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INTRODUCTION

This handbook is designed to provide guidelines to pre and post kidney transplant patients and their families. It is yours to keep. The handbook includes instructions about diet, medications and activity after discharge. It also provides blank forms to keep records of temperature, blood pressure and weight, as well as all medicines that your child will be taking. These records are **very important** in helping us understand how to best take care of your child according to his or her needs. **Please read this manual regularly and carefully, and be sure to bring this information with you when you come to all clinic visits.**

Although renal transplant providers and transplant coordinators will be directing 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. Providers, Transplant Coordinators, Dietitians, Psychologists, Social Workers, and Child Life Specialists are here to assist in the care of your child. It is okay to feel nervous about going home. Your transplant team is always available to assist you.

Solid Organ Transplant (SOT) B2300

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Fax 214-456-8405

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 comprehensive care for pediatric patients needing heart, kidney, liver, and intestinal transplantation. Focused on patient family-centered care, the dedicated team of transplant specialist will support, guide, educate, and care for you and your child through the phases 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, allowing for accessible, continuous, and comprehensive care of your child within the Children's system. With the mission of exceeding expectations of treatment and care of children needing organ transplantation, the Solid Organ Transplant Program strives to advance the medical, social, and scientific aspects of pediatric transplantation...to make live better for children.

Having performed more than 1000 transplants, a rare accomplishment in the field of pediatric transplantation, below are accomplishments of the transplant program at Children's.

Heart Transplant

Children's has performed more than 140 heart transplants since performing Dallas' first pediatric heart transplant in 1988. Children's has the highest volume 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.

Kidney Transplant

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

Liver Transplant

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

Intestinal Transplant

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

The Transplant Team

Kidney transplantation is an expensive procedure that requires the expertise of many specialists trained in surgical techniques, preoperative care, postoperative care and immunosuppressive management. For this reason, we use a team approach to coordinate the kidney transplant patient's care. In addition, all of the kidney transplant team members are pediatric experts.

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

Pediatric Nephrologists

The transplant nephrologists are pediatric nephrologists with additional expertise in kidney transplantation. They will work with your child's primary healthcare provider(s). After kidney transplantation, the transplant nephrologists will become your child's nephrologists. 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 physicians who will transplant the new kidney into your child's body. The transplant surgeons are skilled 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 every day to check your child and review lab test results and other procedures.

Transplant Advanced Practice Nurse

The transplant advanced practice nurses are nurses with a higher degree of education and practice experience. The advance practice nurse typically extends the care provided by physicians in the care of patients and understanding their specific needs. They collect patient history, conduct physical exams, diagnose acute and chronic illnesses, and order or perform diagnostic tests for the pre and post transplant patient.

Transplant Coordinators

The transplant coordinators are experienced registered nurses who are responsible for coordinating all aspects of the transplantation process, from referral by the local physicians to evaluation, and on through post transplantation, discharge and follow up care. The transplant coordinator works with the nephrologist, your local physician, transplant physician and surgeons to coordinate your child's care. The coordinator is always available to answer any questions you may have about transplantation, and the transplant process.

Financial Coordinators

A Financial Coordinator is available to help families with financial considerations throughout the transplantation process. The financial coordinator will contact your insurance company to obtain a benefit summary and determine if approval is required for evaluation and transplant. At the

time of evaluation, a financial coordinator will discuss the details of your benefits and identify additional financial resources. The financial coordinator will provide guidance when applying for state/federal programs (ie. Medicaid, Supplemental Security Income). Should you have any questions or concerns related to health insurance, we encourage you to contact your financial coordinator.

Social Workers

A social worker will help you cope with the many stresses that often accompany the transplantation 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 the transplant surgery such as transportation, lodging, and financial assistance. A social worker can also provide counseling and emotional support to help relieve any emotional distress you feel. The social worker will also help arrange your child's discharge from the hospital and make appropriate referrals to outside community resources if necessary.

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' cope with the stresses associated with kidney transplantation. Your child will receive a thorough developmental assessment before the transplant, which will provide the baseline for future annual assessments following the transplant.

Many children with chronic illnesses show minor developmental delays, and if these are detected, remedial help will be recommended. The psychologist will also be interested in any concerns you have about your child's emotional status and behavior. Many parents find it helpful to discuss their concerns, however minor, 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 unique experience that affects every family member. The psychologist has worked with many transplant patients and is highly qualified to help you and your loved ones obtain the most from the new opportunities that transplantation 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 linear growth and muscle development. The dietitian will also work closely with you to develop the best diet for your child. For younger children, the dietitian will explain 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 is available to provide expert nutritional advice for your child's particular needs.

Transplant Pharmacist

The transplant pharmacist is responsible for identifying potential and actual medication related concerns, resolving potential medication related concerns, and preventing potential and actual medication related concerns from becoming problematic. He or she serves as a resource to the

medical team during inpatient rounds and during discussions involving patient care. The transplant pharmacist is also responsible for providing medication education to patients/family members in the inpatient setting.

Primary Nurses

Your child will have a primary nurse during his or her inpatient stay at Children's. The primary nurse will be responsible for developing 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 primary nurse will also be responsible for checking vital signs; administering medications; monitoring I.V. lines, dressings, and drainage tubes; tracking daily intake, output, and weights; ordering lab tests; and performing procedures. Your primary nurse, and other nursing staff, will always be available to answer questions, explain treatments and procedures, and offer assistance for making your stay as comfortable as possible.

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 developing 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; administering 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 assistance for making your stay as comfortable as possible.

Child Life/ Child Development Specialists

To help prepare your child emotionally for transplant surgery and the hospital stay, a child life specialist will explain various pieces of medical equipment and procedures to a child in terms he or she can understand. This process usually includes "medical play", a session when the child can see and touch certain 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 anxieties about the hospital naturally and the child life specialist can address those concerns directly 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 coordinate special events for the children at the hospital.

Chaplains

Hospital chaplains are available to assist patients and families with the faith and spiritual issues that may arise during the course of the transplant experience. At Children's Medical Center, pastoral care support takes the form of daily chapel services, regular pastoral visits, supportive counseling and parent support groups.

The pastoral care department assists 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, radiologists, infectious disease doctors, renal doctors, cardiologists, respiratory therapists, and physical and occupational therapists.

Other staff members, including interns and residents, often accompany your physicians on rounds. These are graduate, licensed physicians who are receiving additional training in specialized medical or surgical skills under the supervision and direction of the transplant team.

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

Children’s Medical Center Dallas – Renal Transplant Team Members

Transplant Physicians 214-456-5880

- Michel Baum, MD
- Mouin Seikaly, MD
- Raymond Quigley, MD
- Katherine Twombly, MD

Transplant Surgeons 214-456-5166

- Dev Desai, MD
- Meelie Debroy, MD
- Juan Arenas, MD

Transplant Advanced Practice Nurse 214-456-6625

- Nicole Woolen, RN, MSN, CPNP

Transplant Administration 214-456-5166

Dean Henderson, MHA – Administrative Director

John Dickerson, RN, MSN – Clinical Manager

Ashley Sadlon, MHA – Program Manager

Transplant Coordinators

Jerry Perry, RN, CCTN 214-456-3572

Martha Oglesby, RN 214-456-2119

Wanda McPhail, RN, BSN 214-456-5155

Yvonne “Bonnie” Aguero, RN, BSN, CPN 214-456-6414

Transplant Psychologist

Jami Gross-Toalson, PhD 214-456-5849

Transplant Social Worker

Crystal Winter, LMSW 214-456-6182

Transplant Dietician

Jill Rockwell, RD/LD 214-456-5644

Transplant Child Life

Melanie Sweat, CCLS 214-456-6447

Transplant Pharmacist

Lindy Huang, Pharm D 214-456-9366

Transplant Financial Counselors

Patricia Puente 214-456-6037

Noemi Manriquez 214-456-8750

Kidney Transplant Administrative Assistant

Chasity Webb 214-456-2546

Transplant Related Departmental Phone Numbers

Solid Organ Transplant Clinic 214-456-8600

800-846-6768

Nephrology Clinic 214-456-5880

Inpatient kidney transplant nursing station (C5) 214-456-2972

Pediatric Intensive Care Unit (12th floor) 214-456-7882

Kidney Function Explained

Functions of the Kidney

Normally, a person has two kidneys. However, it is possible for just one kidney to adequately perform all of the necessary functions for the body. Your kidneys have many functions. The main function is to remove waste products from the body. The filtered wastes are then removed from the body in the urine. Two of these waste products are creatinine and blood urea nitrogen (BUN). The creatinine and BUN levels in your blood are very important values that are measured to determine how well your kidneys are working.

Other functions include:

- ◆ Regulation of the production of red blood cells. This is done by the kidneys releasing a hormone called erythropoietin
- ◆ Controlling blood pressure by releasing the enzyme called rennin
- ◆ Absorption of calcium in the body, activating vitamin D
- ◆ Production of growth hormones
- ◆ Removal of toxins and drugs from the blood
- ◆ Regulation of the amount and type of fluid in the body

What happens when the kidneys fail?

When kidney function stops or decreases, there is a buildup of waste products and excess fluid in the body. This can be harmful to the body. After 85% of kidney function is lost, other methods are necessary to rid the body of the waste products and fluids. Dialysis and kidney transplantation are two treatment options for chronic kidney failure. A successful transplant may improve your energy level and eliminate the need for fluid restrictions and dialysis.

What is a Kidney Transplant?

Transplantation is the surgical placement of a healthy kidney from a human donor into your child's body. If successful, the donor kidney will take over the functions of your diseased kidneys. Transplantation gives your child freedom from dialysis treatments.

Where do kidneys for transplant come from?

A kidney for transplant can come from two sources:

- ◆ A living donor can be either a person who is closely related to the recipient (living related or LRD), or a person who is not related by blood (living non-related LNRD), but who has a strong emotional bond with the recipient.
- ◆ A cadaveric donor is a person who has recently died, and the family has agreed to donate the organs for transplantation.

How long have kidney transplants been performed?

