and dates of measles, mumps, chicken pox, etc. (if your child has been vaccinated) are important. If immunizations are not up to date, you will be required to complete them prior to active status 1 listing. **Once transplanted, the child cannot receive any live virus vaccinations** (such as the chicken pox, measles, mumps, or rubella vaccines).
- ◆ A pap smear for young ladies only if sexually active.

What is the role of the Kidney Transplant Selection Committee?

The Kidney Transplant Selection Committee is made up of pediatric nephrologists (kidney doctors), transplant surgeons, transplant coordinators, dietitians, social workers, psychologists, child life specialists, chaplain and other members of the multi-disciplinary team. As a group, they review the transplant evaluation information to decide if transplant is the best treatment option. The committee may make further suggestions if any concerns are found during the evaluation process.

What happens to the patient's native or their own kidneys?

Your child's kidneys are not removed unless there is a medical or surgical reason to remove one or both. Your doctor may recommend that one or both kidneys be removed either before transplant or at the time of transplant. This is done only if there are medical problems related to kidney disease (high blood pressure, repeat urinary tract infections, high urine output, etc.) that are not controlled with other treatment.

What is Tissue Typing?

Tissue typing is done by drawing a sample of your child's blood to identify blood type, (called ABO typing) and to identify the small proteins that are called antigens, (known as HLA typing). *Tissue Typing (or HLA Typing)* [**H**uman **L**eukocyte **A**ntigen] identifies the antigens that a child inherits from their birth mother and father. The mother and father each have two sets of antigens, any children will receive one set from each parent, but siblings may not receive the same set as each other. This may mean that siblings could match completely, partially or not at all. Any person wishing to donate must have an ABO type and tissue typing done to determine compatibility (or matching) with your child. Tissue typing and ABO typing are also done on deceased donors.

What are Antibodies?

An antibody is a protein that is made by the blood when a substance unknown to the body is exposed to or infects your child. This can happen through blood transfusions, previous transplants, or pregnancy. Antibodies are a part of the rejection process.

What is a "High Reactor?"

Antibody screening is a blood test to decide if your child's immune system is reactive, and can be used to forecast the percentage of antibodies. The higher the percentage of antibodies (high reactor), the longer it may take to find a compatible or matching kidney as the available "pool" becomes smaller.

What is a "cross-match" test?

Your child's blood and the donor's blood are mixed together in a tray. If the blood cells do not burst, it is called a negative cross match and the transplant may take place. If the cells burst, it is considered a positive cross match and the transplant cannot take place. A positive cross match means that the donor kidney would be attacked by your child's immune system. This is called rejection.

It takes about 4-5 hours to complete this test. This test will be done prior to any possible transplant. If your child is called in several times for a deceased donor kidney transplant, it will be done each time.

How do I know if a family member/friend can donate?

A family member/friend over the age of 18 can be considered as a potential donor. As discussed above, the first things to find out are:

- ◆ ABO typing or blood type
- ◆ Body Mass Index (BMI-looks at the relationship between height and weight)
- ◆ General health (smoking, drinking, overweight, diabetes, medical problems, etc)

What happens if no family member matches?

If there is not a family member who can donate, your child's name will be placed on the UNOS waiting list for deceased donors.

FINANCIAL AGREEMENT

Key Points

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

Transplants are life changing. It is a serious lifetime commitment and is expensive. The decision for transplant is a partnership between you, your child's doctors, and the transplant team. It is important to keep insurance coverage to support the cost of the transplant and for on-going care and medications.

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

Not notifying your transplant team of insurance changes can also change listing status. Please be aware that Children's Medical Center at Dallas is unable to pay for your medications. Your Transplant Financial Coordinator can help you in reviewing the other options to insurance plans.

THE LIVING DONOR

Key Points:

- *Requirements of the living donor*
- *Cost of a living donor kidney*
- *The many tests that the living donor may have done*
- *The risks for the living donor*
- *The surgery process for the living donor*
- *Side effects and life after donating*

Who will perform the pre-transplant evaluation on the potential donor?

The medical evaluation is done by UT Southwestern University Hospital - St. Paul in Dallas. Once it is determined the donor has a compatible blood type and the BMI (Body Mass Index) is acceptable, the donor's information is sent to a pre-transplant coordinator at UTSW – St Paul. **All appointments and results are coordinated by UTSW – St Paul.** When the workup/evaluation is completed, the donor is presented to UTSW Transplant Selection Committee. The committee decides if the donor is medically and mentally able to donate a kidney. The UTSW pre-transplant coordinator then presents their findings to Children's Transplant Selection Committee.

All donor evaluation/outcomes are communicated through the UTSW Donor Coordinator, NOT through Children's Transplant Coordinators.

What is expected of the potential living donor?

The potential donor must be willing to donate a kidney, be in good health (physically and mentally), have two *normal* kidneys, and must have a matching blood type with the recipient.

Who pays for the donor evaluation and hospitalization?

The donor evaluation and hospital stay are paid for by either your child's insurance policy, the ESRD Medicare program, or Medicaid. There is *no* cost to the donor. The donor does not receive any money for donating their kidney. The donor will be out of work for several weeks and will need to plan for lost time at work. This may be lost wages and transportation costs. Our financial counselor and social worker will help you with the financial side of your child's transplant regarding living donor coverage.

What tests are required for the donor?

- ◆ ABO (Blood Type) and tissue typing to determine blood & tissue *compatibility(matching)*.
- ◆ Body Mass Index (BMI) determination. The measurements used to determine BMI are height and weight. Age and gender may also be reviewed. It is important that the potential donor fall within a certain BMI range for the best possible outcomes.
- ◆ Blood and urine tests to find out if the donor has any illness that might prevent donation of the kidney.

- ◆ Medical history and physical exam to evaluate the general health of the donor. Anything abnormal found in the history or exam would need further work-up. Certain diseases, such as diabetes, high blood pressure, heart disease or cancer would prevent someone from donating a kidney.
- ◆ EKG: to determine the presence of any heart rhythm abnormalities.
- ◆ Psychological evaluation to examine the motivation of the donor and to provide support.
- ◆ Helico CT scan: is a special x-ray which is done to examine the anatomy and structure of the kidney and to look for cysts, tumors, etc.

What are the risks?

During evaluation:

- ◆ A possible problem with the Helico CT Scan is allergic reaction to the dye. (Helico CT is one of the last tests done during the evaluation process)

During and after surgery risks:

- ◆ Possible problems with anesthesia (medication used to put a patient to sleep)
- ◆ wound infection
- ◆ pneumonia
- ◆ bleeding
- ◆ DVT (deep vein thrombosis, such as a blood clot in the leg).
- ◆ Although the risk of death is extremely low, there have been reports of donor deaths in the past.

It has been shown that living kidney donors have a normal life span after donation. Some high contact sports (sky diving, motorcycle riding, bull riding) may cause an increased risk to a kidney donor. If the donor's remaining kidney is hurt in an accident or stops working they would not have a second kidney to take over. Women of child bearing age usually do not experience any difficulties during pregnancy, but should start prenatal care early.

How long does the evaluation take?

The length of time depends upon the donor's schedule, scheduling for the different doctor's appointments and whether additional testing is needed (if any results are found that are not normal). Testing and consultations are done on an outpatient basis. The results of each test are reviewed with the adult kidney doctor before going to the next appointment. If abnormal results are found during this process, the donor evaluation will be stopped until more information on the abnormality is complete. The donor evaluation process will take several visits to complete.

Do some people have a difficult time making the decision to donate a kidney?

Yes. Some people think about this issue for some time before making a decision. It is important to consider *all* of the facts about being a donor and to honestly evaluate your feelings. This can be done through talks with friends, family, and members of our transplant team.

What happens after the tests are completed?

When the tests are completed, we will schedule an appointment for the donor to meet the donor surgeon. If the donor surgeon agrees the donor is a good candidate, all results are shown to the Kidney Transplant Donor Selection Committee at UT Southwestern – St. Paul for discussion and approval. Once a potential donor is approved, a date will be set for the transplant.

How is the donor kidney removed?

The actual removal of the kidney will be done by a Transplant Surgeon, and will be done at the UTSW University Hospital at St Paul Dallas.

The kidney donation surgery (called a donor nephrectomy) .

Laparoscopic Technique

The laparoscopic technique uses many short incisions, or cuts, (approx. 1 inch) that are used to stick in a specialized camera and other surgical instruments allowing the surgeon to free the kidney from its surrounding tissues. At the end of the surgery, the kidney is taken out through a 3 to 4 inch cut in the lower abdomen or belly area. Because there are many small incisions, the surgeon is able to enter the belly area without having to divide the muscles. Recovery is usually faster and less painful. Normally, donors can be released from the hospital with in a few days. The donor still should not lift over 10 lbs. but can normally return to work in about 3 weeks.

The risk related with laparoscopic technique is that the surgeon has only limited control of the surgical area. Not everyone is a candidate to undergo laparoscopic donation. Your doctor or surgeon will decide if you are a candidate for this procedure, after looking at your evaluation test results.

Sometimes, blood transfusions have been needed during kidney removal.

When is the transplant surgery scheduled?

The scheduled date will depend upon the organization of many things:

- ◆ recipient's health
- ◆ donor's schedule
- ◆ availability & schedules of surgeons
- ◆ availability of operating rooms

The transplant office will work with you and the surgeons to schedule an appropriate date.

When will the donor be admitted to the hospital?

Admission will be in the morning, *the day of the scheduled surgery*. On admission, the donor will have blood work done as well as a chest x-ray and EKG. An IV will be started before surgery and the surgeon and anesthesiologist will visit with the donor.

Who takes care of the donor in the hospital?

The adult surgery team is responsible for the donor's care during this hospitalization. The nurses are specially trained to take care of adult kidney donors. The actual surgery will take place at the UTSW University Hospital at St Paul Dallas.

Do the donor and recipient go to surgery at the same time?

The donor usually goes into the operating room (OR) first (by about 1 hour), unless the recipient is going to have additional surgery (such as removal of the native kidneys), prior to getting the kidney from the donor.

How long does surgery take?

The donor's surgery usually takes about 3-4 hours. After surgery, the donor will go to the recovery room and will then be sent to a hospital room.

What happens after surgery?

After surgery, the donor may have:

- ◆ a nasogastric tube (a tube that goes into the nose) which goes down into the stomach to keep it empty (sometimes for a day or two)
- ◆ an intravenous line (IV) to give fluids until they can take fluids and food by mouth (usually a day or two)
- ◆ A catheter or tube in their bladder (Foley) to keep it empty and to measure urinary output.
- ◆ Stockings or tight socks on their legs to prevent blood clots.

The nurses will check the donor's temperature and blood pressure often, and encourage them to cough and take deep breaths to prevent pneumonia. They will be encouraged to sit up on the side of the bed the next morning and then up in a chair.

What about the incision(s)?

There are several small incisions. These can be closed with steri-strips (small white Band-Aid), sutures (strong surgical thread) and/or surgical glue (Dermabond).

How long is the hospital stay for the donor?

The average hospital stay for laparoscopic donation is usually 2-3 days.

Does the donor have any restrictions or limits after donation?

For the traditional "open" method, the donor will not be allowed to go back to work for 3-6 weeks depending upon the type of job they have. If laparoscopic donation is an option, time off work will be shorter. Restrictions may include:

- ◆ NO driving for 1-3 weeks after going home.
- ◆ NO lifting anything over 10 pounds for 6 weeks following surgery.

The surgeon will go over any other restrictions with the donor after surgery.

Does the donor take special medication or have a special diet after donation?

No. The donor is encouraged to eat a well-balanced diet, get plenty of exercise and practice a healthy lifestyle.

When can the donor travel a long distance in a car?

The donor may ride as a passenger in a car as long as they are comfortable. This should be discussed with the surgeon and exact instructions can be given.

Is there need for a follow up visit after donation?

The donor will be seen by the surgeon at one week and one month after donation.

