Kidney & Kidney–Pancreas
Patient Education Manual

LOMA LINDA UNIVERSITY
MEDICAL CENTER
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Our dedicated team of physicians, nurses, and clinical professionals are committed to providing patients and families with the best possible care throughout the transplantation process. Patients and families can depend on the Transplantation Institute staff for guidance through every phase of care – from the initial patient evaluation and financial counseling through post-operation care and medication guidance.

This patient education manual has been designed as a reference in order to help patients and families understand the kidney, transplantation process. While it is a valuable educational tool, it does not replace the knowledge and professional guidance that physicians, nurses, and other transplant team members will provide. Patients and family members are strongly encouraged to ask questions regarding the transplantation process or anything related to their hospital stay. A transplant coordinator will be assigned to each patient for guidance throughout the transplantation process.

Your transplant coordinator is ____________________________________________________________, and can be reached at _________________________________.

Welcome to the Loma Linda University Medical Center (LLUMC) Transplantation Institute. Since the first kidney transplant in 1967, the Transplantation Institute has performed over 1,800 kidney transplants and over 180 kidney-pancreas transplants.
The Transplant Team

Case Managers
Professionals who take care of the discharge planning needs of the patients and families after the transplant.

Dietitians
Professionals who conduct nutritional evaluations of each patient and teach them the dietary guidelines after the transplant.

Financial Coordinators
Financial professionals who are available to help with financial or insurance issues.

Immunologist
Laboratory technicians who perform lab tests that match kidneys to recipients. They also monitor the immune system before and after the transplant.

Nurse Practitioners
Nurses who work with the surgeons in caring for the patients while in the hospital.

Social Worker
Professionals who conduct psycho-social evaluations of patients at the first clinic appointment. They also lead support groups and work with the transplant coordinator and the family throughout the transplantation process.

Surgeons
Physicians who perform the transplant surgery.

Transplant Coordinators
Nurses who are assigned to the patients and help them through the transplantation process.

Transplant Pharmacists
Pharmacists who teach patients about the prescribed medicines and monitor patient medication in-take after the transplant.
Introduction to the Kidneys and Pancreas

Five main functions of the kidneys
• Clean blood and remove waste products
• Balance water and salt to control weight and fluid in the body
• Control blood pressure
• Help make red blood cells and build strong bones
• Control the amount of potassium, sodium, calcium, and phosphorus in the blood

What are the parts of the urinary tract?
• There are two (2) kidneys. This is where urine is made.
• There are two (2) ureters that drain the urine from the kidneys to the bladder.
• There is one (1) bladder. It is like a balloon and holds urine until you are ready to urinate.
• There is one (1) urethra that drains urine from the bladder to the outside of the body.
• Renal arteries are tubes (blood vessels) that bring blood to the kidney.
• Renal veins are blood vessels (tubes) that take blood away from the kidney.
Treatment Choices

- Continuous Ambulatory Peritoneal Dialysis or CAPD
- Continuous Cycling Peritoneal Dialysis or CCPD
- Hemodialysis
- Transplant

Anyone who has kidney failure can be evaluated for transplant. However, transplant may not be a good choice for everybody. There are advantages and disadvantages to having a transplant.

Advantages

- You will not need dialysis after the new kidney starts working!
- There will be very few diet restrictions and no fluid restrictions.
- You will enjoy a more active life with work, school, or travel.
- You may be able to have children after transplant.

Disadvantages

- After transplant you will see the transplant physician in clinic and have your blood drawn on a regular basis between one to three times per week. Physician follow up with your nephrologist/kidney doctor will continue for as long as you have the new transplanted organ, frequency will lessen.
- You will have to take immunosuppressant medicines every day as long as the organ is working.
- There may be long term side effects of the immunosuppressant medicines, including infections or cancers.
Patient Evaluation
You must have an evaluation before you will be considered for a transplant. This evaluation process has many steps. It will start with a visit to the transplant clinic. During this visit you will have a physical evaluation, a psycho-social evaluation, and some laboratory tests. At this time, you and your family will attend a transplant information class. Insurance and financial information will also be reviewed with you.

Your responsibilities in getting your evaluation done are to:

• Keep your scheduled appointments.
• Tell the transplant coordinator when you have your tests done or if you cancel an appointment.
• Make sure your test results are sent to your coordinator.

The Physical Evaluation and Laboratory Tests
Some of these tests will have to be done at your dialysis center.