The first successful kidney transplant was performed in the United States in 1954 between identical twins. The first successful cadaveric kidney transplant was done in 1962 which was also the first transplant to use immunosuppressive medications for the prevention of rejection.

What are the advantages of kidney transplantation?

There is a common consensus that children who receive a kidney transplant will have a better quality of life than children on dialysis. Although close medical supervision is still required after transplantation, your child will no longer be dependent upon a machine. With a successful transplant, your child will resume a more normal life, with fewer dietary and fluid restrictions. Some children who receive a kidney transplant begin to grow at a more normal rate and may actually have “catch up” growth.

What are the disadvantages of kidney transplantation?

The medications needed to prevent the body from rejecting the transplanted kidney often have side effects. A transplant physician will go over the list of potential risks and complications before you decide on transplantation. Although not all transplant patients experience all of the side effects, you need to be aware of some of the following risks:

- ◆ Acute and/or Chronic rejection may occur despite the medications your child takes to prevent rejection
- ◆ Increased incidence of infection, therefore special care must be taken to prevent exposure to other people who are sick
- ◆ Increased risk of malignancy (cancer)
- ◆ Cataracts
- ◆ Joint and bone disease
- ◆ Weight gain
- ◆ Diabetes may be caused by corticosteroids taken to prevent rejection

Who is eligible for transplant?

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

- ◆ Any child who has irreversible end stage renal disease (ERSD) is able to be *considered* for kidney transplant.
- ◆ Your child must weigh *at least* 10 kg which is around 20 pounds.
- ◆ Your child must be at least 2 years of age. Children under the age of 2 do not do well with cadaveric transplants. Children under 18 months of age are not considered to be as good of candidates for live donor transplant.
- ◆ You should discuss transplantation with your physician. For some children, transplant may not be the treatment of choice initially. There may be other medical conditions that prohibit transplantation until a later time.

Timing is everything. The first transplant is usually the best transplant. Our goal is to make this first transplant as close to perfect as possible. Waiting a few extra months seems a wise investment in most cases.

Is dialysis necessary before the transplant?

Each situation is different. If there are indications that kidney failure is progressive and your child is close to dialysis, it is possible for your child to be evaluated for transplant prior to beginning dialysis. In addition, complicated Medicare and/or insurance rules control this procedure to some degree. However, there are some situations where transplant is possible without dialysis. Your transplant team will work with you to determine the best course of action for you.

What starts the transplant process?

Talk with the physician caring for you. If it is felt that transplantation is the treatment of choice, then the transplant office will be notified. Financial verification is the first step of the transplant process. There are many different insurance plans and it is important that the verification process be followed, so that the payment source for the pre-transplant evaluation, living donor evaluation or cadaveric kidney expenses, hospitalization for both recipient and living donor and finally, the post transplant follow up visits will be identified.

This process can take a short time or up to several weeks. You will be kept informed of the status of your application by the transplant office.

Who pays for transplant?

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

It is important to realize that it is unlawful 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 compensated for time off work, lodging, 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 are considerate of employees who need time off to donate a kidney.

Will my child be involved in research protocols?

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

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

The Transplant Evaluation

What are the steps of the transplant evaluation?

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

1. *Medical Evaluation:* The recipient has a complete medical evaluation including medical history, physical examination and a series of tests to determine if your child is healthy enough to receive a kidney transplant. The time it takes to complete this evaluation is dependent upon the patient's dialysis schedule, when testing can be scheduled, and getting additional tests or consults if another medical condition (other than renal failure) is identified.
2. *Tissue Typing / ABO Blood Type:*
 - ◆ *Tissue Typing* is actually a *blood* test, (not a sample of tissue). These special blood tests are used to determine your HLA antigens (your genetic make-up). Blood is taken from the child (recipient) and any potential donors. This is how we determine matching between donor and recipient.
 - ◆ *ABO Blood Type* determines blood group compatibility. The donor and recipient must have *compatible* blood groups.

These are important tests used in both living related donor and cadaveric transplants to obtain the best kidney for your child.

3. *Presentation to the Transplant Selection Committee:* After the recipient evaluation is complete, the patient is presented to the Transplant Selection Committee for final approval. Following approval, the living related donor work up is begun or if there is no living related donor, the patient will be registered with the United Network for Organ Sharing (UNOS), the national wait list for all patients awaiting organ transplantation.

What tests are done?

- ◆ Blood tests in addition to the usual blood tests for your kidney disease include viral antibody titers, hepatitis screen, and HIV.
- ◆ A chest x-ray to determine if your child has any lung problems.
- ◆ A cardiac evaluation including EKG, echocardiogram and a visit with the cardiologist is done to determine if there are any abnormalities in the way your child's heart functions.

- ◆ A voiding cystourethrogram (VCUG) is a special x-ray done to evaluate the urinary drainage system including the bladder and ureters (the tubes that carry the urine from the kidney to the bladder). . During this test, a small catheter will be inserted into the bladder. The test will evaluate the bladder (size, shape and capacity) and show if urine backs up into the kidney during voiding. This is called reflux. If there a problem is discovered, further evaluation may be needed.
- ◆ A sonogram of the patient’s kidneys is an imaging study where a transducer (similar to a microphone) is guided across the patients skin to the determine size, and anatomical structure of the kidney.
- ◆ An exam by a urologist (a specialist in the care of the urinary system). He will also look at the results of the VCUG and sonogram.
- ◆ Urine tests include a culture (looking for infection) and a 24-hour urine collection (to measure residual kidney function).
- ◆ A pap smear for girls/young ladies age 16 and older.
- ◆ An eye exam by an ophthalmologist.
- ◆ A dental exam to identify any potential dental problems that would need to be rectified prior to transplant.
- ◆ A special x-ray to determine the stage of bone development and the patient’s “potential” for growth.
- ◆ Immunizations and childhood disease status is 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, it will be important to complete them if possible prior to transplant. Once transplanted, the child cannot receive any live virus vaccinations (such as the chicken pox, measles, mumps, or rubella vaccines).

What is the function of the Renal Transplant Selection Committee?

The Renal Transplant Selection Committee is made up of pediatric nephrologists, transplant surgeons, and other members of the multi-disciplinary team who, as a group, review the medical evaluation to determine if transplantation is the best treatment option. The committee may make further recommendations if any concerns are identified during the evaluation process.

What happens to the patient's native kidneys?

The patient's own kidneys are not usually removed unless there is a medical or surgical reason to remove one or both. Your physician 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 associated with kidney disease (hypertension, recurrent urinary tract infections, etc.) that are not controlled with medical management.

What is Tissue Typing?

Tissue typing is done by obtaining a sample of the patient'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 biological mother and father. A child receives one set of antigens (called a haplotype), from each parent which means that each parent will be a one haplotype with their child. If siblings inherit the same sets of antigens from each parent, they would be an "identical match" with each other. If siblings inherit different antigen sets from each parent, there would be no antigens that matched between the siblings. Any relative wishing to donate must have an ABO type and tissue typing done determine compatibility with the transplant recipient. Tissue typing and ABO typing are also done on cadaveric donor kidneys.

What are Antibodies?

An antibody is a protein substance produced by the body in response to the introduction of a specific protein (antigen) that is foreign to our body. This occurs through blood transfusions, previous transplants, or pregnancy. Antibodies are a component of the rejection process.

What is a "High Reactor"?

Remember the definition of the antibody above? Antibody screening is a blood test, usually done monthly (while preparing for transplant), to determine the patient's immune system reactivity. The white cells in the blood are tested against known antigens from other people in the general population. The result will show the percentage of antigens against which the recipient's (your child's) immune system has formed antibodies. This is an important piece of information along with the ABO type and tissue typing when identifying a compatible kidney and minimizing rejection. The higher the percentage of antibodies, the longer it may take to find a compatible kidney.

However, if you have a high level of antibodies detected in the patient's blood, a sample of that blood is placed on a special tray along with other transplant recipients who are "high reactors". When a cadaveric kidney becomes available with a compatible blood type with the recipient, a cross match test is done, using the blood sample from that tray.

What is a "cross match" test?

The "cross match test" measures the level of antibodies the recipient has against the antigens of a specific kidney donor. This is done by using fresh blood samples from the donor and the

recipient. The blood *cells* from the donor are incubated with the blood *serum* (liquid part) from the recipient. If the recipient has “antibodies” against the antigens of the potential kidney donor, the donor cells would be killed. This is called a “positive cross match” and indicates the kidney would be rejected if transplanted. If this occurs, the transplant must be cancelled. A “negative cross match” indicates that the recipient does not have detectable antibodies against the potential kidney donor and the transplant can take place.

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

Remember the definition “high reactor”(above)? Because your child’s blood is on a special “high reactor” tray, he or she might be called in for a cadaveric kidney based on a “negative cross match test” from this tray. However, when you get to the hospital and a fresh blood sample is obtained, it is possible that the cross match test could be positive.

On the other hand, many times this preliminary cross match is positive and you will not even know that the test is done. It is important for you to remember that the transplant team is screening all available kidneys to find the one most compatible for your child, even if you are not aware of it.

How do I know if a family member can donate?

A family member over the age of 18 can be considered as a potential donor. As discussed above, the initial considerations are:

- ◆ ABO typing
- ◆ Body surface area (BSA) determination.

What happens if no family member matches?

If there is not a family member who can donate, the child’s name will be placed on the national and local cadaveric waiting list.

Financial Agreement

Transplants are life giving and life changing. It is a serious commitment and an expensive undertaking which represents a partnership between you, your physicians, and the transplant team. It is essential to maintain adequate, uninterrupted insurance coverage to support the cost of the transplant and necessary on-going care and medications. It is important that you understand the terms and conditions of your current insurance plan. If your insurance changes or is terminated, please notify your transplant financial coordinator, prior to or within one week of the change. Your failure to do so can result in an insurance denial and/or personal liability for any and all charges associated with the procedures(s). Non notification of these changes can also affect listing status.

Please be aware that Children's Medical Center at Dallas is unable to support your medication requirements. Your Transplant Financial Coordinator can assist you in reviewing the prospective options to insurance plans.