WAITING FOR TRANSPLANT

Key Points:

- ***Timeframes and how the waitlist works***
- ***Defining the waitlist***
- ***Getting support during the waiting time***
- ***The matching of the donor and the recipient***

The Wait

Depending on your child's medical condition, his or her listing status may change one or more times during the wait for a transplant. It is difficult to predict how long your child will be waiting for a deceased donor kidney. The waiting time depends on blood type, availability of deceased donor kidneys, as well as your child's antibody level. During this time, you will be asked to bring your child to Transplant Clinic from time to time for follow-up visits. Also, you will need to call the Pre-Transplant Coordinator if your child develops a fever or any other symptoms of sickness such as runny nose, cough, vomiting or diarrhea. If your child develops an infection or cold during the wait for a donor kidney, he or she will not be able to receive a transplant until they have gotten better. This is because high doses of immune-suppressing medications are given at the time of transplant that could allow an infection to invade your child's body. This can be deadly if your child is transplanted and you did not tell anyone that they are sick.

How do I know if my child has been placed on the transplant waitlist?

The Pre-Transplant Coordinator will call you to let you know your child has been added on the waitlist. **It is important that the transplant office have current telephone numbers and back-up contact numbers (for family or friends) where you can be reached 24 hours a day, in case a kidney becomes available.** Be sure that this includes numbers where you can be reached if you take a trip.

Are there hotels/restaurants nearby for parents and family?

Yes, there are several hotels and restaurants near Children's Medical Center. The financial counselor and/or social worker can help you find further information. The Ronald McDonald House may also have rooms available. Their availability depends on how many guests they have and other restrictions. You and any guests must have a government issued ID to stay there. If you do not have an ID then you cannot stay there.

Where can I go for personal help and support?

The members of the transplant team: doctors, nurses, social workers, psychologist and child life specialists are available to give you information and support. There is also a chaplain who is assigned to the transplant team.

This information was pulled from the Transplant Living's website at <http://transplantliving.org/beforethetransplant/allocation/matchingorgans.aspx>.

Multiple Listing

A patient may wish to register and be listed at more than one transplant center. However, each center decides who it accepts as candidates. Each center also reserves the right to decline patients who are listed at other centers. Patients should tell the centers they contact that they plan to be listed at multiple transplant centers. Waiting time starts after each center evaluates a patient and places him/her on the organ transplant waiting list.

Transfer of Waiting Time

You can transfer your child's waiting time to the new center. After the new center finishes their evaluation and lists your child, the time can be transferred. You should then notify your child's original center that they need to remove your child from their waiting list.

How does the waiting list work?

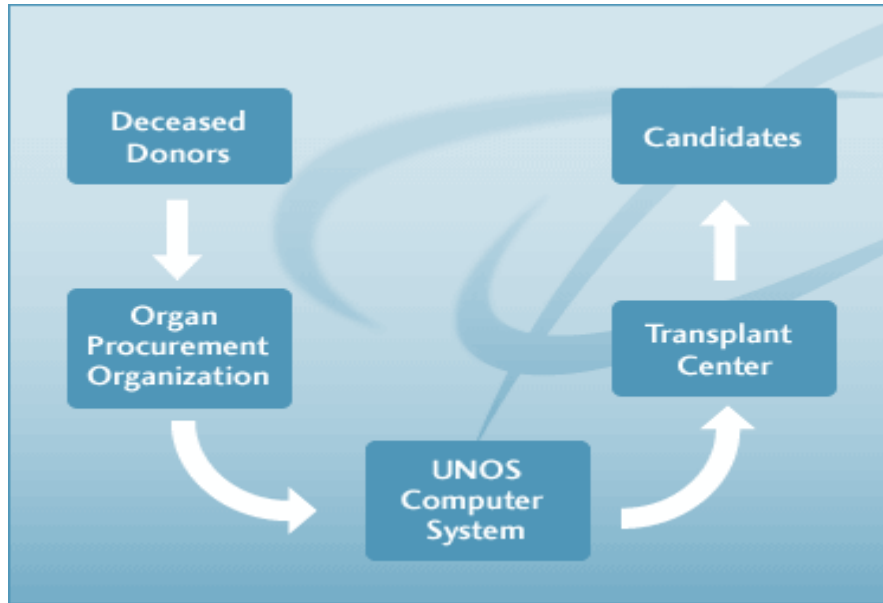
The U.S. Government has a branch that protects the health of all American citizens. This branch is called the Department of Health and Human Services' Health Services & Resources Administration (HRSA). Under contract with the HRSA, United Network for Organ Sharing (UNOS) keeps a centralized computer network called UNetSM. Transplant professionals can look at this computer network 24 hours a day, seven days a week. UNOS is the organization that manages all the U.S. organ transplants. They are regulated or controlled by HRSA. Their website is UNOS.org.

UNet is an internet program that electronically connects all the transplant hospitals and organ procurement organizations. This website is available 24 hours a day, 7 days a week. Because UNet uses the Internet, it allows access to all these transplant professionals. However, in order to protect the confidential medical data, all users must use have a secure password.

Matching Donor Organs with Transplant Candidates

A patient that becomes brain dead in a hospital on a breathing machine can be an organ donor. This is hard to predict, because we do not know when people will die. Once a patient is determined to be brain dead and the family chooses to donate their loved ones organs, the Organ Procurement Organization is called by the ICU. The Organ Recovery staff will log into the UNet system. They enter all the needed information about the donor. The system uses this information to match the medical facts of the recipients waiting with those of the donor. The system then makes a ranked list of patients who are matched up with each organ. This list is called a "match run." Factors affecting ranking may include:

- ◆ tissue match (this refers to the antigen testing)
- ◆ blood type (A,B, O, AB)
- ◆ length of time on the waiting list (longer time means closer to the top of the list)
- ◆ immune status (antibodies that were tested for in evaluation)
- ◆ distance between the potential recipient and the donor (for example, donor is in El Paso, recipient is in Dallas-it will take about 4 hours for the kidney to get to Dallas)



The organ is offered to the transplant team of the first person on the list. Often, the top transplant candidates will not get the organ for one of many reasons. When a patient is called, he or she must be available, healthy enough to have major surgery and willing to be transplanted immediately. Also, a blood test to look at compatibility between the donor and potential recipient may be required. If the organ is refused for any reason, the transplant hospital of the next patient on the list is called. The process continues until a match is made. Once a patient is found, called in, and all testing is complete, surgery is scheduled and the transplant takes place.

The Five Steps of the Matching Process

1. **An organ is donated.** When the organ becomes available, the Organ Procurement Organization (OPO) managing the donor gets the specific information to the surgeon through UNOS. The OPO procurement team reports medical and genetic information, including organ size, and condition, blood type and tissue type by entering this information into UNet.
2. **UNOS generates a list of potential recipients.** The UNOS computer generates a list of patients waiting for a transplant that have medical and blood profiles compatible with the donor. The computer ranks patients by this information, as well as clinical characteristics and time spent on the waiting list.
3. **The transplant center is notified of an available organ.** Organ donor coordinators at the OPO or the UNOS Organ Center contact the centers whose patients appear on the local list.
4. **The transplant team considers the organ for the patient.** When the transplant center is offered an organ, acceptance or refusal of the organ is based upon medical criteria, organ condition, patient condition, and patient availability and organ transportation. By policy, the transplant team has only one hour to make a decision.
5. **The organ is accepted or declined.** If the organ is not accepted, the OPO continues to offer it for patients at other centers until it is placed.

THE TRANSPLANT SURGERY

Key Points:

- ***The Phone Call***
- ***Be honest if your child has ANY flu like symptoms including a FEVER. If your child gets a transplant and they have a fever it can be deadly.***
- ***Do not let your child eat or drink after the call***
- ***Get to hospital as soon as possible***
- ***What to bring when your child is admitted for a transplant***
- ***Breakdown of events before and after the surgery***

How will I be contacted about a possible deceased donor kidney for my child?

You will receive a phone call from a Transplant Coordinator telling you that there is a possible deceased donor kidney available for your child. The Coordinator will ask you many questions including some of the following:

- ◆ When was your child's last dialysis (if on dialysis)?
- ◆ Is there any redness, swelling or pain around the hemodialysis or peritoneal dialysis catheter site?
- ◆ Is your child sick or have they been sick recently? Do they have a fever, cough, or runny nose?

It is important to understand that your child may be called in many times before actually getting a transplant.

It is also very important to be honest and let the coordinator know if your child has been sick. It can be DEADLY for your child to get a transplant while they are sick.

Are there special instructions to follow when called for a deceased donor kidney?

The Transplant Coordinator will give you instructions including the following:

- ◆ Where to report to (depending on the time of day, you may report to admitting or directly to the Renal floor)
- ◆ No more food or drink for the child (this will take effect immediately or a specific cut-off time may be given). It is very important you follow this instruction.

When am I admitted to the hospital?

- ◆ For *deceased donor transplant*, your child will need to come to the hospital as soon as possible after being called by the transplant coordinator that a kidney is available.
- ◆ For *living related donor transplant*, your child will be admitted the day before the scheduled surgery.

What happens when I arrive at the hospital?

- ◆ Your child will be evaluated by the transplant doctor to be sure that he or she does not have any infections, or other medical problems that would stop the transplant from happening.
- ◆ Your child will have blood drawn for routine laboratory tests as well as for the cross match. Remember this is the test between the recipient's blood and the donor's blood. This test takes approximately 4-5 hours to complete once the donor blood is at the laboratory.
- ◆ Your child will get a chest x-ray and an EKG.
- ◆ Your child will meet with the anesthesiologist (Doctor that puts your child to sleep).
- ◆ You will sign surgery consents, which give your permission for the transplant surgery.

Is there any special preparation before surgery?

- ◆ Before the surgery, your child will have an intravenous line (an IV) placed in his or her arm. This will be used to give medications and fluids before, during and after surgery.
- ◆ Your child will **not be able to eat or drink** anything for 6-8 hours prior to surgery.
- ◆ If having a living donor transplant, the evening meal before surgery will be liquids only.
- ◆ Your child will be bathed or will shower with a special antimicrobial soap.

What do I need to bring to the hospital?

Most people prefer to bring their own slippers, pajamas, robe and personal care items, such as shampoo, body wash, deodorant, etc. In addition, you may want to bring your child's favorite toy animal, games, Ipad, Ipod or books.

Who can stay with my child while he or she is in the hospital?

Your family may visit with your child while in the ICU (Intensive Care Unit) and when he or she goes to a regular room. The patient rooms have a convertible chair/bed on which **one** adult can spend the night.

How long does the surgery take?

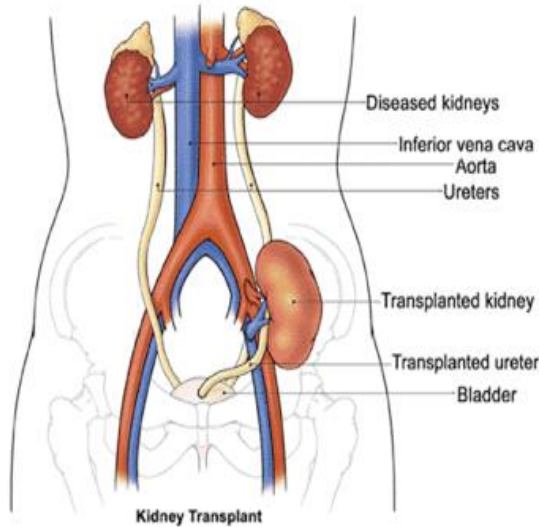
The kidney transplant surgery takes approximately 4 hours. If more surgery is done at the same time, it may take longer. The operating room staff will update your family about the how the surgery is going throughout the procedure.

Where is the new kidney placed?

The new kidney is placed in the front on either side of the lower abdomen or belly area. It is placed there for several reasons:

- ◆ It is easier to connect the blood vessels from the donor kidney to the recipient's vessels in this location.
- ◆ The hip bone helps to protect the new kidney.
- ◆ It is easier to connect the ureter (the tube that carries urine from the kidney to the bladder) to your bladder. The bladder is like a balloon that holds the urine in the body.
- ◆ It is easier for the doctors and nurses to feel the kidney in this spot.

This is a drawing of the placement of a transplanted kidney:



What will happen after the transplant surgery?

Your child will be taken to the pediatric intensive care unit (PICU) where he or she will stay for 24-48 hours. Here, your child's condition will be monitored very carefully by nurses and doctors specially trained in intensive care. The surgeon and kidney doctor work closely with the PICU staff. Your child's urine (pee) will be measured closely every hour.