It is very important that copies of these tests be available at your first appointment:

• Recent history and physical exam.
• Laboratory tests: Done monthly at your dialysis center.
• Chest x-ray: If done in the last year.
• EKG (electrocardiogram): If done in the last year.
• Renal/abdominal ultrasound: If done in the last five years.
• Mammogram: If done in the last year. (women only)
• Gynecologist examination and PAP smear: If done in the last year. (women only)
During the first transplant clinic visit, the doctor will review these records. The doctor will also examine you and talk to you about your past medical and surgical history. The transplant coordinator will meet with you and talk to you about transplantation. He/she will tell you about other tests that may be needed to finish your evaluation.

Blood Typing - There are four different blood types. They are A, B, AB, and O. Every person has one of these blood types. The donor’s blood type does not have to be the same. However, it must be “compatible” with your blood type for you to receive the kidney and/or pancreas.

<table>
<thead>
<tr>
<th>Blood Type</th>
<th>Can receive a kidney from</th>
<th>Can donate a kidney to</th>
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<tr>
<td>O</td>
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<td>AB</td>
<td>O, A, B, AB</td>
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Viral Testing - It is important for us to know if you have been exposed to hepatitis, cytomegalovirus (CMV), Epstein-Barr virus (EBV), or acquired immune deficiency syndrome (AIDS). We will test you for these at your clinic appointment.

Tissue typing - This test is done on white blood cells. The white blood cells have special “markers” that tell your “tissue type”. You inherit tissue type from your mother and father. This test is used to match a kidney and/or pancreas to you.

Panel Reactive Antibody (PRA) - This test shows how active your immune system is. It is easier for you to get a kidney if your immune system is calm or measures 0%. PRA samples will have to be drawn on a monthly basis once you are listed. Blood will be drawn at your dialysis center and sent to our laboratory. Your immune system may be active from blood transfusions, pregnancy, a previous transplant or a current infection.

Crossmatch Testing - This test is done when a donor kidney is available. Your blood is mixed with the donor’s blood. If there is no reaction (negative crossmatch) it means you are “compatible” with the donor. If there is a reaction (positive crossmatch), the kidney will not work for you because it is “incompatible”.

Dental Evaluations - You need to have a dental check-up before you will be listed for transplant. Your dentist must tell us that your teeth and gums are healthy. You will also need to be checked by your dentist every year while you are waiting for your transplant.

Vaccinations - You will need some vaccinations before you get a transplant. These are:
- Diphtheria and tetanus (every 10 years)
- Pneumonia (every 5 years)
- Flu (every year)
- Hepatitis B series vaccine is recommended
- PPD skin test required

The Psycho-Social Evaluation - This is done by the Transplant Social Worker. Together you will talk about:
- How kidney failure has changed the way you live
- How you think a transplant will change your life
- Who you can count on for support (family and friends)
- What to do if the use of alcohol, tobacco, and/or drugs has been a part of your life

Other Tests
The transplant doctors will ask for any special tests they think you will need. For example, people with diabetes will need more tests for their heart. Your transplant coordinator or dialysis doctor can help you make arrangements for these tests.

Support group and family conferences are also a part of the evaluation process. The support group meets once a month. Besides offering education about transplant, the support group also offers patients a time to meet others who have had similar experiences. You and your family are encouraged to come. Family conference is a time when you, your family, and several transplant team members will meet to discuss how transplant will affect all of you.

The Financial Evaluation - You will talk with the financial coordinator about your finances, and what your medical insurance covers for your transplant. It would be helpful to have a family member attend this interview with you. Some of the topics that will be discussed are:
- Medicare and other Social Security benefits
- Possible funds to pay for your transplant evaluation
- Possible disability for yourself and/or your live donor
- Fundraising if your insurance does not cover all of your transplant
- How to handle Medi-Cal eligibility for transplant
- Bills and statements that you receive from the doctors or hospital
- Payment of immunosuppressive medications after transplant
Patient Selection

When all of your tests are done, the Patient Selection Committee will meet to discuss your case. They want to make sure anything that could be a problem has been taken care of. At this point you are not yet on the list. This committee will determine if you are eligible to be put on the organ donor waiting list.

The members of this committee are:

- Transplant surgeons
- Nephrologist
- Transplant coordinators
- Financial coordinator
- Immunologist
- Transplant social worker

After looking at all of the information, the committee makes one of the following choices:

- A transplant is a good choice for you.
- More tests are needed and your case will be discussed again.
- A transplant at LLUMC is not a good choice for you.