The Living Donor

What is expected of the potential living donor?

The potential donor must be sincerely willing to donate a kidney, be in good health (physically and mentally), have two *normal* kidneys, and be Blood Type and Tissue Type *compatible* with the recipient.

Who pays for the donor evaluation and hospitalization?

The donor evaluation and hospitalization are paid for by either the recipient's insurance policy, the ESRD Medicare program, Medicaid or by the donor's individual insurance policy. There is *no* cost to the donor. There is *no* financial compensation for donating a kidney. The donor will be out of work for several weeks and needs to plan for lost time at work, as lost wages and transportation costs are *not* reimbursed. Our financial counselor and social worker will help you with the financial aspects of transplant. We need to make you an appointment to meet with them before beginning the transplant process.

What tests are involved in being a donor?

- ◆ ABO (Blood Type) and tissue typing to determine blood & tissue *compatibility*.
- ◆ Body Surface Area (BSA) determination. The BSA is the total surface area of the human body. The primary components used to determine one's BSA are height and weight, though other factors such as age and gender may be considered. It is important that the potential donor fall within a certain BSA range to ensure the best possible outcomes.
- ◆ Blood and urine tests to determine if the donor has any disease process that might prevent donation of the kidney.
- ◆ Medical history and physical examination: to evaluate the general health of the donor. Any abnormalities found in the history or exam would need further investigation. Certain diseases, such as diabetes, high blood pressure, heart disease or cancer would prevent someone from donating a kidney.
- ◆ An EKG: to determine the presence of any heart rhythm abnormalities.
- ◆ A psychological evaluation to assess the motivation of the donor and to provide support.
- ◆ A Helico CT scan: is a special x-ray which is done to evaluate the anatomy and structure of the kidney and to look for the presence of cysts, tumors, etc.

- ◆ A skin biopsy: in which a tiny piece of skin is removed from the potential donor's arm. This is done as an outpatient, under *local* anesthesia. A cross match (to test compatibility) is done using the *cells of the donor skin* and the *serum (blood) from the recipient*. The skin has cellular composition closer to that of the kidney.

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

The medical evaluation is done by the UT SOUTHWESTERN UNIVERSITY HOSPITAL - ST. PAUL in Dallas. Once Children's determines the donor has a compatible blood type and the BSA is within an acceptable range, 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 is completed, the donor is presented to Children's Transplant Committee by UTSW – St Paul's pre-transplant coordinator. The committee decides if the donor is medically and mentally able to donate a kidney. It is important to note that the transplant staff at Children's cannot disclose any information related to any aspect of the potential donor's candidacy, or the outcome of the donor evaluation.

What are the risks?

A potential kidney donor will have an extensive medical evaluation to determine whether or not he or she is healthy enough to undergo the donation process. Even after a thorough evaluation, risks may still be present. For example, a risk associated with the Helico CT Scan (one of the last tests done during the evaluation process) is allergic reaction to the dye. There is always some risk associated with anesthesia during any kind of surgery. During kidney donation surgery (as with any surgical procedure), there is risk for a wound infection, pneumonia, bleeding or thrombophlebitis (blood clot in the leg). Although the risk of death is extremely low, there have been reports of donor deaths in the past. These deaths have been due to post-operative complications, most of which are preventable. 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) might pose an increased risk to a kidney donor. If the donor's remaining kidney is injured in an accident or becomes diseased, 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 seek early prenatal care.

How long does the evaluation take?

The length of time depends upon the donor availability, appointment availability and whether additional testing is needed (if an abnormality is found). Testing and consultations are conducted on an outpatient basis. The results of each test are reviewed with the adult nephrologist before proceeding to the next. If an abnormality is identified during this process, the "donor evaluation" will be stopped until further evaluation of the abnormality is done and the donor is cleared to continue. This 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, clergy and/or members of our transplant team.

What happens after the tests are completed?

When the tests are completed, all of the results are presented to the Renal Transplant Selection Committee for discussion and approval. Once a potential donor is approved, we will schedule an appointment for the donor to meet the surgeon and a date will be set for the transplant.

What surgical options are available for having my kidney removed?

The actual removal of the kidney will be done by an *Adult* Urological surgeon, and will be performed at the UTSW University Hospital at St Paul Dallas.

The kidney donation surgery (called a donor nephrectomy) can be performed using one of two possible surgical techniques. These techniques are discussed in detail with the donor well in advance of the procedure, but the technique used will depend upon the **results** of some of the tests. Here is a brief description of each technique:

The Traditional “Open” Technique

The “open” technique involves an 8-12 inch incision in the flank or front area, below the ribs. The kidney is removed through this incision. However, like any major open surgery, this operation causes substantial post-operative pain, which can be effectively managed with medication during the post-operative period. The donor feels much better after 2 or 3 days and usually goes home on the 5th or 6th day after the surgery. After discharge home, you must not drive for 3 weeks or lift objects over 10 lbs for 6 weeks. Depending upon your profession, you may not return to work for 4-6 weeks after surgery.

Laparoscopic Technique

Laparoscopic nephrectomy is a less invasive surgical procedure for kidney donors and an alternative to the open operative procedure described above. The laparoscopic technique utilizes several short incisions (approx. 1 inch) that are used to insert a specialized camera and other instruments allowing the surgical team to free the kidney from its surrounding tissues. At the end of the procedure, the kidney is removed through a 3 to 4 inch incision in the lower abdomen. Because there are several small incisions, the surgeon is able to enter the abdomen without actually dividing muscles. There is less pain. Recovery is faster than after the traditional open procedure. Usually, donors can be released from the hospital in just a day or two. They still should not lift over 10 lbs but can usually return to work in approximately 3 weeks.

The risk associated with laparoscopic technique is that the surgeon has only limited control of the surgical area. This makes surgical complications more of a possibility than in the open technique. However, with proper donor selection and the understanding that the team will

'convert' the 'closed' technique to the 'open' technique if there is any concern, the added risk is minimal. Not everyone is a candidate to undergo laparoscopic donation. Your doctor or surgeon will evaluate whether you are a candidate for this procedure or not, based on your transplant evaluation test results.

Although some physicians have expressed anxiety that potential trauma incurred by the kidney upon extraction through this small incision might impair kidney function, limited published results indicate that the performance of kidneys removed through traditional means versus laparoscopic means are equivalent.

Although blood transfusions have been required in some persons undergoing laparoscopic kidney removal, transfusions have also occasionally been required using the 'open' approach as well. Whether or not the laparoscopic approach will result in an increased likelihood of blood transfusion is difficult to predict.

When is the transplant surgery “scheduled”?

The scheduled date will depend upon the coordination of several things:

- the recipient's health
- the donor's availability
- the availability & schedules of the recipient's and donor's surgeons
- the availability & schedules of the recipient's and donor's anesthesiologists
- the availability of operating rooms at the recipient's and donor's admitting hospital

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

When will the donor be admitted to the hospital?

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

Who takes care of the donor in the hospital?

The adult surgical 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, unless the recipient is going to have additional surgery (such as removal of the native kidneys), prior to receiving the kidney from the donor.

How long does surgery take?

The donor's surgery takes approximately 3-4 hours for traditional "open" procedure, slightly longer for laparoscopic technique. After surgery, you will go to the recovery room 1st and then return to your room. The recipient will come out later and will go straight to the ICU.

What happens after surgery?

After surgery, the donor may have:

- ◆ a nasogastric tube (in the nose) which goes into the stomach to keep it empty (sometimes for a day or two)
- ◆ an intravenous line (IV) in a vein to give fluids until they can take fluids and food by mouth (usually a day or two)
- ◆ a catheter in their bladder to keep it empty and to measure urinary output.
- ◆ anti-embolism stockings 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)?

The incision for the traditional "open" technique is approximately 8-12 inches long and runs below the line of your lowest ribs. The incision is closed with surgical staples, which are removed during the first visit with the surgeon after discharge.

For the Laparoscopic procedure there are several small incisions.

How long is the hospital stay for the donor?

The average hospital stay for the traditional "open" technique is 5-7 days after surgery depending upon how well you progress post-operatively. For laparoscopic donation it is shorter (usually 2-3 days).

Does the donor have any restrictions 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.

- ◆ They will not be able to drive a car for 1-3 weeks after going home.
- ◆ They should not lift anything over 10 pounds for 6 weeks following surgery.

- ◆ The surgeon will go over any other restrictions with the donor.

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, just like everyone else.

When can the donor travel a long distance in the car to go home?

The donor may ride as a passenger in a car as long as extreme fatigue is not a concern. This should be discussed with the surgeon and exact instructions obtained.

Is there need for a follow up visit after donation?

The donor will be seen by the surgeon at 1 week and 1 month after donation.

WAITING FOR TRANSPLANT

The Wait

Depending on your child's medical condition, his or her status may change one or more times during the wait for a donor kidney. It is difficult to predict how long your child will be waiting for a cadaveric kidney. The waiting time is dependent upon blood type, availability of cadaver kidneys, as well as your child's antibody reactivity. During this time, you will be asked to bring your child to Transplant Clinic periodically for follow-up visits. Also, you will need to call the transplant coordinator if your child develops a fever or any other symptoms of illness such as runny nose, cough, vomiting or diarrhea. If your child develops an infection during the wait for a donor kidney, he or she will not be able to receive a transplant while the infection is active. This is because the high doses of immunosuppressant medications that are given at the time of transplant could allow an infection to overwhelm your child's body.

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

The transplant coordinator will notify you that your child has been placed on the waitlist. At this time, it is important that the transplant office have current telephone numbers and "emergency" numbers 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 special instructions to follow when called for a cadaveric kidney?

If you are called in for a possible cadaveric kidney, do not eat or drink anything until instructed to do so. The transplant team will give you specific instructions. You should make plans to come to the hospital immediately after being called.

If I have a living related donor, when will my child be admitted to the hospital?

Your child and his or her donor will be admitted the day before the scheduled transplant surgery. The recipient will be admitted to C5 at Children's, and the donor will be admitted to UTSW at St. Paul.