Your child will have:

- ◆ One to two IVs. Fluid will be given through these to help your child keep enough fluid in their body. Their new kidney should be working and they should be peeing a lot. The IV fluids will help keep them well hydrated so they can keep a good blood pressure. This balanced blood pressure helps keep the blood flow good to the new kidney.
- ◆ A tube in the bladder (catheter or foley) to accurately measure urine output and to keep the bladder empty so it can heal properly. It is up to the surgeon as to how long the catheter will stay in, but it is normally for 4-5 days.
- ◆ An oxygen mask (which all patients have following surgery) until fully awake and breathing normally.
- ◆ A "clip" on a finger to measure oxygen level in the blood.
- ◆ Five small pads on the chest that monitor the heart. These will be removed when your child goes to a room on the kidney floor.
- ◆ There will be a bandage covering the incision site. The stitches or staples will usually be removed in 10-14 days. Sometimes, a special glue may be used instead, this does not need to be removed and will come off by itself.

** Remember, it is important to take deep breaths and cough to prevent pneumonia.

Who takes care of my child?

Your child's care is led by the kidney doctor. However, all members of the transplant team work together in your child's care on a daily basis in transplant rounds (members of the transplant team meet to discuss your child's care). This also includes the staff nurses on the kidney floor. These nurses are trained in the care of kidney patients and will care for your child during their hospital stay. The Kidney Transplant Coordinator will meet with you to teach you how to take care of your child and the new kidney.

(Renal is the medical term for kidney. If you hear someone say the renal floor it means the kidney floor. The same goes for renal team or renal doctor; it means kidney team or kidney doctor.)

When will the transplanted kidney begin to work?

Many transplanted kidneys begin to produce urine as soon as the kidney is connected in the Operating Room. In some cases, it may take time for the kidney to make urine. Your child may not make urine until after being transferred to the ICU. This may be due to the kidney being without a blood supply for an extended period of time (acute tubular necrosis or ATN). This usually is a reversible condition and usually improves with time.

Is dialysis needed after the transplant?

If your child's transplanted kidney does not work after surgery, he or she may need dialysis until the kidney begins to work. Dialysis will not damage the new kidney, but will help to remove waste products until your child's kidney is able to do it normally.

Will my child be on a special diet after transplant?

With a working kidney, your child's diet may not be as restricted or limited like before transplant. However, there will be some salt restriction since salt is one of the factors in controlling blood pressure. Many transplant patients gain weight after transplant. If this becomes a problem, the dietitian will work with you on a diet plan. Remember, the dietitian is an important member of the team and is available to work with you and answer your questions.

NUTRITION

Key Points:

- ***Your child's diet will change after transplant***
- ***Encourage your child to drink plenty of water***
- ***Limit fat, salt, and sweets that your child eats***

Nutrition plays an important role in both preparing for transplant and healing after transplant. It is also important for keeping good health in the years after transplant. A dietitian will be available to work with your child both in the hospital and when you go home. The dietitian will work with your family to create a nutrition plan for your child and his or her needs.

Pre-Transplant

Before transplant, it is very important to follow the diet told to you by your kidney doctor. If your child is currently receiving dialysis, the dialysis dietitian will continue to follow your child and help you manage your child's diet restrictions until transplant.

Immediately After Transplant

Nutrition immediately after transplant is different for every child. However, most children are able to start eating within a few days of transplant. The doctor or nurse will let you and your child know when he or she is able to start eating. Once your child is able to start eating, he or she will first be given clear liquids. Examples of clear liquids are juice, popsicles, broths, water, tea, and jello. If your child is able to eat and drink the clear liquids without vomiting, your child will be placed on a no added salt diet and no concentrated sweets diet. Your dietitian will discuss these restrictions with you and your child in more detail after transplant.

Post-transplant

The basic principles of diet after kidney transplant are:

1. Keep a Normal body weight and height for age
 - ◆ If your child is underweight, it is important to work towards normal weight. Normal body weight provides fats and proteins for protection during periods of stress (surgery) or infection.
 - ◆ If weight loss is needed, your dietitian will work with you to decide on a diet to help with weight loss.
 - ◆ Long term use of some immunosuppressive medications may result in weight gain. Weight will be monitored during follow-up visits and changes in diet will be made by your dietitian who is available as needed.
2. Focus on fruits and vegetables.
 - ◆ Be sure to carefully wash all fresh fruits and vegetables prior to eating
 - ◆ Fruits and vegetables are full of vitamins and minerals, fiber, and are low in calories.
 - ◆ Half of your child's plate should contain fruits and vegetables at meals.
 - ◆ Provide fruits and vegetables at snack time

3. Decrease the cholesterol and fat amount in the diet.
 - ◆ Prednisone may cause an increase in triglyceride levels (fat that can clog your veins).
 - ◆ A decrease in the cholesterol and saturated fat amount in the diet is recommended.
 - ◆ Try to use Polyunsaturated fats (olive oil, safflower oil, peanut oil and corn oil)
 - ◆ Try not to use Trans and saturated fats (beef fat, pork fat, shortening, coconut and palm oil, eggs, stick margarine and butter) these will increase blood cholesterol levels.
 - ◆ Immunosuppression medicines can raise cholesterol levels so it is recommended to follow a low-fat and low-cholesterol diet even if blood cholesterol levels are normal.
4. Restrict sodium intake.
 - ◆ Prednisone causes your body to hold on to sodium.
 - ◆ Large amounts of sodium may cause you to keep fluid inside your body (fluid retention).
 - ◆ A low-sodium diet is encouraged to avoid fluid retention and to help control high blood pressure.
 - ◆ Salt substitutes (such as Mrs. Dash) which contain the mineral potassium should be avoided since some immunosuppression medicines can cause high blood potassium levels.
 - ◆ Your dietitian will discuss which foods should not be eaten and ways to use herbs and spices for seasoning.
5. Limit sugar and concentrated sweets.
 - ◆ Prednisone may cause an increase in blood sugar levels.
 - ◆ You should limit sugars and concentrated sweets (regular candy or cookies, fruit juices).
 - ◆ Focus on whole grains. Choose 100% whole grain cereal, rice, pasta, breads, and crackers.
6. Drink plenty of fluids, especially water.
 - ◆ It is necessary for transplant patients to drink a lot of water, especially in hot weather and with exercise. Drinking enough fluid during the day will also help protect the kidney from side effects of certain medicines. Water helps flush the “junk” or toxins out of the body through the kidneys.
7. Practice food safety.
 - ◆ Immunosuppression medicines put your child at higher risk of getting an infection.
 - ◆ Make sure foods are cooked to the proper temperatures.
 - ◆ Do not eat raw fish or seafood, unpasteurized milk (fresh milk from the cow/goat), uncooked eggs, and unwashed fruits and vegetables.

Your dietitian will provide you with more information.

MEDICATIONS

Key Points:

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

Medications are essential to the success of your child's kidney transplant. Without these medications, the body will reject the new kidney. The body's response to the new kidney is to fight it off as it would a cold or virus. Medications are given to your child's specific needs to prevent the body from fighting or rejecting the new kidney. The medications must be taken as directed; do not change or stop giving your child's medications unless told to do so 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 recognize the side effects when they occur.

Within the first few days after transplant, your family will begin to give medications to your child, with the help of your nurse. You will be given a schedule for the medicines that you may update each time a change in medications is made.

Before discharge from the hospital, we will teach you:

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

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

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

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

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

Different medications can affect the way the body absorbs the immunosuppression medicines and may interact with them in an unwanted way. Therefore, do not give your child any over the counter medicines or medicines prescribed by a doctor who does not know your child's medical history without first talking with the transplant team. Please call the Transplant Team if a doctor has prescribed a new medication for your child to be sure it is ok for them to take.

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

General Medication Information

- ◆ Prescription refills are taken care of during normal business hours, Monday through Friday. Please plan to refill your child's medications early enough so that you do not run out. It is important you call the pharmacy 7 days before you run out of medication so the pharmacy has time to fill the medication and ship it to your home/for you to pick it up.
- ◆ Generics of brand name immunosuppressants (Prograf, Neoral and Cellcept) are available. It is important to stay on the brand name unless your transplant doctor tells you it is ok to take the generic.
- ◆ Always give your child the medications as directed. Follow the directions given by your transplant provider, not what is printed on the label of the medicine since the dose may be changed before a refill is given to you from the pharmacy.
- ◆ Do not stop giving any medication without being told to do so.
- ◆ Do not add any over-the-counter medications or supplements, including herbal remedies, unless your transplant provider knows about it.
- ◆ Contact your transplant provider if you notice any physical changes or mental changes in your child (mental changes can include but are not limited to changes in behavior, anger, sadness, increased sleepiness, etc).
- ◆ Take doses at the same time every day to avoid missing doses.
- ◆ If your child vomits within 30 minutes of taking their immunosuppression medicines, you will need to call the Transplant Coordinator who will ask you to give the dose again. If your child vomits after giving the medicines for the second time, do NOT give the medicine again, call the Transplant Coordinator.
- ◆ If your child vomits after 30 minutes of taking their immunosuppression medicines, you will need to call the Transplant Coordinator. You will NOT give the medicines again.
- ◆ Keep medicines away from heat, light and moisture (such as the bathroom vanity or kitchen cabinets).
- ◆ Call your pharmacy if any medicine "doesn't look right" for any reason.
- ◆ Do not try to make up for missed doses unless told to do so by your transplant provider.
- ◆ 1 cc is the same as 1 ml
- ◆ Check expiration dates on all medicines. Throw away and replace medicines that have expired.
- ◆ **Do not give your child any drugs containing an NSAID (non-steroidal anti-inflammatory drug) such as: Ibuprofen, Motrin, Midol, and Aleve unless told to or approved by your transplant doctor. NSAID's used together with Prograf or Cyclosporine can cause renal (kidney) problems.**
- ◆ Always keep medicine with you in carry-on luggage when traveling. This way, you will have it in case your checked luggage is lost.

Immunosuppression Medicine

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

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

The following is a list of medications which are commonly prescribed to post-transplant patients. Your child will be on some, but may not be on all of these. The medications prescribed for your child will be personalized to meet his or her individual needs. This list is meant for informational purposes only. Your transplant providers, transplant pharmacist and transplant coordinators will provide education and ensure that you develop a good understanding of the medicines your child is taking.

Diabetes

Some of the anti-rejection medications that your child may take can cause diabetes. This will be seen by an increase in the sugar level on blood work. Sugar in the blood is called glucose. Your child may have signs of diabetes like feeling thirstier than normal, peeing more, having blurred vision, squinting to see, or being confused.

Your child's blood will be tested a lot after transplant, and we will be checking the glucose levels. However, if you notice your child having these symptoms at home please call your transplant coordinator immediately.

In some patients, the blood sugar can be controlled by weight loss, careful diet limitations, and exercising. But some patients need a pill or tablet and may even need insulin shots. If your child gets diabetes, you will be taught how to deal and manage it. It is important to encourage your child to play and move around to help keep their exercise level up.

Prograf (Tacrolimus)

Why you give it

Prograf is an immunosuppression medicine. Prograf helps prevent rejection by suppressing the activity of the immune system (tells your body not to fight the new kidney).

How it comes

Prograf currently comes in 0.5mg (yellowish) capsules, 1 mg (white) capsules and 5 mg (grayish/red) capsules. Prograf is also available as a 0.5mg/ml compounded suspension, which has to be mixed by the pharmacy.

When to Give

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

How to Give

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

Side Effects

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

- ◆ Increase in blood sugar.
- ◆ Low magnesium level in the blood.
- ◆ High potassium level in the blood.
- ◆ Inability to sleep.
- ◆ Tremors (fine shaking of the hands) may occur while on this medicine and/or immediately after taking the medicine. If it worsens and/or interferes with your daily activities, contact the transplant office
 - This is a common side effect that will decrease over time as the Prograf dose is reduced.
- ◆ Diarrhea; sometimes with nausea and vomiting
- ◆ High blood pressure.
 - Your child may be on medicines to lower blood pressure. If he or she has headaches or dizziness spells, you should call your transplant provider because these may be signs of high blood pressure.
- Increased risk of infection.

- You should notify the transplant provider/coordinator of any fever, cough, rash or mouth sores. You must call your transplant provider right away if your child has been around someone with chickenpox.
- Potential damage to the liver or kidneys.
 - There will not be any specific symptoms you will notice. Your child may have elevations in certain blood work results, such as BUN, creatinine, potassium and liver function tests.
- Risk of post-transplant lymphoproliferative disease (cancer)

Storage

- ◆ Store at room temperature.