The transplant coordinator or the surgeon will call and tell you what has been decided after the committee has met.

After the Committee Meets

When the committee decides that you are a candidate for a new kidney and/or pancreas, your name will be placed on the waiting list. This means you are “activated” for transplant. If you have a living donor, their evaluation starts now.

If you are waiting for a cadaver donor, your name will be put on the national list with UNOS (United Network for Organ Sharing).

A word about the transplant list... The United Network for Organ Sharing (UNOS) is a national agency that was formed to help distribute organs equally to patients who are waiting for transplant. They work 24 hours a day to help match patients to available organs.

When you are “activated,” your name is put on this list. All patients accepted for transplant have their name on this list. When a kidney is available, the UNOS computer prints out a list of patients throughout the United States with the closest match. The names on the list are determined by blood type, tissue type, and length of time on the waiting list.

While Waiting

The average waiting time on the transplant list varies but can be five years or longer. It is important for us to keep in touch with you. Call us anytime during this waiting period. Please call the transplant coordinator right away if any of these things happen before your transplant:

- Blood transfusion
- Change your telephone number or address
- Go on vacation or out of town
- Change dialysis units
- Hospitalization
- Change medical insurance
- Change in health status

Points to Remember

- The waiting list is open to everyone who needs a new kidney.
- The average waiting time may be about five years.
- The time you wait depends on your blood type, your tissue type, your immune system, and how long you have been on the transplant list.
- You will have to be ready to come to the hospital on short notice. This is because the kidney (kidney/pancreas) must be transplanted within hours when it becomes available.
Kidney Donations and the Transplant List

Where Does the Kidney and Pancreas Come From?

A kidney that is transplanted may come from three different kinds of donors as listed below. A pancreas can only come from a cadaver donor.

Cadaver Donor

A cadaver donor kidney (kidney/pancreas) is one that comes from a person who has just died. The family of this person has given permission for the kidneys, and possibly other organs, to be donated for someone who needs a transplant.

Live Related Donor

A live related donor kidney comes from a blood relative, like a parent, brother, sister, or an adult child.

Live Unrelated Donor

A live unrelated donor kidney comes from someone who is not related to the person, like a spouse or a friend.

Points to Remember

- If you are thinking about a live donor transplant, there is one basic rule: THE DONOR MUST BE WILLING TO GIVE YOU THE KIDNEY WITHOUT PRESSURE FROM ANYONE.
- The donor has to be between the ages of 18 - 60 years old.
- A donor cannot have the following health problems: diabetes, high blood pressure, Hepatitis C, or be very overweight.
- You and the transplant team can plan when you will have the transplant surgery.

Other information that might be helpful to know

- The donor will not have to pay for the testing or the surgery. This is paid for through Medicare.

The donor will have many tests before the surgery. There will be laboratory tests, x-rays, a physical exam, and a visit with the social worker. This testing is done to make sure that the donor is healthy. It helps to limit complications for both the donor and for you.

The transplant coordinator will arrange for testing of the potential donor.

The donor will need to have 6-8 weeks off from work to recover from the surgery. If the donor has been working before the surgery, it may be possible for them to receive state disability payments while they are recovering.

For more information about living donors ask the living donor transplant coordinator.

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For more information about living donors ask the living donor transplant coordinator.
The Call
When a donor kidney (kidney/pancreas) becomes available, the transplant surgeon or coordinator will call you. You need to come to the hospital immediately. The transplant will take place within hours of the phone call so do not eat or drink anything. If you are on peritoneal dialysis, bring enough supplies to the hospital for five (5) exchanges.

The Admission Process
Before surgery you will be admitted to the hospital. There are certain things that will be done to make sure you are ready for surgery. These are:

- Chest x-ray
- EKG (electrocardiogram)
- Urine tests
- Blood tests
- A history and physical done by the nephrologist, surgeon, and anesthesiologist.

You will also have an IV started (a needle put into a vein). You will be given immunosuppressive medications and medications to protect you from infection. Two of your family members may stay with you until you go to surgery. While you are in surgery they can wait in the surgical waiting area in the main lobby. The transplant surgeon will talk to them when the surgery is over.

Surgery and Post-Operative Recovery
The kidney transplant surgery usually takes about two to three hours. The new kidney will be placed in the left or right groin area. The renal artery and vein of the new kidney will be attached to the blood vessels that take blood to and from your legs. The urethra of the new kidney will then be attached to the bladder, so it can drain urine from the new kidney. After surgery you will be taken to the transplant unit (4100). You will be attached to a heart monitor and will have a special IV line to monitor and give fluids. You will also have a catheter in your bladder to measure the urine output from the new kidney. The average length of stay in the hospital after kidney transplant surgery is about four to six days.