What do I need to bring to the hospital?

Most people prefer to bring their own slippers, PJ's, robe and personal toiletries. In addition, you may want to bring your child's favorite toy animal, games, or books.

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

Your family may visit with your child often 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.

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 provide you with further information. The Ronald McDonald House may also be available, depending upon occupancy and other restrictions.

Where can I go for personal help and support?

The members of the transplant team: physicians, nurses, social workers, and child life specialists are available to give you information and support. There is also a chaplain who is assigned to the transplant team. If one of us cannot help, we can refer you to someone who can.

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

Multiple Listing

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

Transfer of Waiting Time

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

How does the waiting list work?

Under contract with the U.S. Department of Health and Human Services' Health Services & Resources Administration (HRSA), United Network for Organ Sharing (UNOS) maintains a centralized computer network called UNetSM. Transplant professionals can access this computer network 24 hours a day, seven days a week.

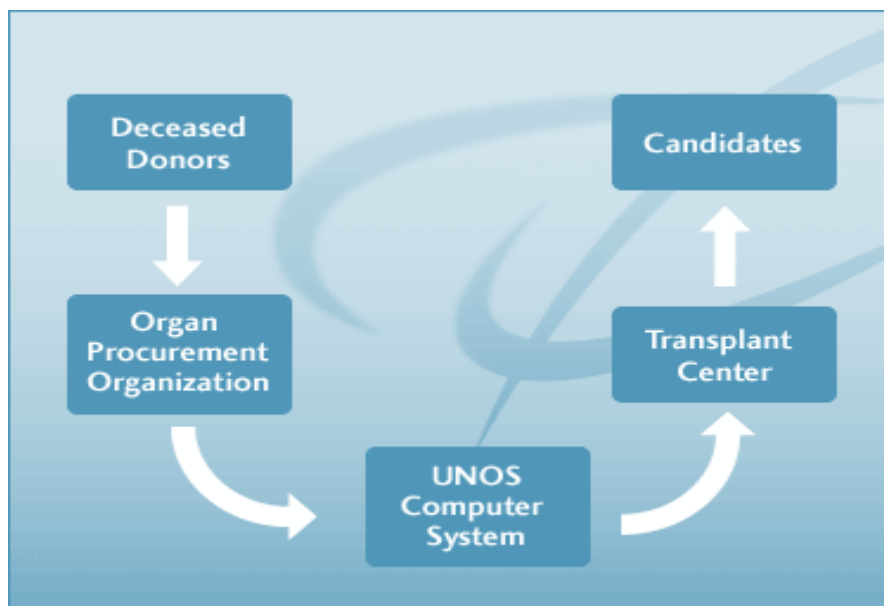
UNet electronically links all transplant hospitals and organ procurement organizations in a secure, real-time environment. Because UNet uses the Internet, it allows access to all these transplant professionals. However, in order to protect the confidential medical data, all users must use have a secure password.

Matching Donor Organs with Transplant Candidates

When a deceased organ donor is identified, a transplant coordinator from an organ procurement organization accesses the UNet system and enters necessary medical information about the

donor. The system uses this information to match the medical characteristics of the candidates waiting against those of the donor. The system then generates a ranked list of patients who are suitable to receive each organ. This list is called a "match run." Factors affecting ranking may include:

- ◆ tissue match
- ◆ blood type
- ◆ length of time on the waiting list
- ◆ immune status
- ◆ distance between the potential recipient and the donor
- ◆ degree of medical urgency (for heart, liver, lung and intestines)



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

The Five Steps of the Matching Process

1. **An organ is donated.** When the organ becomes available, the Organ Procurement Organization (OPO) managing the donor sends information to 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.
1. **UNOS generates a list of potential recipients.** The UNOS computer generates a list of potential transplant candidates who have medical and biologic profiles compatible with the donor. The computer ranks candidates by this biologic information, as well as clinical characteristics and time spent on the waiting list.
2. **The transplant center is notified of an available organ.** Organ placement specialists at the OPO or the UNOS Organ Center contact the centers whose patients appear on the local list.
3. **The transplant team considers the organ for the patient.** When the team is offered an organ, it bases its acceptance or refusal of the organ upon established medical criteria, organ condition, candidate condition, staff and patient availability and organ transportation. By policy, the transplant team has only one hour to make its decision.
4. **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

When am I admitted to the hospital?

- ◆ For *cadaveric transplant*, your child will need to come to the hospital as soon as possible after being notified by the transplant coordinator that a kidney is available.
- ◆ For *living related donor transplant*, your child will be admitted at 12 noon the day prior to the scheduled surgery.

When happens when I arrive at the hospital?

It doesn't matter what kind of kidney your child will receive, the procedures that are done are the same. The only difference is that the pace at which things are done is a little more hectic with a cadaveric transplant than with a living related transplant.

- ◆ Your child will be evaluated by the transplant physician to be sure that he or she does not have any infections, or other medical problems that would prevent the transplant.
- ◆ Your child will have blood drawn for routine laboratory tests as well as for the serum cross match. Remember this is the test between the recipient's serum and the donor's cells. This particular test takes approximately 4-5 hours to complete once the donor serum is received by the laboratory.
- ◆ Your child will get a chest x-ray and an EKG.
- ◆ Your child will meet with the anesthesiologist.
- ◆ You will sign operative permits, which provide your consent for the transplant surgery.

Is there any special preparation before surgery?

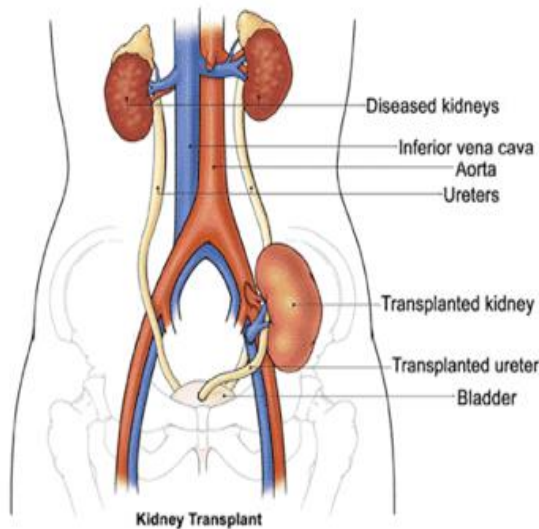
- ◆ The evening before surgery, your child will have an intravenous line, called an IV, placed in his or her arm. This will be used to give medications and fluids before, during and after surgery.
- ◆ Your child will not be able to eat or drink anything for 6-8 hours prior to surgery.
- ◆ The evening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

Where is the new kidney placed?

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

- ◆ It is easier to connect the 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.
- ◆ It is easier for the physicians and nurses to feel the kidney in this position.

This is an illustration of the placement of a transplanted kidney:



How long does the surgery take?

A kidney transplant takes approximately 4 hours. If additional surgery is done at the same time, it may take longer. Periodically throughout the procedure, the operating room staff will update your family about the progress of the surgery.

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

physicians specially trained in intensive care. Your transplant surgeon and transplant nephrologist work closely with the PICU staff.

Urine output is measured closely every hour. Fluids are replaced through the IV so that a fluid balance is maintained.

Your child will have:

- ◆ Intravenous lines, usually two, to replace urine output and maintain positive fluid balance.
- ◆ A catheter in the bladder to accurately measure urine output and to keep the bladder empty so that it can heal properly. It is up to the transplant surgeon as to how long the catheter will remain, but it is usually for 4-5 days.
- ◆ An oxygen mask (which all patients have following surgery) until fully awake and breathing effectively.
- ◆ A “clip” on a finger to measure your oxygen concentration level.
- ◆ Three round pads on the chest that monitor the heart. These will be removed when your child returns to his or her room on C5.
- ◆ There will be a bandage covering the incision site. The sutures or staples will usually be removed in 7-10 days.

As with the living donor, it is important for to take deep breaths and cough to prevent pneumonia.

Who takes care of my child?

Your child’s care is directed by the pediatric transplant nephrologist. However, all members of the transplant team participate in some aspect of your child’s care. In addition, the staff nurses on the nephrology unit are trained in the care of all renal patients and also participate in the medication teaching and discharge process. They are a vital part of the team.

When will the transplanted kidney begin to work?

Many transplanted kidneys begin to produce urine as soon as the donor and recipient blood vessels are connected in the operating room. In some cases, urine output may be delayed. This may be due to acute tubular necrosis (ATN) which is often a result of the kidney being without a blood supply for an extended period of time. This is a reversible condition and usually improves with time.

Is dialysis needed after the transplant?

If your child’s transplanted kidney does not function adequately following surgery, he or she will need dialysis until the kidney begins to function. Dialysis will not damage the new kidney and will help to remove harmful 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 well functioning kidney, your child's diet may not be as restricted as before transplant. However, there will be some salt restriction since salt is one the factors in controlling blood pressure. Many transplant patients experience weight gain following transplant. If this becomes a problem, the dietitian will work with you on an appropriate diet plan. Remember, the dietitian is an important member of the team and is available daily to consult with you and answer your questions. The dietary and nutritional needs of the kidney transplant recipient are discussed in greater detail in the next section.

NUTRITION

Nutrition plays an important role in both preparing for transplant and healing after transplant. It is also important for maintaining good health in the years following transplant. A dietitian will be available to work with your child both in the hospital and in the outpatient clinic. The dietitian will work with your family to develop and implement a nutrition plan designed especially for your child and his or her unique needs.

Pre-Transplant

Before transplant, it is very important to follow the nutrition recommendations of your dietitian and medical team. 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. If your child has had difficulty with growth, an oral supplement may be recommended, such as Suplena or Nepro.

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 medical team or surgeon 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 receive clear liquids. Examples of clear liquids are juice, sodas, popsicles, broths, water, tea, and jello. After clear liquids are tolerated, your child will be placed on a no added salt diet. Your child may also have concentrated sweets restricted. Your dietitian will discuss these restrictions with you and your child in more detail after transplant.