Precautions:

- ◆ Avoid grapefruit and grapefruit juice.
- ◆ If using the liquid form, do not give after the expiration date on the bottle.
- ◆ If using the liquid form, carry an extra bottle when traveling.
- ◆ Always keep medicine with you in carry-on luggage when traveling. This way, you will have it in case your checked luggage is lost.
- ◆ Some drugs interfere with Prograf blood levels. Your doctor will have information on how certain drugs affect Prograf. You should not add any over-the-counter medicines or change any other medicines unless told to do so by your doctor or the transplant team.
- ◆ If your child has diarrhea you must call your transplant coordinator. **Diarrhea that does not stop can increase the blood level of Prograf, which may increase the risk of harmful side effects.**

Neoral (Cyclosporine)

Why you give it

There are two forms of Cyclosporine: Sandimmune and Neoral. These are not the same. Neoral is a more absorbed form of Cyclosporine and is given to suppress the immune system and to prevent rejection. It should **not** be given with Sandimmune. Sandimmune and Neoral can **not** be substituted for each other.

How it comes

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

When to Give

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

How to Give

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

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

Side Effects

- Increased Hair Growth
- High Blood Pressure
- Tremors (fine shaking of the hands) may occur while on this medicine and/or immediately after taking the medicine. If it worsens and/or interferes with your daily activities, contact the transplant office
- Gum swelling/ sensitivity to hot and cold
- Decreased ability to fight infection
- Risk of post-transplant lymphoproliferative disease (cancer)

Storage

- Store at room temperature.

Precautions

- Avoid grapefruit juice.
- Drink right after mixing. **Do not mix in advance** or it will form clumps.

- Some drugs interfere with Neoral blood levels. Your doctor will have information about how certain drugs affect Neoral. You should not add any over-the-counter medicines or change any other medicines unless told to do so by your doctor or the transplant team.
- If you have diarrhea you must call your transplant coordinator. **Diarrhea that does not stop can increase the blood level of Neoral, which may increase the risk of harmful side effects.**
- Avoid rinsing the dosage syringe provided by Neoral as this will cloud the syringe. If syringe becomes wet or needs cleaning, it must be completely dry before using it again.

Steroids **(Methylprednisolone, Prednisone, Prednisolone)**

Why you give it

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

How it comes

Prednisone comes in 20 mg, 10 mg, 5 mg, 2.5 mg, or 1 mg tablets. In smaller children, a liquid solution is available of either 1mg/ml or 5mg/ml can be used.

Prednisolone (Orapred) comes in 3mg/ml solution.

Methylprednisolone comes in 4 mg tablets.

When to Give

The total prescribed dose of steroids should be given once each morning. After breakfast is an ideal time to give the Prednisone. Steroids can be irritating to the stomach and should not be given on an empty stomach.

How to Give

If your child can swallow pills/capsules, he/she will swallow the correct number of capsules as directed. The tablets may need to be divided in half to obtain the right dose. For example, if 5 mg tablets are given and your child's dose is 7.5 mg, you would give 1 1/2 tablet.

If your child is taking the suspension, you will be taught to draw up the right amount using a syringe.

Side Effects

- Increased blood pressure
- Fluid/salt retention. This may cause the body to hold on to fluids and cause swelling of the hands or ankles (edema).
- Increased appetite (feel more hungry). This can cause unhealthy weight gain.
- Increased body fat. This can occur in the face (called "moon face"), over the upper back and stomach.
- Increased stomach acid (heartburn). This may cause or worsen ulcers. An acid reducer is given while your child is on higher doses. Do not give Prednisone on an empty stomach.
- May slow the healing process and decrease the body's ability to fight infections.
- Muscle weakness and weakened connective tissue. This may cause "stretch marks."
- Acne.
- In large doses, steroids can affect bone growth.
- Eye changes. Steroids may cause cataracts or glaucoma. Routine eye exams should be done as instructed by your eye doctor. Your child should be seen by an eye doctor if any problems occur such as blurred or decreased vision.
- Increased blood sugar. This usually happens with higher doses. In some cases, insulin may need to be given until the blood sugar returns to normal as the steroid dose is decreased.

- Increased sensitivity to the sun. Always apply a sunscreen to exposed skin when in direct sunlight for a long period of time (see "Skin Care" section).
- Mood swings-including crying easily, irritable, etc and difficulty sleeping

Storage

- Keep away from heat and light.
- Do not store the medicine in the bathroom, near the kitchen sink or refrigerator because moisture will breakdown the drug.
- Do not freeze the liquid preparation.

Precautions

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

Cellcept
(Mycophenolate Mofetil)

Why you give it

CellCept is an immunosuppression medicine that helps to prevent rejection. It can be used with other immunosuppression medicines such as Neoral or Prograf and Prednisone.

How it comes

CellCept comes in 250 mg (blue and brown) gelatin capsules, 500mg (purple-grey) tablets and 200mg/ml suspension.

When to Give

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

How to Give

Do not give Cellcept 2 hours before or after Magnesium or Iron.

If your child can swallow pills/capsules, he/she will swallow the correct number of capsules as directed. If your child is taking the suspension, you will be taught to draw up the right amount using a syringe.

Side Effects

The most common side effects of CellCept are:

- Diarrhea
- Nausea/ Vomiting
- A decrease in the white blood cell (WBC) count. This will cause a higher the risk of infection.

**Imuran
(Azathioprine)**

Why you give it

Imuran is an immunosuppression medicine that helps to prevent rejection. It can be used with other immunosuppression medicines such as Neoral, Prograf and Prednisone.

How it comes

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

When to Give

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

How to Give

If your child can swallow pills/capsules, he/she will swallow the correct number of capsules as directed. If your child is taking the suspension, you will be taught to draw up the right amount using a syringe.

Side Effects

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

Rapamune (Sirolimus)

Why you give it

Imuran is an immunosuppression medicine that helps to prevent rejection. It can be used with other immunosuppression medicines such as Neoral, Cellcept, Imuran and Prednisone.

How it Comes

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

When to Give

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

How to Give

- You may take Rapamune with or without food; but **take it the same way every day**.
- If you are taking Cyclosporine, you must take **Rapamune 4 hours after** your dose of Cyclosporine. Unless you have been told differently by your transplant team.
- Oral Solution: **The oral liquid medicine must only be mixed with water or orange juice.**

Side Effects

- Rash/acne
- Increase cholesterol/triglycerides
- Increase blood pressure
- Decreased ability to heal wounds
- Swelling in your legs or hands

Storage

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

Nystatin (Mycostatin)

Why you give it

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

How it Comes

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

How to Give

Always shake the liquid well before giving. The liquid should be swished around in the mouth before swallowed. The pastille or tablet should be sucked on so it will slowly dissolve in the mouth. The pastille should not be chewed or swallowed because it will not be as effective. If needed, the Nystatin can be gently brushed on the tongue/mouth with a soft-bristled toothbrush.

Side Effects

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

Storage

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

Precautions

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

**Diflucan
(Fluconazole)**

Why you give it

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

How it Comes

Fluconazole may be given as a liquid or tablet.

How to Give

Give as directed

Side Effects

Fluconazole **increases** Prograf and Cyclosporine levels. As a result, Prograf and Cyclosporine levels will be checked and doses adjusted.

Storage

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

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

Why you give it

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

How it Comes

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

How to Give

If your child can swallow tablets, he/she will swallow the correct number of tablets as directed. If your child is taking the suspension, you will be taught to draw up the right amount using a syringe. Give this medicine with plenty of fluid and encourage increased fluid.

Side Effects

Some of the side effects from trimethoprim and Sulfamethoxazole include:

- Nausea, vomiting, anorexia (not eating)
- Allergic skin reactions (rash or hives)
- Decreased WBC, Anemia & low platelet count
- Elevation of BUN and creatinine
- Sun sensitivity

Storage

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

Precautions

- ◆ If your child develops a rash, bloody urine, fever, chills or become severely tired (fatigued), call the Transplant Coordinator immediately. You may be instructed to stop this medicine (do not stop without talking to the Transplant Team first).
- ◆ If your child has difficulty breathing, call 911 immediately.

**Valcyte
(Valganciclovir)**

Why you give it

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

How it Comes

Valganciclovir comes in a 450mg tablet and a 50mg/ml suspension.

How to Give

If your child can swallow tablets, he/she will swallow the correct number of tablets as directed. If your child is taking the suspension, you will be taught to draw up the right amount using a syringe.

Side Effects

Some of the reported side effects include the following:

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

Storage

Protect suspension and tablets from light and moisture.

Precautions

- Be sure to wash your hands after touching this medicine.

Zovirax
(Acyclovir/Valacyclovir)

Why you give it

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

How it Comes

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

Valacyclovir comes in a 500mg and 1000mg tablet.

How to Give

If your child can swallow tablets, he/she will swallow the correct number of tablets as directed. If your child is taking the suspension, you will be taught to draw up the right amount using a syringe.

Side Effects

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

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

Storage

Protect capsules and tablets from light and moisture.

Precautions

There are no special precautions with the oral preparation.

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

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

Why you give it

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

How it Comes

They come in capsules, oral dissolving tablets and suspensions.

How to Give

If your child can swallow tablets, he/she will swallow the correct number of tablets as directed. If your child is taking the suspension, you will be taught to draw up the right amount using a syringe.

Side Effects

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

Storage

Keep away from heat, light and moisture.

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

Why you give it

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

How it Comes

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

How to Give

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

Side Effects

Monitor for diarrhea

Storage

Keep away from heat, light and moisture.

Precautions

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

Magnesium Supplement
(Magnesium Oxide, Magnesium Hydroxide)

Why you give it

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

How it Comes

Magnesium comes in tablet and suspension.

How to Give

If your child can swallow tablets, he/she will swallow the correct number of tablets as directed. If your child is taking the suspension, you will be taught to draw up the right amount using a syringe.

Side Effects

Monitor for diarrhea

Storage

Keep away from heat, light and moisture.

Precautions

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

**Persantine
(Dipyridamole)**

Why you give it

Dipyridamole is used to prevent blood clots.

How it Comes

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

How to Give

If your child can swallow tablets, he/she will swallow the correct number of tablets as directed. If your child is taking the suspension, you will be taught to draw up the right amount using a syringe.

Side Effects

- Bleeding Gums
- Bruising

Storage

Keep away from heat, light and moisture.

Precautions

There are no special precautions with the oral preparation

Aspirin

Why you give it

Aspirin is used to prevent blood clots.

How it Comes

Aspirin comes in many different strengths. The 81mg baby aspirin is the preferred strength.

How to Give

If your child can swallow tablets, he/she will swallow the correct number of tablets as directed. Aspirin may also be chewed and swallowed.

Side Effects

Side effects are uncommon but can include stomach upset (ulcers).

Storage

Keep away from heat, light and moisture.

Precautions

There are no special precautions with the oral preparation.

REJECTION AND INFECTION

Rejection

Key Points

- ***Learn the signs and symptoms of rejection***
- ***Know how the doctors test for rejection***
- ***Know the medications used to treat rejection***
- ***Know how to help your child prevent chronic rejection***

Rejection is the body's natural way of trying to fight off the new kidney which it considers as "foreign" (not its own). Because the body continues to try to reject the new kidney, you will need to take immunosuppression medicines for the life of the transplanted kidney. The best way to lower the risk of rejection is for your child to take all of his or her medicines each day as they are supposed to (correct times). Even with these medicines, *almost everyone will have an episode of rejection at some time*. The signs of rejection may not always be obvious to you, so it is very important that you keep a record of vital signs, keep all clinic appointments, and have your child's blood work done as scheduled.

Signs and Symptoms of Rejection

Listed below are some of the signs and symptoms of rejection that you *may or may not* notice. If you experience any of these symptoms, call the renal transplant coordinator **immediately**.

- ◆ Temperature above 100°F
- ◆ Decreased urine output (for infants, count the number of wet diapers)
- ◆ High blood pressure
- ◆ Pain, swelling or tenderness over the new kidney
- ◆ General feeling of fatigue (feeling tired), muscle aches, loss of appetite (flu-like symptoms)
- ◆ Large weight gain or puffiness
- ◆ Increase in blood creatinine level
- ◆ Vomiting and Diarrhea

It is important to know that with some rejection episodes, there may be no symptoms at all. In these instances, only an increase in the blood creatinine level will show your doctor that there may be a problem.