The kidney–pancreas surgery takes about four to six hours. After the new kidney has been transplanted, the pancreas which is attached to a small piece of bowel (the duodenum), is then sewn to your bowel. This allows the pancreas to drain directly into the bowel. When the surgery is over you will be taken to the Intensive Care Unit. After surgery you may have a breathing tube in your mouth to assist you with breathing. In the ICU you will be attached to a heart monitor and will also have a special IV line to monitor and give fluids. In addition, you will have a catheter to drain the urine from the new kidney. The length of time you stay in ICU depends on your overall medical condition. The remainder of your recovery will be on the transplant unit (4100). The average hospital stay after kidney/pancreas surgery is seven to fourteen days.

Activity after Surgery
One to two days after surgery you will be getting out of bed. At first you will sit on the edge of the bed or in a chair. When you are able to get up, it is important to start walking. Walking helps prevent complications, such as blood clots, pneumonia, and poor wound healing. It will also help build your strength and speed recovery.

Transplant Unit Visitor Guidelines
Visiting hours on the adult unit are 1:00 to 8:00 p.m. Visitors are restricted to two visitors at a time. No children under age 14 are allowed on the unit. For your protection, your visitors will have to wash their hands before going into your room and wear a mask while visiting. Family members are not allowed to stay overnight in the hospital room. It is very important that your family and friends do not visit if they are sick.
After the Transplant

Post-transplant Tests
Here are some tests that give us information about how you and your new kidney and/or pancreas are doing after your surgery.

**Complete Blood Count (CBC)**
There are two specific values that we look at in this blood test:
- **Hemoglobin (Hgb)** - measures the ability of the red blood cells to carry oxygen to your body tissues. If the value is low it could mean that you are bleeding, anemic, or are having a reaction to medication. Normal values are 12-17 mg/dl for males and 11-15 mg/dl for females.
- **White blood cells (WBC)** - measures the ability of your body to fight infection. A high WBC may mean you have an infection. A low WBC may be from your medications or a virus. Normal WBC count is 4.0-11.5.

**Electrolytes**
There are specific values we look at in this panel of blood tests
- **Creatinine** - Tells us how well your kidney is functioning. When this number goes up it may be rejection or a side effect of your medications. Normal blood creatinine is 0.7-1.3 (depending on your body size.)
- **Bicarbonate** - It helps balance the amount of acid in your body. The normal bicarbonate level is 20-30.
- **Potassium** - It is important to keep the level around 3.5-5.0 to prevent life-threatening complications. Your doctor will closely watch these levels.
- **Amylase** - This is an enzyme that is made by the pancreas. It tells us how well your pancreas is functioning.
- **Urinalysis** - This is a urine test that shows if you have blood, protein, and/or bacteria in your urine. You may be given antibiotics after your transplant to decrease the risk of urinary tract infections.
- **Cyclosporine, Prograf®, or Rapamune® Drug Levels** - These levels show how well you are absorbing your anti-rejection medication. Your medication dose is adjusted according to the blood level. A high level can be harmful to your transplanted kidney and/or pancreas. A low level may lead to rejection. Your drug level will be measured often for the rest of your life.

*Note: It is important to have your blood level drawn before you take your medicine in the morning.*

**Diagnostic Tests**
- **Kidney Ultrasound** - This measures blood flow, location, and size of your kidney. It uses sound waves to make a picture of your kidney.
- **Kidney Biopsy** - This test looks at cells from your new kidney to see if there is a problem like a rejection episode.

**Common Problems after the Transplant**
You and your family will need to be dedicated to keeping your transplanted kidney and/or pancreas healthy and working. This means you will need to do what you have been taught by the transplant team. Sometimes you may have problems after your transplant even when you follow all the directions.

**Some Problems That May Affect Your Transplant**
- **Infection** - Your body may not be able to fight infection as it did before transplant surgery. This is caused mainly by the immunosuppressive medications you are taking. Your doctor balances your medications carefully to keep your new organ working and to keep the risk of infection low.
- **Cytomegalovirus (CMV)** - This is a common infection seen after transplant. It is a herpes virus that you may have, or that you get from the donor, or another person. You are most likely to get CMV in the first four (4) months after your transplant surgery. This is when you are taking the highest doses of immunosuppressant medications. Your white blood cell count may also be very low. Ganciclovir (Cytovene®) or valganciclovir (Valcyte®) is the medicine used to treat CMV. You will need to watch for flu-like symptoms, fatigue, and/or joint pain.