Post-transplant

The basic principles of diet after renal transplant are:

1. Achieve and/or maintain normal body weight for age.
 - If your child is underweight, it is important to work towards an appropriate weight. Normal body weight provides adequate fat and protein reserves for protection during periods of stress or infection.
 - If weight reduction is indicated, your dietitian will determine the appropriate calorie level 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 adjustments in diet will be made by your dietitian who is available for consultation as needed.
2. Focus on fruits and vegetables.
 - Fruits and vegetables are full of vitamins and minerals, fiber, and are low in calories.
 - Half of your child's plate should contain fruits and vegetables at meals.

- Provide fruits and vegetables at snack time.
3. Modify the cholesterol and fat content of the diet.
 - A reduction in the cholesterol and saturated fat content in the diet is recommended.
 - Polyunsaturated fats are substituted for trans and saturated fats since these will help lower blood cholesterol levels.
 - Immunosuppressive medications can raise cholesterol levels so it is recommended to follow a modified fat and cholesterol diet even if blood cholesterol levels are normal.
 4. Restrict sodium intake.
 - The use of prednisone causes sodium retention.
 - Excess amounts of sodium may contribute to fluid retention.
 - A diet moderately restricted in sodium is advised to avoid fluid retention and to help control high blood pressure.
 - Salt substitutes which contain the mineral potassium should be avoided since some immunosuppressive medications can cause high blood potassium levels.
 - Your dietitian will discuss which foods should be avoided and ways to use herbs and spices for seasoning.
 5. Limit sugar and concentrated sweets.
 - Prednisone may cause an increase in blood glucose and triglyceride levels.
 - It is recommended to limit sugars and concentrated sweets.
 - Focus on whole grains. Choose 100% whole grain cereal, rice, pasta, breads, and crackers.
 6. Drink plenty of fluids, especially water.
 - It is recommended that transplant patients stay well hydrated, especially in hot weather and with exercise. Drinking adequate amounts of fluid during the day will also decrease kidney toxicity caused by medications.
 7. Practice food safety.
 - Immunosuppressive medications put your child at higher risk of developing an infection.
 - Make sure foods are cooked to the proper temperatures.
 - Avoid raw fish and seafood, unpasteurized milk and juices, uncooked eggs, and unwashed fruits and vegetables.
 - Your dietitian will provide you with more information that will help prevent food borne illnesses.
-

MEDICATIONS

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 instructed by a member of the transplant team. We expect parents and eventually the child, to understand the actions of each medication; so please be sure to ask questions to clarify any information given to you. Understanding the medications enables you to better identify the side effects when they occur.

Within the first few days following transplant, your family will begin to administer medications to your child, with the assistance of your nurse. You will be provided a schedule for the medications that you may change each time an adjustment in medications is made.

Before discharge from the hospital, we will teach you:

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

The medication schedule should be updated with each change to dose or administration time. We urge you to 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 inform you and you should make the change on the schedule. Should you have any questions, please confirm the change with your nurse. By making the changes yourself, you will feel comfortable making such changes after discharge home. During hospitalization, your nurse will verify that the entries are correct.

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

Be sure to store all the medications in their original containers. This will be helpful in keeping up with the expiration dates, who prescribed each drug, etc. Store all medications away from heat, direct light and moisture, each of which can cause deterioration of the drug. Always administer medications at the same time of the day consistently. Each of the routine medications needs to achieve a stable level in the blood. Monitoring of these blood levels will be done at

intervals and the test results are used to make adjustments in medication dosages. Therefore, it is crucial that medications are given in a consistent manner.

Your child must take all their medications as they are prescribed. If your child experiences nausea, vomiting or diarrhea and cannot take medications, please contact the Transplant office immediately for instructions. If a dose is missed at the prescribed time, please give the dose as soon as possible; however, if it is near the time of the next dose do not double the amount in order to catch up the missed dose. Instead space the doses apart and return to schedule the following day.

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

Always bring your child's medication schedule to the clinic so that changes may be made if necessary. You may also wish to provide your child a copy of medications to keep with them. Should your child require hospital admission, please bring all your medications with you together with your medication schedule to make the admission process easier for both of us.

Should you have any questions or encounter difficulties, contact the transplant office immediately. There is a transplant coordinator on call 24 hours a day to answer questions.

General Medication Information

- ◆ Prescription Refills are handled during normal business hours, Monday through Friday. Please plan in advance to refill your child's medications so that you do not run out. It is vital the pharmacy is notified that you are in need of a refill 7 days in advance in order to ensure a timely refill.
- ◆ Generic formulations of brand name Immunosuppressants such as: Prograf, Neoral and Cellcept are available. It is important to remain on the brand name unless otherwise notified by your transplant physician.
- ◆ Always take as directed. Follow the dosage directions given by your transplant provider, not what is printed on the label of the medication. Since, the dose may be adjusted before a refill is provided from the pharmacy.
- ◆ Do not discontinue any drug without being instructed to do so.
- ◆ Do not add any over-the-counter medications or supplements, including herbal remedies, unless your transplant provider is aware of it.

- ◆ Contact your transplant provider if you notice any physical or mental changes in your child.
- ◆ Take doses at the same time every day to avoid missing doses.
- ◆ If your child vomits within thirty minutes of taking their immunosuppressive medications give the dose again. If your child vomits after thirty minutes of taking their medications do not give a second dose, and call the transplant coordinator for further instructions. Please contact the transplant coordinator if vomiting persists.
- ◆ Store medications away from heat, light and moisture (such as the bathroom vanity or kitchen cabinets).
- ◆ Contact your pharmacy if any medication doesn't look "right" for any reason.
- ◆ Do not try to make up for missed doses unless instructed to do so by your transplant provider.
- ◆ 1 cc is the same as 1 ml
- ◆ Check expiration dates on all medicines. Discard 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 directed or approved by your transplant physician. NSAID's used in conjunction with Prograf or Cyclosporine can cause renal (kidney) problems.

Immunosuppressive Drugs

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

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

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

transplant coordinators will provide education and ensure that you develop a thorough understanding of the medications prescribed.

Prograf **(Tacrolimus)**

Purpose

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

Description

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

When to Give

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

How to Give

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

Side Effects

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

- ◆ Increase in blood sugar.
- ◆ Low magnesium level in the blood.
- ◆ High potassium level in the blood.
- ◆ Inability to sleep.
- ◆ Tremors of the hands. This is a common side effect that will decrease over time as the Prograf dose is reduced.

- ◆ Diarrhea; sometimes associated with nausea and vomiting
- ◆ High blood pressure. Your child may be on medicines to lower blood pressure. If he or she has persistent headaches or dizziness, you should notify your transplant provider because these may be signs of high blood pressure.
- ◆ Increased risk of infection. Any fever, cough, rash or mouth lesions should be reported to the transplant provider. You must notify your transplant provider immediately if your child has been exposed to chickenpox and he or she has never had chickenpox.
- ◆ Potential damage to the liver or kidneys. There will not be any specific symptoms you will notice. Your child may have elevations in certain blood work results, such as BUN, creatinine, potassium and liver function tests.
- ◆ Potential for post transplant lymphoproliferative disease (cancer)

Storage

- ◆ Store at room temperature.

Precautions:

- ◆ Avoid grapefruit and grapefruit juice.
- ◆ If using the liquid form, do not give after the expiration date on the bottle.
- ◆ If using the liquid form, carry an extra bottle when traveling.
- ◆ Always keep medicine with you in carry-on luggage when traveling. This way, you will have it in case your check-on luggage is lost.
- ◆ Some drugs interfere with Prograf blood levels. Your physician will have information regarding how certain drugs affect Prograf. You should not add any over-the-counter medications or change any other medications unless approved by your physician or the transplant team.
- ◆ If your child vomits a dose of Prograf within 30 minutes of administering the dose try the following: (if your child vomits greater than 30 minutes of the dose do not redose.)
- ◆ Wait half an hour and then give one to two ounces of fluid (7-Up, ginger ale, root beer, Coke, water, etc.)
- ◆ If fluid is tolerated for 30 minutes repeat the dose of medication.
- ◆ If vomiting continues, notify your transplant coordinator.

- ◆ If your child has diarrhea that lasts more than 24 hours, you must notify your transplant coordinator. **Persistent diarrhea can increase the blood level of Prograf, which may increase the risk of harmful side effects.**

Neoral (Cyclosporine)

Purpose

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

Description

Neoral comes in 25mg and 100mg soft gelatin capsules. Neoral is also available as a 100mg/ml microemulsion 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 essential that you follow the dosage schedule as directed

How to Give

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

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

Side Effects

- Increased Hair Growth
- High Blood Pressure

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

Storage

- Store at room temperature.

Precautions:

- Avoid grapefruit juice.
- Drink immediately after mixing. Do not mix **in advance** or it will form clumps.
- If using the liquid form, do not give after the expiration date on the bottle.
- If using the liquid form, carry an extra bottle when traveling.
- Always keep medicine with you in carry-on luggage when traveling. This way, you will have it in case your check-on luggage is lost.
- Some drugs interfere with Neoral blood levels. Your physician will have information regarding how certain drugs affect Neoral. You should not add any over-the-counter medications or change any other medications unless approved by your physician or the transplant team.
- If you vomit a dose of Neoral try the following:
 1. Wait half an hour and then take one to two ounces of fluid (7-Up, Ginger Ale, Root Beer, Coke, Water, etc.)
 2. If fluid is tolerated for 30 minutes repeat the dose of medication. When giving liquid Sandimmune, many children retain the Sandimmune better if it is given mixed in Root Beer or another soda instead of milk.
- If vomiting continues, notify your transplant coordinator.
- If you have diarrhea that lasts more than 24 hours you must notify your transplant coordinator. **Persistent diarrhea can affect the blood level of Neoral, which may increase the risk of harmful side effects.**

- Avoid rinsing the dosage syringe provided by neoral as this will cloud the syringe. If syringe becomes wet or requires cleaning, it must be completely dry before using it again.