Diagnosing Rejection

Rejection is most often diagnosed by lab work and symptoms, but sometimes other tests are needed to help in the diagnosis. These include:

- ◆ Renal ultrasound (sonogram)
- ◆ Biopsy

Kidney Biopsy

- ◆ Your child cannot have food or drink after midnight before the biopsy. Medications should be given with a small amount of water on the morning of the biopsy.
- ◆ Your child will be admitted to the hospital and an IV will be placed in his or her arm. Blood tests will be performed prior to the biopsy to look at the blood's ability to clot.
- ◆ Medication is given to make your child sleepy and relaxed before the test is performed. The area to be biopsied is "numbed" with Lidocaine, like dentists use
- ◆ The biopsy is performed in the operating room with an ultrasound machine.
- ◆ A special needle is inserted into the kidney to take a *tiny* piece of kidney tissue.
- ◆ A band aid is placed over the biopsy site.
- ◆ Your child will remain on bed rest after the biopsy until 8 a.m. the following day. They are only allowed out of bed to use the bathroom.
- ◆ Complications of a kidney biopsy may include:
 - Pain
 - Bloody urine
 - Bleeding (sometimes requiring surgery)
 - Rarely, loss of the kidney

Types of Rejection

There are two types of rejection: acute and chronic

Acute rejection

- This may occur *any time* after transplant, but it most commonly happens during the first three months.
- This is usually a *sudden event* diagnosed by any or all of the signs and symptoms described earlier.
- If caught early, it is *usually reversible (fixable)*, with little or no damage to the new kidney.
- **This may occur if medications are missed or not taken as instructed.**

Chronic rejection

- This is a slow, gradual loss of kidney function (can occur over a long period of time) which may eventually lead to dialysis or another transplant.
- There usually are no symptoms except for rising creatinine levels, worsening lab results and high blood pressure.
- This process cannot be completely prevented or reversed.
- This can occur because of repeat UTIs or repeat acute rejections.

- You can help your child prevent chronic rejection by having them take their immunosuppressive medications at the same time everyday

Treatment for Rejection

After rejection is diagnosed, the treatment used depends on what kind and how serious the rejection. Usually, treatment consists of giving high-dose steroids (IV Prednisone) and also increasing anti-rejection (immunosuppression) medicines. It is important to get rejection treated as soon as possible. Your child's new kidney continuing to work depends on getting medical treatment immediately.

Infection

Key Points

- ***Know the signs and symptoms of infection***
- ***Keep your kids away from sick people***
- ***Call your coordinator if your child has any signs of infection***
- ***Call your coordinator if any doctor wants to put your child on any medication***

Signs and Symptoms of Infection

Listed below are some of the signs and symptoms of infection. If you experience any of these symptoms, call the renal transplant coordinator **immediately**.

- ◆ Temperature higher than 100°F
- ◆ High or low blood pressure
- ◆ Pain, swelling or tenderness over the new kidney
- ◆ Redness or drainage at an incision or catheter site
- ◆ General feeling of fatigue (feeling tired), muscle aches, loss of appetite (flu-like symptoms)
- ◆ Diarrhea or vomiting
- ◆ Red or brown urine

Urinary Tract Infection (UTI)

Urinary tract infections can involve the urethra, bladder or kidneys. If you experience any of these symptoms, call the renal transplant coordinator **immediately**:

- ◆ Burning or pain when peeing
- ◆ Feeling the need to pee often and urgently (may be small amounts at a time)
- ◆ Bad or strong smelling urine
- ◆ Blood in urine (red or brown urine)
- ◆ Temperature higher than 100°F

UTI Prevention

- ◆ Regular and frequent peeing (every 2-3 hours)
- ◆ Avoid bubble baths
- ◆ Drink plenty of water
- ◆ Females:
 - Wear cotton underwear
 - Be sure to wipe from front to back

Common Colds

Immunosuppression medicines cause your child's body not to be able to fight infection as easily as a normal person. This can cause your child to get infections more easily.

You can help your child by not letting him/her be around sick people. If someone in your household is sick, make sure they use a separate drinking glass and cover their mouth when sneezing or coughing. Encourage all family members to wash their hands often, especially when someone in the house is sick.

Anytime your child develops a fever you need to let your transplant coordinator know immediately. If your child has a cough that does not go away it's important to call your transplant coordinator. If you take your child to the primary care doctor and they prescribe your child medication, call your coordinator BEFORE giving it to them.

Flu

The flu, also known as influenza, is a viral infection. Symptoms include: fever, cough, sore throat, a runny nose, and muscle aches. The flu vaccine is highly encouraged for transplant recipients and their families. Your child and family are encouraged to get the flu vaccine that is the injection (shot). You May NOT get the nasal spray vaccine as it is a live vaccine. Remember: Your child can NOT have LIVE VACCINES.

Candida Infections

Candida or yeast can cause many infections in transplant patients. The most common is Thrush. This is seen in the mouth and throat. Thrush causes white, patchy sores in the mouth or throat; pain or tenderness; a white layer on the tongue, and problems with swallowing. Candida can also occur in the surgical wound, eyes or respiratory and urinary tracts. Vaginal infections may occur and normally cause a discharge that may be yellow or white. To prevent this from getting worse after transplant your child will be on Nystatin. Nystatin is an antifungal medication. Yeast or candida is a fungus. Your child will need to swish this yellow medication in their mouth and swallow it. If the fungal infection gets severe your child may need to be hospitalized. Call your transplant coordinator immediately if you think your child has signs of thrush.

Pneumocystis Jiroveci Pneumonia (also called PCP)

This is a germ that is a lot like a fungus. It lives in the lungs. In patients that take immunosuppression medicine it can cause pneumonia. Your child will first show signs of a mild, dry cough, fever and can have weight loss or sweating at night. If your child has any of these symptoms, call your coordinator immediately. Your child will be take a medication called Bactrim to help prevent PCP. If your child cannot take Bactrim, there are other oral medicines available or a breathing treatment with a medication called Pentamidine can be given once a month.

Infection Control Guidelines for Transplant Patients

Key Points

- ***Wash your hands***
- ***Keep sick visitors away from your child and the hospital***
- ***Make sure your child wears their N95 mask when out of their room***

Multidrug-resistant bacteria (also known as MDRO's or antibiotic resistant organisms) are defined as those infections that are resistant to certain drugs.

Two examples are:

1. Methicillin Resistant Staphylococcus Aureus (MRSA)
2. Vancomycin Resistant Enterococcus (VRE)

MRSA and VRE are spread by having contact with someone that has the infection or contact with contaminated surfaces. If a patient is determined to have an MDRO, they are placed on "contact precautions." This is designed to prevent the spread of these infections. Contact precautions require gloves and gowns upon entering the patient's room and removal of these prior to leaving the room. Families and visitors are asked to wear gowns and gloves if holding the patient or if they expect contact with a body fluid (changing a diaper), especially if they are going to be around other patients and families. Otherwise gowns and gloves may not be required for visitors. Families and visitors must wash hands when entering and leaving a patient's room. The patient may not be able to leave the room while in the hospital.

Any patient that has VRE is considered permanently colonized (has become part of their body's normal bacteria), since this organism cannot be completely cleared with available antibiotics. These patients should never have physical contact with other transplant patients even outside the hospital (including parties and camps). Patients with MDRO are able to attend school. Preventing the spread of these infections is very important and hand washing is absolutely required.

Visitors

- ◆ Any person with signs or symptoms of an infection, including cold or flu, should not be allowed to visit patients in the hospital or at home until they are well.

Hospital Floor

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

Personal Items at the Hospital

- ◆ All personal items must be cleaned with alcohol wipes before touching a transplant patient.
- ◆ Personal items that are washable are preferred. The number and size of stuffed animals should be minimized (1-2 favorites).
- ◆ Potted plants and fresh flowers are not allowed in the patient's room.
- ◆ Down comforters (feather) are not allowed. Down pillows are allowed if covered by a plastic pillow case with a zipper closure.
- ◆ Exterior wrapping/packaging is to be removed from gifts that have been shipped/mailed to transplant patients prior to entering the patient's room.

N95 Mask

- ◆ Patients are asked to wear an N95 mask when outside of their hospital room during the transplant admission and for approximately 6-8 weeks after transplant when at the hospital (for labs, etc) or when out in public (in a store, mall, etc).

Avoiding Infection

- ◆ Wash your hands often and encourage you child and other family members to do the same
- ◆ Keep your hands away from your face and mouth
- ◆ Ask friends not to visit when they are not feeling well
- ◆ Stay away from people with colds or other infections
- ◆ Wash hands before and after dressing changes, and wear a face mask to prevent infection
- ◆ If someone at home becomes sick have them use separate drinking glasses, cover their mouth when sneezing and coughing, and wash their hands. It is necessary to clean surfaces (door knobs, bathrooms, kitchens, etc) more often
- ◆ Avoid handling animal waste (especially birds and chickens) and avoid contact with animals who roam outside (this includes changing litter boxes or bird cages)
- ◆ Do **NOT** let your child have **LIVE** vaccines; always check with your transplant team before **you or your child** receives live vaccine. **This includes everyone in the house.**

Herpes Viral Infections

Key Points

- *Know the symptoms of Herpes Virus*
- *Call coordinator immediately if you think your child is infected*

Herpes viral infections include:

- ◆ Herpes Simplex type 1 (HSV-1) cold sores by the mouth
- ◆ Herpes Simplex type 2 (HSV-2) genital herpes
- ◆ Varicella-Zoster Virus (VZV) chicken pox and shingles
- ◆ Cytomegalovirus (CMV) flu-like illness
- ◆ Epstein-Barr virus (EBV) mononucleosis & post-transplant lymphoproliferative disease

Herpes viruses, once exposed, are always present in the body but may not cause an active infection. Later, the virus reactivates or 'acts up' to cause another infection. What reactivates the virus is not known, but stress or a decreased immune system almost always has a role.

Herpes Simplex Virus (HSV) Type 1 and Type 2

Cold Sores and Genital Herpes

HSV Type 1 usually causes lesions or sores on the lips and mouth. Type 2 most commonly causes genital infections. The blood work before transplant, tests for IgG antibodies. These are antibodies that your body makes when it is invaded by a virus. The presence of IgG antibodies against HSV means a previous infection with either Type 1 or Type 2. A positive result indicates the possibility of reactivation post-transplant. If a herpes infection happens soon after transplant, the sores can spread easier because your child's immune system is down. Be sure to report symptoms immediately.

Symptoms

- ◆ Before sores appear: Your child may feel an itching, numbness, or tingling sensation (prodrome). He or she may describe it as a prickly pain or dull pulse-like throb. It's good to remember these symptoms as a warning of future infections.
- ◆ Sores: These first appear as reddened areas and later as miniature water blisters. The lesions last 7 to 28 days. These sores are very contagious.
- ◆ Crusting-over period: Cleanliness and dryness are necessary for healing.

Treatment

- ◆ Keep clean and dry.
- ◆ Do not put salves on the lesions - they can spread the virus to a larger area or delay healing.
- ◆ Do not pick or touch - if you do, wash your hands before touching other areas of your body.
- ◆ Stay out of the sun and wind as much as possible.

HSV Transmission

- ◆ The virus spreads when mucous membranes (mouth, ears, eyes, or nose), genitalia, or any break in the skin (cut or scratch) comes into direct contact the virus.
- ◆ You should use a different towel to wipe lesions than the towel you use to wipe other parts of your child's body to avoid spreading the virus.
- ◆ The herpes virus requires darkness, moisture, and warmth to survive, which makes spread by non-living objects (like toilet seats) very unlikely.

What causes the recurrence of HSV?

- ◆ Stress is very common in transplant patients. Physical and mental stresses like menstruation, illness, anxiety, friction, and chafing/rubbing may lead to the HSV lesions appearing.
- ◆ Immune-suppression (medication-related or through other diseases that affect the immune system) contributes to recurrence
- ◆ Sunlight is a common cause of recurrent HSV (cold sores) - another important reason to wear sunscreen and chapstick.