Steroids

(Methylprednisolone, Prednisone, Prednisolone)

Purpose

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

Description

Methylprednisolone will be dispensed in 4 mg tablets.

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

Prednisolone will be dispensed in 3mg/ml solution.

How to Give

The total prescribed dose of steroids should be given once each morning. The tablets may need to be divided in half to obtain the proper dose. For example, if 5 mg tablets are dispensed and your child's dose is 7.5 mg, you would give 1 1/2 tablet. It can be irritating to the stomach, and therefore, should not be given on an empty stomach. After breakfast is an ideal time to give the Prednisone.

Side Effects

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

- Fluid/salt retention. This may cause the body to retain fluids and produce swelling of the hands or ankles (edema) and increase blood pressure.
- Increased appetite. This can lead to unhealthy weight gain.
- Increased fat deposits. This condition can occur in the face (called "moon face"), over the upper back and abdomen.
- Increased stomach acid. This may cause or worsen ulcers. An acid reducer is given while your child is on higher doses. Do not give Prednisone on an empty stomach.

- May slow the healing process.
- Decreases the body's ability to fight infections.
- Muscle weakness and weakened connective tissue. This may cause "stretch marks."
- Acne.
- In large doses, Prednisone can affect bone growth.
- Eye changes. Prednisone may cause cataracts or glaucoma. Routine eye exams should be done as instructed by your ophthalmologist. Your child should be seen by an ophthalmologist if any problems occur such as blurred or decreased vision.
- Increased blood sugar. This usually occurs 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 prolonged period of time (see "Skin Care" section).
- Mood swings-includes crying easily, giggly moods, irritable, etc.
- Insomnia or 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 physicians 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 capsules)

Purpose

CellCept is another immunosuppressant drug that helps to prevent rejection. It is used in combination with other immunosuppressant medications such as Neoral or Prograf and Prednisone.

Description

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

When to Give

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

How to Give

Separate cellcept from magnesium by 2 hours before or after.

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

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

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

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

If you are having difficulty giving the medicines, please contact the transplant office.

Side Effects

The most common side effects of CellCept are:

- Diarrhea

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

Imuran (Azathioprine)

Purpose

Imuran is another immunosuppressant drug that helps to prevent rejection. It is used in combination with other immunosuppressants such as Neoral or Prograf and Prednisone.

Description

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

When to Give

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

How to Give

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

Side Effects

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

Rapamune (Sirolimus)

Purpose

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

Description

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

When to Give

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

How to Give

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

Side Effects

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

Storage

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

Nystatin (Mycostatin)

Purpose

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

Description

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

How to Give

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

Side Effects

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

Storage

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

Precautions

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

Diflucan (Fluconazole)

Purpose

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

Description

Fluconazole may be given as a liquid or tablet.

How to Give

Give as directed

Side Effects

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

Storage

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

Trimethoprim and Sulfamethoxazole

(Bactrim, Cotrim, Septra, TMP-SMX)

Purpose

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

Description

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

How to Give

Give as directed. Shake suspension well.

Side Effects

Some of the side effects from trimethoprim and sulfamethoxazole include:

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

Storage

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

Precautions

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

Ganciclovir and Valganciclovir (Valcyte)

Purpose

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

Description

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

How to Give

Give as directed.

Side Effects

Some of the reported side effects include the following:

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

Storage

Protect suspension and tablets from light and moisture.

Precautions

There are no special precautions with the oral preparation.

Acyclovir/Valacyclovir (Zovirax)

Purpose

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

Description

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

Valacyclovir comes in a 500mg and 1000mg tablet.

How to Give

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

Side Effects

Based on clinical practice experience with patients in the U.S. reported adverse side effects are uncommon. Some of the reported side effects include the following:

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

Storage

Protect capsules and tablets from light and moisture.

Precautions

There are no special precautions with the oral preparation.

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

Acid Reducing Agent

(Prevacid, Nexium, Prilosec & Protonix)

Purpose

Immunosuppressive medications can increase stomach acid and can cause or worsen ulcers. An acid reducing agent will buffer this stomach acid. The acid reducing agent may be discontinued when the risk of ulcer formation is decreased.

Description

They come in capsules, oral dissolving tablets and suspensions.

How to Give

Give as directed.

Side Effects

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

Storage

Keep away from heat, light and moisture.

Phosphorous Supplement

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

Purpose

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

Description

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

How to Give

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

Side Effects

Monitor for diarrhea

Storage

Keep away from heat, light and moisture.

Precautions

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

Magnesium Supplement

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

Purpose

Magnesium is an important mineral for the body and important for many function of the body. A magnesium supplement is used to treat low magnesium.

Description

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

How to Give

Give as directed.

Side Effects

Monitor for diarrhea

Storage

Keep away from heat, light and moisture.

Precautions

Separate magnesium by at least **2 HOURS** before and after Cellcept.

Pravastatin (Pravachol)

Purpose

Pravastatin is used to lower bad cholesterol and increase your good cholesterol.. In kidney transplant patients, they are used to protect blood vessels in the kidney and prevent a special type of rejection.

Description

Pravastatin comes in 10mg, 20mg, 40mg and 80mg tablet.

How to Give

Give as directed.

Side Effects

- ◆ GI side effects
- ◆ Muscle cramps

Storage

Keep away from heat, light and moisture.

Precautions

There are no special precautions with the oral preparation.

Vitamin C & E

Purpose

Vitamin C & E are antioxidant. In kidney transplant patient, they are used to protect the blood vessels in the kidney and prevent a special type of rejection.

Description

They come in both liquid and capsule.

How to Give

Give as directed.

Side Effects

Based on clinical practice experience with patients in the U.S. reported adverse side effects are uncommon.

Storage

Keep away from heat, light and moisture.

Precautions

There are no special precautions with the oral preparation.

Aspirin

(81mg Baby Aspirin)

Purpose

Aspirin is used to prevent blood clots.

Description

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

How to Give

Give as directed.

Side Effects

Based on clinical practice experience with patients in the U.S. reported adverse side effects are uncommon.

Storage

Keep away from heat, light and moisture.

Precautions

There are no special precautions with the oral preparation.

Dipyridamole (Persantine)

Purpose

Dipyridamole is used to prevent blood clots.

Description

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

How to Give

Give as directed.

Side Effects

- ◆ Bleeding Gums
- ◆ Bruising

Storage

Keep away from heat, light and moisture.

Precautions

There are no special precautions with the oral preparation.

POST TRANSPLANT CONSIDERATIONS

SKIN CARE

Patients on immunosuppressant medications are *much* more sensitive to the sun than are other people. 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, the risk of skin cancer is *greatly* increased. Remember to reapply the sunscreen frequently as water and perspiration can decrease its effectiveness. Also, try to limit your child's exposure to the sun's rays between 10:00 a.m. and 2:00 p.m. If you notice any changes in your child's skin such as newly raised areas, sores that won't heal or changes in warts or moles, be sure to notify your renal transplant doctor. A dermatologist may need to be consulted.

ACNE

Acne may be present on the face, chest, back or shoulders and is often a side effect of steroids. The easiest way to help control this acne is to remove any extra oil, dead skin, or bacteria. Wash the affected areas three times a day, scrubbing gently with a soapy wash cloth. Rinse soap off the skin to leave open and clean.

The purpose of this treatment is to keep the skin dry. If the skin becomes too dry, stop washing the areas until it recovers its natural moisture. (Do not apply lotions or creams to treat dry skin).

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

If acne doesn't improve with these techniques, or if infection occurs, contact the transplant office. The usual acne medications are often not effective in treating acne.

HAIR GROWTH

Increased hair growth in undesirable areas is often a side effect of prednisone, cyclosporine, or other medications. This problem may be a concern to girls, especially adolescents, when it involves increased facial hair. 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 or Revlon Depilatory, may be used. Use special caution 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 eyes and mouth, and follow the directions on the container carefully. It is important during this time to continue to take your transplant medications. Do not ever discontinue any medications without instructions from your renal transplant doctor.

DENTAL CARE

It is very important that you have excellent dental care after transplant. A dental check-up is necessary at least twice a year, more often if your dentist feels it is warranted.

One of the side effects of immunosuppressant medications and some blood pressure medications is gum overgrowth. This enlargement of the gums is aggravated by the presence of plaque. Routine daily hygiene especially after your child's immunosuppressant dose is very effective in decreasing the *severity* of the gum overgrowth. Severe overgrowth of the gums needs prompt attention to prevent periodontal disease.

When making an appointment, tell the dentist that your child has had a kidney transplant and will need an antibiotic before and after any treatment (including cleanings) to prevent infection. Penicillin or Amoxicillin may be used according to the American Heart Association recommendations unless your child is allergic to it. If your child is allergic to penicillin, your dentist needs to call the transplant office before choosing another antibiotic. We want to be sure that any antibiotics prescribed will be compatible with your current medications.

FOR TEENAGERS AND YOUNG ADULTS

Smoking

Smoking can cause lung cancer, damage to the lungs and an increased 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 immunosuppressant medications. Although smoking is unhealthy for all, it is particularly harmful to transplant patients.

Sexuality

The issues of sexuality in transplant patients are the same issues that confront all young women and men. Sexual activity involves the risk of unwanted pregnancies and contracting sexually transmitted diseases (STDs). Such diseases include syphilis, gonorrhea and Chlamydia, herpes, and human immunodeficiency virus (HIV).

Abstinence is the surest way to avoid sexually transmitted diseases. However, if abstinence is not the chosen protection method, the use of latex condoms during intercourse may greatly reduce the

risk of STDs and accidental pregnancies. Preventing accidental pregnancy is the responsibility of both the man and the woman.

Female transplant patients need to visit a gynecologist and have a pap smear and breast examination every year. 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. Pregnancy after transplantation may be risky to both you and your baby. Please check with your renal transplant doctor for recommended birth control methods.

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

Within the United States

We advise you to wear your Medic-Alert bracelet, and carry your family notebook and a laboratory request letter with you. Be sure to take an adequate supply of medications 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 entering.
- ◆ Obtain a letter from the transplant office to verify all your medications including acetaminophen (Tylenol, laxatives, etc.). This needs to be with you when you show your passport and go through customs.
- ◆ Only water from adequately chlorinated sources is safe. In areas where chlorinated water is not available, or where hygiene and sanitation are poor, drink:
 - Beverages, such as tea and coffee, made with boiled water.
 - Canned or bottled water and/or soft drinks
- ◆ 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 drugs as we do in the United States.

Where water is contaminated ice must be considered contaminated 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 discarded. Water on the outside of beverage cans or bottles might also be contaminated. Wet containers should be dried before opening and pouring, and surfaces which are contacted directly by mouth should be wiped clean prior to drinking. If no other source of safe drinking water can be obtained, tap water which is uncomfortably hot to the touch is usually safe. After cooling at room temperature in a clean container, it may be used for brushing teeth or drinking.

- ◆ Select food with care to avoid illness. In areas of the world where hygiene and sanitation are poor, avoid unpasteurized milk and milk products, such as cheese. Raw vegetables should also be avoided. Eat only what can be peeled or has been cooked and is still hot.
- ◆ Swimming in contaminated water may result in eye, ear or intestinal infections particularly if your head is submerged. Only chlorinated pools may be considered safe places to swim.
- ◆ If you need medical care while abroad, consult your travel agent, the American Embassy or Consulate for names of physicians or hospitals.

Swimming

In general swimming in a chlorinated pool that is well maintained is safe as long as your child has no wounds or skin breakdown. It is best to have your child shower or rinse off when exiting a pool. It is also important to prevent them from swallowing water while in the pool. These factors may prevent the spread of parasites such as cryptosporidium which is an infection that can cause diarrhea and can also infect the liver.

We strongly discourage swimming in a lake or pond due to the microorganisms that inhabit these environments, which may be harmful to someone that is immune-suppressed.

Infection Control Guidelines for Transplant Patients

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

Two examples are:

1. Staphylococcus Aureus, resistant to Methicillin (MRSA)
2. Enterococci, resistant to Vancomycin (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 multidrug-resistant bacteria they are placed on "contact precautions." This is designed to prevent the spread of these infections. Gloves and gowns are indicated upon entry into the patient's room. Families and visitors are to wear gowns and gloves if holding the patient or if they anticipate contact with a body fluid e.g. changing a diaper, especially if they are likely to socialize with 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. Patient movement from the room may also be restricted.

Any patient colonized/infected with VRE is considered permanently colonized, 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 vital and hand washing is absolutely required.

Visitors

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

Hospital Floor

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

Personal Items at the Hospital

- All personal items must be cleaned with alcohol wipes before touching a transplant recipient.
- The number of personal items in rooms will be reduced to avoid clutter and dust collection.
- Personal items that are scrubbable (not furry, stuffed animals) are preferred. The number and size of stuffed animals should be minimized.
- Potted plants and fresh flowers are not allowed in the patient's room.
- Personal comforters and clothing are to be machine or hand washed and re-washed, if soiled.
- Down comforters are not allowed. Down pillows are allowed if covered by a plastic pillow case with a zipper closure.
- Paper products may be taken directly into the room without cleansing.
- 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 instructed to wear an N95 respirator before leaving the vehicle and keep the mask in place until they reach their destination within the hospital.

Infection Control Valet

- In times of construction on the campus of Children's Medical Center Dallas the risk of mold and airborne fungal exposure is increased. The hospital may designate an infection control valet to reduce your child's exposure of these infections when entering the hospital. The N95 mask should be worn regardless of self parking or utilization of valet parking. If you have questions regarding the availability of infection control valet or self parking please direct these to your child's transplant coordinator.

POSSIBLE COMPLICATIONS

Rejection

Rejection is the body's natural way of trying to fight off the new kidney which it considers as "foreign" tissue. Because the body continues to try to reject foreign tissue, you will need to take immunosuppressant medications for the life of the transplanted kidney to help prevent this from happening. The best way to minimize the risk of rejection is for your child to take all of his or her medications each day. Even with these medications *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 maintain records of vital signs, keep all clinic appointments, and have your child's blood work performed as scheduled.

Signs and Symptoms of Rejection

Listed below are some of the signs and symptoms of rejection that you *may* 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, muscle aches, loss of appetite (flu-like symptoms)
- ◆ Large weight gain or puffiness
- ◆ Increase in blood creatinine level

It is important to note that many rejection episodes result in minimal or no symptoms at all. In these instances, only an increase in the blood creatinine level can suggest to your doctor that there is a problem.

Diagnosing Rejection

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

- ◆ Renal ultrasound (sonogram)
- ◆ Renal scan

- ◆ Biopsy
- ◆ Glofil

Kidney 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 assess clotting function.
- ◆ Your child cannot have food or drink after midnight before the biopsy. Medications may be given with a small amount of water on the morning of the biopsy.
- ◆ Medication is given to make your child sleepy and relaxed before the test is performed.
- ◆ The biopsy is performed in the x-ray department with the ultrasound machine.
- ◆ Your child will be given medicine to let him or her sleep during the procedure. The area to be biopsied is “numbed” with Lidocaine, like dentists use.
- ◆ A special needle is inserted into the kidney to take a *tiny* sample of kidney tissue.
- ◆ A bandage or dressing is placed tightly over the biopsy site.
- ◆ Your child will remain on bed rest after biopsy until 8 a.m. the following day.
- ◆ Complications of a kidney biopsy may include:
 1. Pain
 2. Bloody urine
 3. Bleeding (sometimes requiring surgery)
 4. Rarely, loss of the kidney

Types of Rejection

There are two types of rejection: acute and chronic

- ◆ Hyper-acute rejection
 - This may occur within the first day of transplantation
 - It often results in the loss of the transplanted kidney within the first few days after transplant

- ◆ Accelerated acute rejection
 - This occurs within the first week after transplantation.
 - It can be treated with medication.
 - Sometimes a procedure called plasmaphoresis is used to treat this.
- ◆ Acute rejection
 - This may occur *any time* after transplant, but it most commonly occurs 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*, with little or no damage to the new kidney.
 - This also may occur if medications are missed or not taken appropriately.
- ◆ Chronic rejection
 - This is a slow, gradual loss of kidney function 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.

Treatment for Rejection

After acute rejection is diagnosed, the treatment used depends upon the severity and kind of rejection. In general, treatment consists of increased or more anti-rejection (immunosuppressant) drugs, such as Solu Medrol (steroids).

HERPES VIRAL INFECTIONS

Herpes virus includes:

- ◆ Herpes Simplex type 1 (HSV-1) - causes cold sores
- ◆ Herpes Simplex type 2 (HSV-2) - causes genital herpes
- ◆ Varicella-Zoster Virus (VZV) - causes chicken pox and shingles
- ◆ Cytomegalovirus (CMV) - causes flu-like illness
- ◆ Epstein-Barr virus (EBV) - causes mononucleosis, and Lymphoproliferative disease

Herpes viruses, after causing their first infection, lie dormant somewhere in the body. Later, the virus reactivates to cause subsequent infections. What exactly reactivates the virus is unknown, although stress or decreased immunity 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 on the lips and mouth. Type 2 most commonly causes genital infections. The presence of IgG antibodies against HSV indicates a previous infection with either Type 1 or Type 2. A positive result indicates the possibility of reactivation post transplant. If a herpes infection occurs soon after transplant, the sores can spread easier because of the high immune-suppression. 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 sensations as forewarning 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. Probably not contagious at this point.

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, genitalia, or any breaks in the skin directly contact the virus.
- ◆ You shouldn't use the same towel to wipe lesions that you use to wipe other parts of your child's body to avoid spread of the virus.
- ◆ The herpes virus requires darkness, moisture, and warmth to survive, which makes transmission by inanimate objects (like toilet seats) very unlikely.

What causes the recurrence of HSV?

- ◆ Stress is the most common factor and for transplant patients. Physical and biochemical stresses such as menstruation, illness, anxiety, friction, and chafing may lead to recurrences.
- ◆ Immune-suppression contributes to recurrence
- ◆ Sunlight is a common cause of recurrent HSV (cold sores) - another important reason to wear sunscreen and Chap Stick.

Varicella-Zoster Virus (VZV)

Chicken Pox

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

The presence of IgG antibodies against varicella-zoster virus (VZV) indicates a past infection with the virus and hence the possibility of reactivation after transplant.

Symptoms

- ◆ The 24 to 48 hours before the rash appears symptoms may include: fever, poor appetite, general flu-like feeling and runny nose. A person is contagious during this period.
- ◆ Rash and sores usually first appear on the chest, back or abdomen, and then spreads to the face and the extremities. Red spots appear first and then the center appears as a clear, tiny water blister. The fluid contains VZV. After the vesicle 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 renal doctor on call.
- ◆ Treatment for chicken pox is: Acyclovir given intravenously in the hospital.
- ◆ Transplant patients who have never had chicken pox or have no detectable antibodies for varicella and are exposed must be treated with Varicella-Zoster Globulin (VZIG) within 48 hours, but no later than 72 hours after exposure.
- ◆ VZIG will not be effective after 72 hours from exposure. A varicella blood test to detect antibodies may need to be drawn.
- ◆ VZIG is administered as a intramuscular injection (shot) usually given as shots given in the thigh or buttocks based on your child's weight.
- ◆ 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 a IV). This involves 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 transmission of this virus to other children with decreased immunity.

Shingles (Herpes Zoster)

Shingles, also called Herpes Zoster, is caused by a reactivation 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 drainage from these lesions.

Symptoms

- ◆ One to three days before rash appears symptoms may include: pain, tingling, and/or burning on side of your child's chest, neck, forehead, back, hip or leg.
- ◆ Rash and sores appear in clusters of miniature blisters. These sores are accompanied by significant pain. Keeping lesions covered will prevent infecting 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 in an IV).

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

Cytomegalovirus

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 renal transplant doctor when you have a fever so that the best treatment can be provided.