Varicella-Zoster Virus (VZV)

Key Points

- *Know the symptoms of Chicken Pox and Shingles*
- *Know that a person is contagious until ALL the sores are scabbed over*
- *Call your coordinator immediately if you think that your child has chicken pox*

Chicken Pox

Chicken pox, also known as varicella, is a highly contagious disease that most commonly occurs in children. It is spread through the air primarily by cough and nasal secretions and by direct touching with skin lesions. To get chicken pox, one must be in close contact with someone with the illness. The growing period is from 10 to 21 days. To prevent your child from getting chicken pox, avoid contact with people who have chicken pox or shingles. This may mean that your child, and the person with chicken pox, have to live apart for several days until the person with chicken pox is no longer contagious.

If your child has had the chicken pox before they have had the vaccine, taking immunosuppression medications to prevent rejection, can give the virus a chance to 'act up' or reactivate. It is important to look for symptoms and call the coordinator immediately if you see them.

Symptoms

- ◆ The 24 to 48 hours before the rash appears symptoms may include: fever, not eating like normal, general flu-like feeling and runny nose. A person is **contagious** during this period.
- ◆ Rash and sores normally first appear on the chest, back or abdomen, and then spreads to the face, arms and legs. Red spots appear first and then the center appears as a clear, tiny water blister. The fluid contains the chicken pox virus. After the blister breaks, the lesion scabs over. *A person is contagious until the lesions scab over.*
- ◆ During the crusting over period no new lesions appear and all lesions are healed or scabbed. *A person is not contagious during this period.*

Treatment

- ◆ **All transplant patients who get chicken pox must notify the transplant office immediately for treatment.** If it is after office hours, please call the operator to page the on-call Transplant Coordinator.
- ◆ Treatment for chicken pox is: Acyclovir given through the IV in the hospital. It may be necessary to continue a medication by mouth for several days after discharge from the hospital for continued treatment of the chicken pox.
- ◆ Transplant patients who have never had chicken pox or have no detectable or measureable antibodies for varicella and are **exposed** must be treated with Varicella-Zoster Immune-Globulin (VZIG) within 48 hours, but no later than 72 hours after exposure. Your transplant coordinator will know if your child has detectable antibodies by their pre transplant blood work.

- ◆ If your child does not receive VZIG within 72 hours after exposure and lesions are present, a medicine called Acyclovir will be given (usually in an IV). This means hospitalization for several days to a week.
- ◆ A varicella-zoster vaccine is available to all persons who have not yet had chicken pox. This vaccine is given prior to kidney transplantation, but *cannot* be given after transplantation.

Note: If your child has varicella-zoster, contact your transplant coordinator before you bring your child to the hospital. Special isolation precautions are needed to avoid spreading this virus to other children with lowered immunity.

Shingles

Shingles, also called Herpes Zoster, is caused by a reactivation or restart of the same virus that causes chicken pox. This virus can become reactivated and cause an outbreak of shingles. Your child can get chicken pox when exposed to the fluid from these lesions or sores.

Symptoms

- ◆ One to three days before a *rash* appears symptoms may include: pain, tingling, and/or burning on oneside of your child's chest, neck, forehead, back, hip or leg.
- ◆ Rash and sores appear in clusters of miniature blisters. These sores are very painful. Keeping lesions covered will prevent them from spreading to someone who has never had chicken pox.
- ◆ During the crusting-over period no new blisters appear and all areas are scabbed over. Your child is *not* contagious during this period.

Treatment

Call your renal transplant coordinator immediately. Your child will be admitted to the hospital to receive a medication called Acyclovir (usually by IV).

Note: If your child has herpes zoster, call your transplant coordinator team before you bring your child to the hospital. Special isolation precautions are needed to avoid the spread of this virus to other children with decreased immunity.

Cytomegalovirus and BK Virus

Key Points

- ***Know the symptoms of CMV infection***
- ***Know the symptoms of BK virus infection***
- ***Call your coordinator if you think your child is infected or has a fever***

Cytomegalovirus (CMV) is a member of the herpes family. The symptoms of CMV may be very mild or may become serious if the virus invades the blood, lungs, liver, eyes, kidney, or other organs. Like shingles, the virus can become reactivated during times of stress or reduced immunity. Fever is often the first symptom. Fever, however, can also be caused by rejection and other infections. It is important to call your kidney transplant coordinator when you have a fever so that the best treatment can be provided.

Four Sources of CMV Infection

1. Contact with someone who has an active CMV infection
2. Reactivation of previous CMV
3. From the transplanted organ
4. From blood transfusions

If the recipient or the donor had a CMV infection in the past, then your child medication will take medication to prevent re-activation of this virus. The medication is given orally for 6 months after transplant (sometimes longer).

CMV levels in the blood are checked during routine blood work. This test is usually done every three months, but may be done more frequently if necessary.

CMV Characteristics

- ◆ CMV tends to occur four weeks or more after transplantation.
- ◆ The first symptom is generally a fever that spikes once a day to 102 degrees Fahrenheit, or more, for many weeks.
- ◆ Other common complaints are those of flu-like symptoms including muscle weakness, loss of hunger, and tiredness.
- ◆ CMV often has no symptoms and may be suspected by a medical provider if the blood creatinine is high and the WBC (white blood count) is low.

Transmission Concerns

This infection takes repeated contact with someone who is shedding the virus. Hand-washing after exposure to secretions is the first line of defense to prevent the spread of infections. Your kidney transplant provider will order blood tests to determine whether or not your child has an active CMV infection.

Treatment

A severe CMV infection can be difficult to treat. It is important to notify your renal transplant coordinator immediately when your child has a fever greater than 100°. However, medications such as Ganciclovir and oral Valganciclovir are available to help prevent and treat this virus. Early treatment helps to reduce the risk of serious complications. Cytogam is an intravenous (IV) medication that may be given to transplant patients who have received a CMV positive kidney or if their CMV status is positive pre-transplant. Your transplant coordinator will make arrangements at the time of discharge for a home health agency to administer Cytogam in your home or at the hospital, if necessary. Your child may feel tired and weak for several weeks or months. Be sure to allow for periods of rest and gradually increase his or her level of exercise.

BK Virus

BK virus causes a viral illness that may show up in immunosuppressed patients. It happens most commonly within the first year after transplant. It may lead to kidney failure and/or graft failure. Your child may not show any signs of infection or may have a high creatinine. Other symptoms may include blood in the urine, lymphocele (fluid collection), obstructive uropathy (not being able to have normal flow of urine), ureteral stenosis or stricture (tube between the kidney and the bladder is kinked or blocked). Hydronephrosis (fluid in or around the kidney) may be seen on a renal sonogram.

Diagnosis is made with a kidney biopsy. There are also urine and blood tests that look for the virus. Treatment includes reducing the amount of immunosuppression medicine that your child takes. Your child will be watched closely for rejection. An antiviral medication may be prescribed for your child to help treat the BK virus.

Epstein - Barr Virus

Key Points

- *Large Lymph nodes, sore throat and fever are symptoms of EBV*
- *Call your coordinator if your child has any symptoms or fever*

Epstein - Barr virus (EBV) is a herpes virus which has been seen all over the world. Between 25 and 70 percent of adolescents and adults who get a primary EBV infection have the clinical infection called mononucleosis. This is called Mono for short. It is normally seen in the junior high age group. It is spread by kissing. It lives in the saliva of the mouth. Symptoms of infectious mononucleosis are fever, enlarged lymph nodes, extreme tiredness and hoarseness. EBV is associated with certain potential cancers including post- transplant lymphoproliferative disease (PTLD).

Post-Transplant Lymphoproliferative Disease

Post-transplant lymphoproliferative disease (PTLD) is a type of cancer that can occur after transplant. It is usually found in lymph nodes and lymph tissue. Lymph nodes can be found in the neck, groin, under arms as well as other places in the body. PTLD can also be found in the tonsils. and the tonsils may be swollen (not related to another illness such as strep) and/or your child may have stomach problems including diarrhea. Viruses, mainly EBV, is what cause PTLD to be a problem.

Treatment

Initially, your Transplant Provider will likely decrease immunosuppression medicine doses to allow your child's immune system to fight off the virus. There will likely be frequent labwork and additional testing that may need to be done. Some of the additional testing may include special radiology tests or removal of the tonsils. If it determined that your child does have PTLD and is not responding to the decreased immunosuppression dose, it may be necessary for strong, chemotherapy-like medications to be used to treat the PTLD. Your transplant doctor will decide on what form of treatment is best. It is important to notify your kidney transplant coordinator at the first sign of fever, enlarged lymph nodes and any other symptoms of concern.

POST-TRANSPLANT CARE

Key Points:

- ***Put sunscreen on your child***
- ***Teach your child to wash their face***
- ***Certain hair removal products are okay***
- ***You must have your child take an Antibiotic BEFORE they have ANY dental work, this means cleanings too***
- ***High Blood Pressure***
- ***Returning to School***
- ***Physical Activity***

Skin Care

While on immunosuppression, your child is *much* more sensitive to the sun than other people. Your child may get a sun burn even if they never did before transplant. It is important to protect their skin by applying sunscreen with a sun protection factor (SPF) of at least 15. A sunscreen of 25 or 30 SPF is even better. Without these sunscreens, your child's risk of skin cancer is much higher. Remember to reapply the sunscreen often because water and sweat can lower its ability to work. Also, try to stay out of the sun as much as possible between 10:00 a.m. and 2:00 p.m. If you notice any changes in your skin such as new raised areas, sores that won't heal or changes in warts or moles, be sure to notify your kidney transplant doctor. A skin doctor may need to look at these.

Acne

Acne (pimples) may be on the face, chest, back or shoulders and is often a side effect of prednisone. The easiest way to help control this acne is to remove any extra oil, dead skin, or bacteria from your child's skin by washing it in the morning and night. Teach them to wash their face three times a day with soap and water. Rinse all soap off the skin. It is important to leave the skin open and clean. Do not apply lotions or creams unless told to do so by the kidney doctor.

If the skin becomes dry (peeling or red), you may use lotion or if this becomes a problem, call your kidney doctor.

- ◆ Do not pick at or scratch these areas.
- ◆ Do not use makeup or cosmetics. (Acne usually does not get better while these are being used).
- ◆ Keep hair away from the areas of acne.

If acne doesn't get better contact the transplant office.

Hair Growth

Increased hair growth on all parts of the body is sometimes a side effect of prednisone, cyclosporine, or other medications. This problem may bother girls, especially teenagers. Shaving

this hair is not recommended as it often causes the hair to grow back thicker and/or darker than before.

Bleaches made especially for facial hair or cream hair removers (such as Nair) may be used. Be careful when trying these creams and bleaches for the first time. Always try a small test area first as these products can be very irritating to sensitive skin. Keep these creams and bleaches away from your child's eyes and mouth, and follow the directions on the container carefully.

Dental Care

It is very important that your child has good dental care after transplant. One of the side effects of immunosuppression medicine and some blood pressure medicines is an increase in the size of gums, which is worsened by dental plaque. Regular brushing, especially after your child's immunosuppression medicine is given, is a good way to decrease the gum overgrowth. Severe overgrowth of the gums needs immediate attention to prevent gum disease.

A dental check-up is necessary at least twice a year, or more often if your dentist feels it is needed. **Do not have any dental work done during the first year after transplant unless discussed with your kidney doctor.**

When making a dentist appointment, you will need to tell the dentist two things:

1. Your child has had a kidney transplant and
2. Your child will need an antibiotic before any treatment (including cleanings) to prevent infection. Amoxicillin or Clindamycin will be used according to the American Heart Association recommendations (unless your child is allergic to these).

High Blood Pressure

You will need to check your child's blood pressure twice daily. Once in the morning and once in the evening.

If your child has any of the following signs of high blood pressure, contact the Transplant Coordinator Immediately:

- Headache
- Dizziness or nausea
- Blurred or double vision

Returning to School

The decision about when your child may return to school is made on an individual basis by your renal transplant provider. Normally, children may return to school about 4-6 weeks after the transplant. Homebound schooling (a school teacher coming to your home) may be available to you until the decision is made for you to return to school.

When your child does return to school, be sure that all teachers and the school nurse are aware that he or she has had a kidney transplant. The Transplant Coordinators can provide you or your child's school with a letter telling them important things to be aware of about your child and informs them of your child's need to carry and drink water throughout the day and need to pee at a minimum of every 2 hours.

If your child has never had the chicken pox, it is very important that you notify your child's teacher that chicken pox may be dangerous to him or her. Ask the teacher to notify you **immediately** if anyone in the class develops chicken pox.

If your child **is exposed to chicken pox**, notify your transplant coordinator immediately and we will arrange for your child to receive medication that could provide protection from this virus. To be effective, this medication must be given within 72 hours of exposure.

Activities

For the first three months after transplant, your child will have some restrictions on activity. There should be no heavy lifting or straining and no exercise that would strain the abdominal muscles, such as sit-ups. During this time, activities that shake the body should also be avoided. After three months, transplant patients may return to doing most of the activities they like. Sometimes you may want to hold your child back from participating in some activities if you have fears of infection, accidents, or other problems. Use your common sense and protect your child - just don't overdo it!

Your child may find that muscles in his or her legs are slightly weak due to lack of use during recovery. Exercises such as walking, bicycling and swimming will all help this weakness. Your child may start these exercises *as soon as you get home*.

After three months, your child may find that sit-ups and other abdominal exercises will improve the tone of the abdominal muscles and help to get rid of the "pot belly."

When your child returns to school, he or she should feel free to play in regular activities just like the other children, but a few restrictions must still apply.

Your child should not participate in contact sports such as:

- ◆ **Football**
- ◆ **Martial Arts**
- ◆ **Wrestling**
- ◆ **Dodgeball**
- ◆ **Basketball**
- ◆ **Soccer**
- ◆ **Gymnastics on the uneven parallel bars**

You may cautiously participate in other sports including:

- ◆ **Baseball,**
- ◆ **Swimming**
- ◆ **Track**

FOR TEENAGERS AND YOUNG ADULTS

Key Points

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

Smoking

Smoking can cause lung cancer, damage to the lungs and a greater risk for lung infections, including bronchitis, asthma, emphysema and pneumonia. Smoking also raises blood pressure which is harmful to your kidney. Any of these can become life-threatening in someone who is taking immunosuppression medicines. Although smoking is unhealthy for everyone, it is very harmful to transplant patients.

Drugs

You should never take or use a drug that is not given to you by your doctor. Drugs (street drugs, illicit drugs, illegal drugs, etc) are broken down in the liver and kidney and can cause damage that cannot be fixed. Using drugs that are given through a needle puts you at risk of putting bacteria or viruses (Hepatitis, HIV) into your blood that cannot be cured and can kill you. Marijuana can cause lung infections. Some drugs can cause dangerously high blood pressures, stroke (bleeding in the brain), confusion, mood swings and changes in behavior.

Alcohol

You should not drink alcohol. Alcohol is broken down in the liver and can cause damage that cannot be fixed. Alcohol causes your body to pee more and this can cause dehydration and kidney damage which may not be able to be fixed. The new kidney is not smart enough to know when to stop peeing and to save water. Alcohol can irritate the stomach and cause ulcers. Alcohol can have a cause a bad reaction when taken while on certain medicines. Alcohol can cause confusion, mood swings and changes in behavior.

Sexuality

Sexuality in transplant patients has the same issues that all young women and men face when growing up. Sexual activity puts you at risk of unwanted pregnancies and getting sexually transmitted diseases (STD). STDs include syphilis, gonorrhea, chlamydia, herpes, and human immunodeficiency virus (HIV). Some STDs cannot be cured. If you ever think you may have come into contact (had any type of sex) with someone that has an STD or if you have any questions, call your kidney transplant doctor.

Abstinence (not having sex) is the surest way to avoid STDs. If you choose to have sex, the use of latex condoms during intercourse may reduce the risk of STDs and accidental pregnancies. Preventing accidental pregnancy is the responsibility of both the man and the woman. Pregnancy after transplant may be risky to both you and your baby. Many of the immunosuppression medicines can cause birth defects or miscarriages.

Female transplant patients need to visit a gynecologist and have a pap smear and breast examination every year by the age of 18 years old or as soon as sexually active. These tests can be done by any gynecologist. All reports should be sent to the transplant office. Self-breast exams should be done every month. If you are sexually active, it is possible for you to become pregnant even though you may not have had your first period.

Call the transplant office immediately if you think you might be pregnant.

We, the staff at Children's Medical Center of Dallas, are always available for questions and consultation. Our role in your care is to help you make an informed decision in a non-judgmental, non-pressure setting.

TRAVEL & SWIMMING

Key Points

- *Take twice as many meds with you*
- *Only let your child drink bottled water*
- *Don't let your child eat unwashed or raw food*
- *Don't let your child swim in ponds or lakes*
- *Make sure your child showers after the pool or ocean*

Within the United States

We advise you to wear a Medic-Alert bracelet. Be sure to take twice as many days of medication as you plan to be gone (if you plan to be gone for 5 days, take 10 days of medicine) and keep them from extreme hot and cold temperatures. If you fly, keep your medications with you on the plane instead of packing them in your luggage.

Outside of the United States

- ◆ Some countries require specific vaccinations prior to visiting. No live vaccines should be given.
- ◆ You can start traveling 6-8 months after a transplant
- ◆ Ask for a letter from the transplant office listing all your medications including acetaminophen (Tylenol), laxatives, etc. This needs to be with you when you show your passport and go through customs.
- ◆ We recommend that you be sure to have enough medication for your entire trip. Some countries do not have the same regulation and quality controls for their medications as we do in the United States. Do not refill your medication in any other country besides the United States.
- ◆ Only water from chlorinated sources is safe for drinking. In areas where chlorinated water is not available, or where cleanliness is poor, drink:
 - Beverages, such as tea and coffee, made with boiled water.
 - Canned or bottled water and/or soft drinks (If not available, you will need to boil water and allow to cool before drinking)

If water is not chlorinated, ice must be considered contaminated (dirty) and should not be used. Ice may contaminate containers used for drinking unless the containers have been thoroughly cleaned with soap and hot water after the ice has been thrown away.

- ◆ Select food with care to prevent illness. In areas of the world where cleanliness is poor, avoid unpasteurized milk and milk products (fresh milk from an animal), such as cheese. Raw fruits and vegetables should also be avoided. Eat only what can be peeled or has been cooked.
- ◆ Swimming in contaminated water may result in eye, ear or stomach infections particularly if your head is under water. Only chlorinated pools may be considered safe places to swim.

- ◆ If you need medical care while out of the country, contact your travel agent, the American Embassy or Consulate for names of doctors or hospitals.

Swimming

Transplant patients should not swim in a lake or pond due to the bacteria that live in the water. These bacteria may be harmful to you. In general, swimming in a chlorinated pool, that is well maintained, is safe as long as your child has no wounds. It is best to shower or rinse off when exiting a pool. It is also important not to swallow pool water. This may help prevent the spread of parasites which can live in chlorinated water (usually not properly chlorinated), such as cryptosporidium, an infection that can cause diarrhea and can also infect the liver.

POST TRANSPLANT FOLLOW UP

Key Points

- *Call the coordinator if your child gets a fever immediately*
- *You should have your labs drawn one hour before your immunosuppression is due*
- *Know how to do a blood pressure on your child*
- *Know how to get into contact with your coordinator*
- *Know the signs of rejection and infection*
- *Know what time the medications are to be given*

Prior to Discharge

Before your child goes home, you will need to be comfortable and be able to show/discuss the following with the Transplant Coordinator:

- ◆ How to set-up and give your child's medications correctly with a knowledge of why he or she is taking these medicines and their side effects.
- ◆ Have an understanding of the information in this notebook
- ◆ How to correctly take a temperature
- ◆ Be able to take your child's blood pressure
- ◆ Know how to record temperature, weight and blood pressure on the record sheet
- ◆ Be able to answer the questions on the discharge test correctly

Record Keeping Reminders

In the back of this handbook there is a section for keeping records of your child's temperature, weight, blood pressure and medications.

It is important that you measure and record the following.

- ◆ **Weight.** Document your child's weight every morning at approximately the same time.
- ◆ **Temperature.** Take your child's temperature every morning and every evening. Remember, chill bumps, shivering or feeling cold could mean your child's temperature is rising and they may have a fever.
- ◆ **Blood pressure.** Take your child's blood pressure every morning and every evening (just before the dose of blood pressure medicine is due).
- ◆ **Medication changes.** Record your child's medication changes as they are made at clinic visits.

Please keep all records up to date and accurate to help us understand how to best treat your child according to his or her individual needs.

Following the Medical Plan

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

- ◆ If you are unable to keep a clinic appointment, or are having difficulty taking your child for labs you must call us so we can work together to problem solve.

If you are having difficulty managing your child's health care needs you may ask for help from anyone on the transplant team including: transplant administration, transplant coordinator, dietician, social worker, child life specialist, psychologist, or financial coordinator.

If you do not follow your child's treatment plan and any of the following occur: missing appointments, not having labs checked on schedule, not refilling medications, not renewing insurance or Medicaid application which result in loss of coverage, etc. is considered medical neglect and child protective services (CPS) may need to become involved.

Contacting the Donor Family

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

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

- ◆ How the process works
- ◆ Confidentiality
- ◆ Writing your letter
- ◆ The donor family's response

How the process works

Although each transplant center has different procedures for contacting donor families, the following guidelines may help you when drafting a letter or card. For specific recommendations and requirements, talk to your transplant team or local OPO.

Mailing your card or letter:

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

Once the transplant center receives your letter:

1. The transplant center will forward your letter to your OPO.
2. A coordinator from the OPO will review it to ensure confidentiality.
3. The coordinator will then contact the donor family to ask if they wish to accept correspondence from recipients.
4. If the donor family does not wish to communicate, the OPO will inform your transplant center accordingly.
5. If the donor family does wish to communicate, the OPO will forward your letter to them.

Confidentiality

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

Writing Your Letter

What information should I include?

- ◆ Your first name only
- ◆ The state where you live
- ◆ Recognize the donor family's generosity and thank them for their gift
- ◆ Describe how long you waited for a transplant and how the wait affected you and your family
- ◆ Explain how the transplant has improved your health and changed your life
- ◆ Describe the impact of your transplant on your own family
- ◆ Explain what has happened in your life since the transplant
- ◆ Mention if you are married, have children, grandchildren, etc.
- ◆ State your hobbies or interests

What information should not be included?

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

Will I hear from the donor's family?

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

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

THE PACT PROGRAM

Pediatric to Adult Health Care Transition (PACT)

At some point in the future, our young adult patients will reach a point in which they would be best cared for at an adult medical center by providers who are best trained to care for adults who have had a transplant. This transition typically occurs between the ages of 18 and 21, at a time in which patients may be undergoing several other life transitions as well. These may include graduating high school, moving out of the family home, beginning college, or starting a new job. We want our patients to be well-prepared to manage their health care needs in these new environments, as well as to begin working effectively with adult health care providers. We also realize that transitioning to a new medical center can be a scary and emotional time for patients and their families. Thus, we have developed a program to ensure that we meet all of the educational and emotional needs of transplant families as they transition to adult health care.

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

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

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

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

If you have questions about the PACT Program or would just like more information, feel free to contact the Transplant Office.

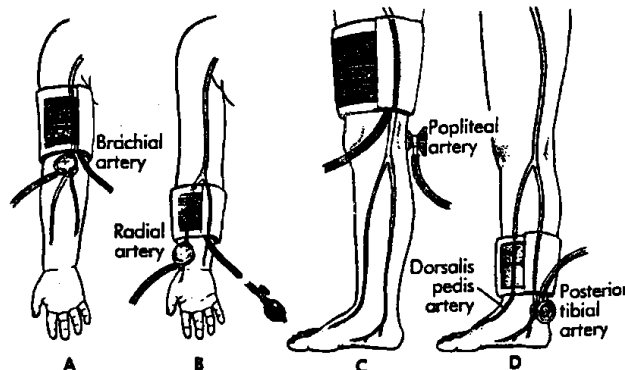
Appendix

BLOOD PRESSURE MONITORING

You will be provided instruction on blood pressure measurement by one of the transplant coordinators prior to discharge from the hospital. You will be sent home with a semi-manual blood pressure monitor.