Three Sources of CMV Infection

1. Reactivation of previous CMV
2. From the transplanted organ
3. From blood transfusions

If the recipient or the donor had a CMV infection in the past, then we will be giving your child medication to prevent re-activation of this virus. The medication is given orally for 6 months post-transplant and also as an IV treatment every few weeks for 6 months.

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 several weeks.
- ◆ Other common complaints are those of flu-like symptoms including muscle weakness, loss of appetite, and fatigue.
- ◆ CMV often has no symptoms and may be suspected by a medical provider if the serum creatinine is elevated 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 renal 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 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. 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.

Epstein-Barr Virus

Epstein - Barr virus (EBV) is a herpes virus which has worldwide distribution. Between 25 and 70 percent of adolescents and adults who undergo a primary EBV infection develop the clinical syndrome of infectious mononucleosis. Symptoms of infectious mononucleosis are fever, enlarged lymph nodes and hoarseness. EBV is associated with certain potential cancers including post-transplant lymphoproliferative disease (PTLD).

Post Transplant Lymphoproliferative Disease

PTLD often presents as a dysfunction of enlarged lymph nodes and gastrointestinal symptoms including diarrhea. Viral infection, particularly with EBV, may be a trigger for the development of PTLD.

Treatment

Preventative antiviral therapy may reduce the incidence of EBV and PTLD. Ganciclovir and Cytogam are used for treatment. Additionally, reduction of immune-suppression may help control PTLD. Medications may be given in lower doses or discontinued. Anti-B-cell antibodies have also been used on experimental basis. Your transplant physician will decide on the method of treatment. It is important to notify your renal transplant provider at the first sign of fever, enlarged lymph nodes and any other symptoms of concern.

BK Virus

BK virus causes a viral illness that may affect immunosuppressed patients. It occurs most commonly within the first year after transplant. It may lead to renal dysfunction and/or graft failure.

Your child may be asymptomatic or may experience an elevation in creatinine. Other symptoms may include blood in the urine, lymphocele, obstructive uropathy, ureteral stenosis or stricture. Hydronephrosis may be seen on a renal sonogram.

Diagnosis is made with a renal biopsy. There are also urine and blood tests that detect the virus. Treatment involves reducing the amount of immunosuppressive medication that you take. You will be observed closely for rejection. An antiviral medication may be prescribed for your child called Cidofovir.

Urinary Tract Infection (UTI)

Urinary tract infections can involve the urethra, bladder or kidneys. It is important for you to be aware of the symptoms and call the transplant office if your child experiences any of the following symptoms:

- ◆ Burning or pain on urination
- ◆ Feeling the need to urinate frequently and urgently
- ◆ Foul smelling urine

- ◆ Blood in urine

- ◆ Fever

UTI Prevention

- ◆ Regular and frequent urination

- ◆ Avoid bubble baths

- ◆ Drink plenty of water

- ◆ Females:

- Wear cotton underwear

- Demonstrate proper hygiene (wipe from front to back)

POST TRANSPLANT FOLLOW UP

Prior to Discharge

Before your child goes home, you will need to demonstrate the following:

- ◆ Set-up and administer your child's medications properly with a knowledge of why he or she is taking these medicines and their side effects.
- ◆ A familiarity with the information in this notebook.
- ◆ Accurately read a thermometer.
- ◆ Accurately obtain a blood pressure reading.
- ◆ Know how to record temperature, weight and blood pressure on the record sheet.
- ◆ Demonstrate acquired knowledge by satisfactorily completing the written "discharge test".

Record Keeping Reminders

In the back of this handbook there is a section for keeping records of your 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, symptoms of chilling may indicate that his or her temperature is rising.
- ◆ **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 regularly and carefully to help us understand how to best treat your child according to his or her individual needs.

Clinic Visits

The frequency of clinic visits will vary depending on the individual patient and his or her kidney function. The following is a guideline:

- ◆ Once a week Weeks 1 through 8 after transplant
- ◆ Once every 2 weeks Week 9 through 4 months
- ◆ Once a month From month 5 to one year
- ◆ Once every 3 months After 1st year
- ◆ Once every 3-4 months After 2nd Year

It is very important for your child's continued good health that you do not miss these appointments.

Note: Please remember that this time table is a guideline. Your doctor may modify the frequency of your visit according to the needs of your child.

Things to remember when you come to clinic

- ◆ *Bring this handbook* with your vital signs and medication records.
- ◆ When you have your child's Cyclosporine, Prograf or Sirolimus level checked, ***do not take the Sandimmune, Neoral or Prograf or Sirolimus until after the blood is drawn.*** Cyclosporine and Prograf levels should be checked within one hour before it is due.
- ◆ Please ***bring all of your child's medications to each clinic visit.*** This will help us make any needed medication changes.
 - It helps to write your questions down as you think of them at home and bring them with you to clinic. Our transplant team is made up of doctors, nurses, dietitians, social workers, psychologists, child life specialists and chaplains. They are available to answer any questions that you may have.

Laboratory Tests

After your child has been discharged, laboratory tests will need to be performed three (3) times per week. If you live far from Dallas, a local laboratory can draw the blood and fax the results to Children's Medical Center of Dallas. The Cyclosporine and/or Prograf specimen(s) should always be sent Federal Express to Children's in order for our laboratory to process the specimen if your

local lab is not able to perform these tests. At discharge the transplant coordinator will send a letter to your local laboratory which explains this procedure.

Below is the usual schedule for the minimum amount of lab work and clinic visits required after transplantation. *Your child's schedule may be different depending on how well the new kidney is functioning.*

General Lab Work Schedule

- ◆ Monday, Wednesday, Friday Weeks 1 through 4 after transplant
- ◆ Twice a week (Mon/Thurs) Week 5 through the first 4 months
- ◆ Once a week (Monday) Months 5 and 6
- ◆ Every two (2) weeks (Mon) From 7 months to one (1) Year
- ◆ Once a month After 1 year and thereafter (first week of month)

Adherence to the Medical Plan

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

- If you are unable to keep a clinic appointment, or are having difficulty taking your child for labs you must communicate with 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.
- You are demonstrating non adherence to your child's treatment plan if 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. This is considered medical neglect and child protective services (CPS) may need to become involved.

OTHER CONSIDERATIONS

Returning to School

The decision about when your child may return to school is made on an individual basis by your renal transplant provider. Usually, 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.***

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 improve 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 participate in regular activities just like the other children, but a few restrictions must still apply.

Your child should not participate in:

- ◆ **Football**
- ◆ **Martial Arts**
- ◆ **Basketball**

- ◆ Wrestling
- ◆ Gymnastics on the uneven parallel bars
- ◆ Soccer

You may cautiously participate in other sports including:

- ◆ Baseball
- ◆ Swimming
- ◆ Track

Swimming Restrictions

Swimming in Chlorinated pools is safe and encouraged. Swimming in lakes or ponds is highly discouraged due to the microorganisms that inhabit these environments, which may be harmful to the Immuno-suppressed individual. If you have any questions or concerns about your child's progress or activity level, contact your renal transplant coordinator.

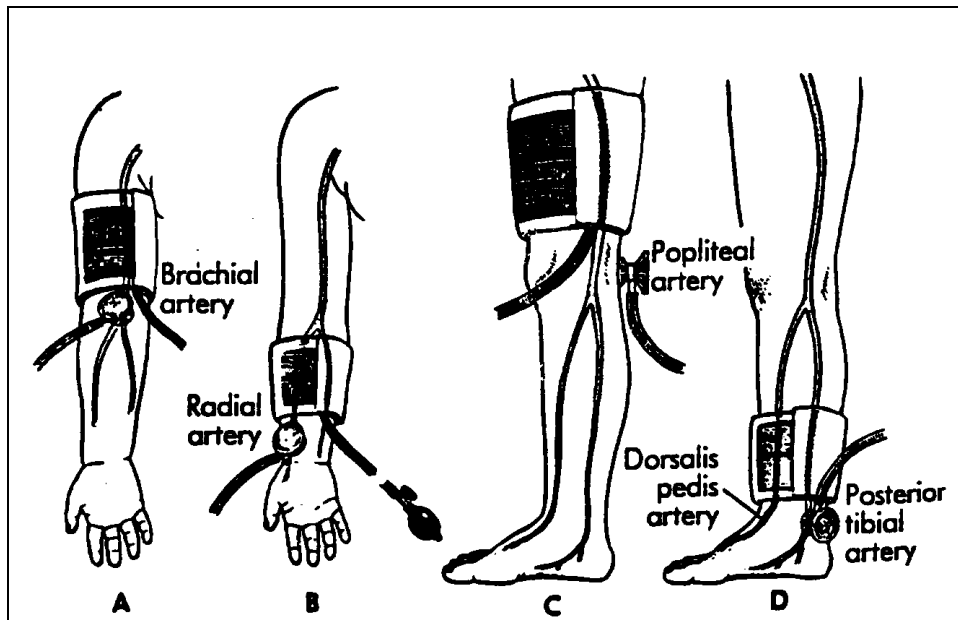
Blood Pressure Monitoring – You will be provided instruction on blood pressure measurement by one of the transplant coordinators prior to discharge from the transplant admission to the hospital.

Steps:

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.

12. Record the measurement on the home log. If the measurement is greater than _____ or less than _____ call your renal transplant provider or transplant coordinator.



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

The next few pages provide a place for you to record your child's vital signs and laboratory values. These records are for your own use and may be of help to the transplant team.

VITAL SIGNS RECORD

Date	Time	Weight	Blood Pressure			Temperature	
			AM	PM	PM	AM	PM

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	CO ₂	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	10-45 U/L
	SGPT/ALT	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 occur 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 functioning and determine if any changes in kidney function exist. It may be done if there is a question as to how well your child's kidney is functioning. In some cases, the serum creatinine does not fully reflect the level of your child's kidney function. 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 menstration, 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. Your 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 fund raising.

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-99

The 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.

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 others' 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
- Physician/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 Jami N. Gross-Toalson, PhD (214-456-5849) or Melanie Sweat, CCLS (214-456-6447).