Steps for measuring a manual blood pressure:

1. Explain to your child that it is time to measure blood pressure. Avoid the use of words like "taking" or "getting", as these words sometimes scare children.
2. Allow your child to touch and play with the equipment, if desired, or practice on a toy or doll. This may help the child cooperate and be less afraid.
3. Remove clothing from the blood pressure measurement site. Have the child sit or lie in a comfortable position. Emphasize that blood pressure measurement is most accurate when the measurement site is level with the heart.
4. Center the cuff over the artery.
5. Wrap the cuff smoothly and securely around the blood pressure measurement site without wrapping it too tightly. A single fingertip should slide under the edge of the cuff.
6. Feel for the pulse over the artery.
7. Place the stethoscope ear pieces in your ears.
8. Place the diaphragm of the stethoscope over the pulse site using a light but firm touch.
9. Close the screw with one hand, then repeatedly squeeze the bulb to inflate the cuff quickly to a point about 20mm Hg above the child's usual systolic measurement.
10. Open the screw slowly to release the pressure.
11. Listen for the pulse sounds (soft beating sound) while opening the screw:
 - ◆ Systolic measurement: the number at which the first sound is heard.
 - ◆ Diastolic measurement: the number at which the sound is no longer heard. In very young children the soft beating sound may be heard all the way down to zero. In this case, teach the family to measure blood pressure by palpation instead of auscultation.



Wong, D. and Whaley, L. (1990). Clinical Manual of Pediatric Nursing, 3rd edition. St. Louis. CV Mosby Co.

NORMAL LABORATORY VALUES

The abbreviations used on the forms are explained below. The chart below contains the normal values for Children's Medical Center of Dallas' laboratory.

Laboratory Test	Abbreviation	Normal Value
Alkaline Phosphatase	Alk P'tase or Alk Phos	105-420 u/l
Albumin	Alb	3.6--5.1 G/dl
Bilirubin-Direct	Bili-D	0.00-0.30 mg/dl
Bilirubin -Total	Bili-T	0.10-1.30 mg/dl
Blood Urea Nitrogen	BUN	5-18 mg/dl
Bicarb	CO2	18-31 mmol/dl
Calcium	Ca	8.0-11.0 mg/dl
Chloride	Cl	98-106 mEq/l
Cholesterol	Chol	125-170 mg/dl
Creatinine	Cr	0.3-1.2 mg/dl
Cyclosporine/Prograf Blood Level	CyA/FK506	Dependent upon method used
Glucose (fasting)	Glu	70-106 mg/dl
Hemoglobin	Hgb	12.0-15.3 g/dl
Magnesium	Mg	1.7-2.4 mEq/l
Phosphorus	Phos	3.3-5.4 mg/dl
Platelet	Plt	150,000-450,000 per mm ³
Potassium	K	3.5-5.0 mEq/l
Liver Function Test	SGOT/AST SGPT/ALT	10-45 U/L 10-56 U/L
Sodium	Na	134-146 mEq/l
Triglycerides	Trig	41-138 mg/dl
White Blood Count	WBC	4,500-11,000 k/mm ³

DEFINITIONS OF LABORATORY TESTS

Sometimes it helps to know why these tests are being ordered. Some of the more common ones are defined below.

Blood Urea Nitrogen (BUN)	BUN is a by-product of the protein we eat and is eliminated through the kidneys. It is an indicator of how the kidney functions.
Serum Creatinine (Sr.Cr.)	Sr.Cr is cleared through the kidneys and indicates renal function.
Bicarbonate (CO ₂)	Healthy lungs and kidneys work together to make a normal acid/base balance in the body.
Creatinine Clearance	Since creatinine in your body is cleared through your kidneys, you can collect all of your urine for a 24 hour period. The result of this test can tell precisely how much creatinine your kidney can clear in a minute and is, therefore, a reliable indicator of kidney function.
Calcium (Ca)	Calcium is necessary to help your blood clot, to build strong bones and teeth, and for muscular functioning. It also helps with your heart and nerve function, and works closely with phosphorus (PO ₄). Exercise helps keep your calcium in your bones.
Magnesium (Mg)	Magnesium is found in bones and is necessary for normal muscle function and blood clotting.
Phosphorus (PO ₄)	Phosphorus works closely with calcium to make strong bones.
Potassium (K)	Potassium is needed to help cells grow, and for your heart and muscles to function properly.
Sodium (Na)	Sodium is in everything we eat. It shows the balance in your body between salt and water.
Hematocrit (Hct)	Hct is the percentage of red blood cells in your blood. A low value may make you feel tired.
Hemoglobin (Hgb)	Hgb is a protein which carries oxygen and is present in red blood cells.
Platelets (Plts)	Platelets help stop bleeding by clumping and forming a blood clot around an injury.
White Blood Cells (WBC)	White blood cells are part of the body's immune system which protects the body from infection. They also contain the cells which contribute to rejection.

OTHER LABORATORY TESTS

Cyclosporine Level, Tacrolimus, Sirolimus	This test indicates the amount of this drug in your blood stream.
Glucose	This test indicates the amount of sugar in your blood stream.

There are other tests that your child may have while in the hospital, or as an outpatient, that helps us evaluate how well his or her newly transplanted organ is doing.

ORGAN STATUS RELATED TESTS	
Renal Ultrasound	A transducer (like a microphone) is guided across the patient's abdomen and side after a sound conducting jelly is applied. Sound waves illuminate the abdominal organs making it possible to accurately measure size, shape, and the presence of abnormal fluid collections.
Glofil	This is a test in which blood is collected at specified times. A calculation is performed which shows the glomerular filtration rate (GFR) of the kidney.

Neutropenia

Neutropenia is a decrease in the neutrophils which are the white blood cells that fight off infection. This can happen because of a viral illness or as a result of a medication. If your child is found to be neutropenic, further work up is needed to discover the cause. We may order viral tests on their next blood draw and monitor their labs more closely. We may also discontinue or switch medications that are known to cause this problem. It is important to monitor closely for symptoms of infection. If your child runs a fever while they are neutropenic, this is an emergency and they must seek care immediately.

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

Neutropenic precautions:

- ◆ Do not eat uncooked or raw fruits or vegetables
- ◆ Strict hand washing, prior to each meal or snack after restroom and as needed
- ◆ Use properly cleaned utensils
- ◆ Do not eat or drink after others
- ◆ Take care of any wound
- ◆ Take care of mouth, do not floss or brush gums excessively for risk of bleeding, also do not schedule routine dental appointments
- ◆ Do not come in contact with live plants or flowers due to germs in soil and standing water
- ◆ Do not come in contact with anyone with an infection, or has received a live virus vaccine.
- ◆ Do not come in contact with pets, especially bird cages, litter boxes, etc.

Glofil Testing

The Glofil is a test to assess how well the kidney is working and decide if any changes in kidney exist. In some cases, the serum creatinine does not fully reflect how well your child's kidney is working. The Glofil measures the "glomerular filtration rate" or GFR of the kidney. The GFR is the amount of blood filtered by the kidneys each minute. It is one indicator of the health of the kidneys.

Pre-test Instructions

- ◆ ***If your child is undergoing the Glofil test and has had any known or suspected allergies to iodine or shell fish, please let the transplant office know.***
- ◆ Additionally, if your female child is more than 10 years old and has experienced menstruation, you she will have to have a urine pregnancy test performed prior to, or on the day of the Glofil procedure. Please inform the transplant office of this at the time we schedule the Glofil procedure so this test can be appropriately scheduled.
- ◆ The Glofil procedure lasts approximately six hours. You may want to bring reading materials, games, a digital music device, etc.
- ◆ Your child will be able to take his or her medicines before and during the Glofil procedure.
- ◆ There are no special preparations for the Glofil test. You child should eat and drink normally before and during the test.
- ◆ The test involves an injection of a radio-isotope and the collection of small blood samples. In general there is no need to lie down or remain motionless during the test. The injection is given in a vein in your child's arm at the start of the test. It is not a medication or a dye; it is simply a safe agent that has a small amount of radioactivity in it. The radioactivity is equal to a fraction of the amount your child would receive from a chest x-ray. The kidneys identify the isotope as they would any other waste product. The rate at which they eliminate the isotope from the blood determines the GFR.
- ◆ Seven blood samples are collected during the test. The test takes from 4-6 hours after the injection. However, this is not continuous test time. There are two periods of time when blood is drawn: During the first period, up to four blood samples are taken only minutes apart. The second period of blood draws begins a few hours later, when three blood samples are taken 30 minutes apart. The samples are used to determine how much Glofil-125 is left in the blood after the kidneys have filtered some out. The remaining Glofil-125 is removed from the body through urination. If you have other obligations, i.e. other small children or appointments, please make prior arrangements as unforeseen circumstances may occur. If you have any questions or concerns about the Glofil procedure, please call 214-456-2980.

ADDITIONAL RESOURCES

Resources for Transplant Patients

The following is a list of resources for children.

(Contact your social worker for more specific information and help with applications.)

American Kidney Fund

(800) 638-8299

The American Kidney Fund is a non-profit, national organization providing direct financial assistance for kidney disease patients, free educational materials and newsletter, transient dialysis assistance, and renal camp funding.

American Association of Kidney Patients

(813) 251-0725

Provides support services to patients, publishes newsletter, brochures, and represents patients to Congress.

AOTA (American Organ Transplant Association)

2306 Texas Parkway, Suite 130

Missouri City, Texas 77489

AOTA can assist families with transportation and lodging for transplantation and upon discharge from the hospital. Also provides transplant information through AOTA Items, a quarterly publication.

ATA (American Transplant Association)

(214) 467-4714

P. O. Box 225978

Dallas, Texas

ATA can assist with setting up a trust fund through their association. The ATA also has a guide to fundraising.

Children's Organ Transplant Association (COTA)

(800) 366-2682

This is an agency that assists families in raising funds for transplants and transplant related expenses. COTA provides local campaigns with on-site staff for start-up, fund raising advice and support, media relations advice and support, campaign start-up kits and more. Provides 501(c) (3) charitable status to local campaigns making larger tax-free donations possible.

End Stage Renal Disease Network of Texas

(214) 669-3311

ESRD Network of Texas serves dialysis and transplant patients, families, and health care teams within the State of Texas. Assures provision of quality care, and acts as an information and referral resource.

National Heart Assistant and Transplant Fund

(800) NHATF-99The National Heart Assistant and Transplant Fund is a non-profit oral organization to assist the transplant community. This organization provides organ donor awareness information, emergency grants, and fund raising.

National Kidney Foundation of Texas

(214) 934-8057

A non-profit national organization funded by individual and corporate contributions. Goals are research, promotion of organ donation, and public education. Patient services include newsletter, Medic Alert bracelets, brochures, and limited emergency patient assistance.

Organ Transplant Fund (OTF)

(800) 489-3863

OTF is a non-profit charity organization assisting with the needs of transplant patients. Provide assistance with fund raising, related bills, travel, food, lodging, information and more.

Social Security Administration

(800) 772-1213

Medicaid and Supplemental Security Income (SSI)

Medicare

SSI can provide monthly benefits for families with a child who has a chronic illness. Eligibility depends on the number in family and gross income. Medicare is the national government program that funds medical expenses for patients with end stage renal disease.

SWTP Foundation

(214) 943-1652

221 W. Colorado, Suite 221, Dallas, TX 75208

The SWTP Foundation is a non-profit organization assisting the needs of transplant recipients. Provides one-time grants to assist with financial needs with associated with transplantation.

Texas Department of Health's Kidney Health Care Program

(512) 465-2654

Provides medication and transportation reimbursement.

Transplant Recipients International Organization (TRIO)

(800) 874-6386 (TRI-O386)

1000 16th Street NW

Washington, D.C. 20036-5705

An independent, non-profit international organization committed to improve quality of life for transplant candidates, transplant recipients and their families, and families of organ/tissue donors. Mission is awareness, support to transplant patients and their families, education, and advocacy.

Ronald McDonald House

(214) 631-7354

5641 Medical Center Drive

Dallas, Texas 75235

The Ronald McDonald House provides a temporary "home away from home" for families of children under 18 years of age who are undergoing treatment for a serious childhood illness. Room rates are based on a sliding scale fee. Kitchen and laundry facilities are in the building. A family can only use this through a social worker's referral.

Local Resources

Local agencies/organizations will provide assistance to patients on an individual basis if they are contacted by the patient's family or transplant social worker. Transportation assistance may also be available through the local transit system or Medicaid transportation.

Local Hotels

A number of hotels within minutes from the Medical Center provide a discount to patients and their families.