**Prevent Infections By Following These Simple Rules**
- Always wash your hands with soap and water:
  - After you go to the bathroom
  - Before you eat
Before you take your medications
~ After working in the yard
• Take good care of your teeth by brushing two times a day.
~ Get a new tooth brush every 3-6 months.
~ Use only your own toothbrush.
~ Go to the dentist twice a year for a checkup and cleaning.
• Stay away from people who have infections such as:
~ Colds
~ Flu
~ Childhood diseases (measles, mumps, chicken pox, or shingles)
• For six (6) weeks after the transplant surgery and during any treatment, stay away from crowded places such as:
~ Church
~ Sports events
~ Concerts
~ Shopping malls
~ Public transportation, such as buses
• When eating or drinking, do not share drinking glasses or silverware. Wear gloves when you are working in the garden or with dirt. Wash your hands after working in the yard.
• Take care of cuts or scratches right away.
~ Clean with soap and water.
~ Apply antibacterial cream that you can buy at a drugstore.
~ Apply a bandage if needed.
• Other ways to fight infection.
~ Wash raw fruits and vegetables well before eating them.
~ Stay away from old barns or silos. The dust can be very harmful.
~ Stay away from activities in the desert, especially after a rain storm.
~ Don’t clean the cat box or the bird cage. Ask someone else to clean these every week or more frequently if needed.
~ Always wear a mask when going to the hospital or doctor’s office for the first six (6) weeks after the transplant surgery.

Rejection
This happens when your body’s immune system thinks your new organ is “foreign” and attempts to destroy it. You will take immunosuppressive medications for the rest of your life to prevent rejection.

There are several types of rejection:
• Hyperacute rejection - happens when the body immediately destroys the new kidney, this is rare because of the crossmatch testing used before transplant.
• Acute rejection - although this can happen at any time after the transplant, most often it happens during the first several months. This can be treated by giving you higher doses of medication by mouth or by intravenous infusion. You may get this treatment as an outpatient if it is recognized early.
• Chronic rejection - this may happen months or years after the transplant. This type of rejection is resistant to treatment with current medications. This will cause your new organ to slowly stop working.

It is very important to report any of the following symptoms to the Transplant Clinic. They may be signs of infection or rejection. Call your doctor if you have any one of the following:
• Fever - temperature that is two (2) or more degrees over your normal temperature
• Muscle and joint aches
• Nausea and/or vomiting
• If you have contact with anyone who has chicken pox, mumps, or measles
• Persistent headache
• Irritability or just not feeling well
• Chills
• Change in your normal blood pressure
• Diarrhea (this can lower your blood Cyclosporine or Prograf® levels)
• Pain, redness, tenderness, or drainage over the transplanted organ surgery site
• Fluid retention/weight gain (2 pounds in 24 hours)
• Cough, phlegm, or hoarseness
• Urinary problems:
  ~ Decrease in urine output, or
  ~ pain or burning during urination
  ~ blood in the urine
  ~ strong odor to the urine
  ~ feeling an urgent need to urinate or the need to urinate frequently

**Diabetes**
The term diabetes means that your blood sugar levels are too high. This can be caused by some of the medications you are taking for your transplant, such as Prednisone, Prograf®, and/or Cyclosporine. You may need to start taking insulin or increase your dose to help control your blood sugar.

**Acute Tubular Necrosis (ATN)**
This is a condition when the kidney doesn’t work right away after transplant. ATN is usually temporary. It can be caused by a long organ storage time on ice before transplant or by medications. The symptoms are treated in two ways: 1) By limiting the salt, protein, potassium in your diet, and fluid intake, or by dialysis; 2) The transplant team will look at the lab results, your weight, your limiting fluid intake, urine output, and vital signs to decide which treatment you will need.

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**Going Home After The Transplant**
You need to be able to recognize any signs of rejection or infection early and report them right away.

You will need to get the following supplies to monitor yourself at home:
• Thermometer
• Blood pressure cuff
• Bathroom scale

Your nurses will teach you how to use these before you go home. You will be taught to measure how much you are drinking and your urine output.

It is your responsibility to
• Keep all doctor appointments, even when you are feeling well.
• Weigh yourself, take your temperature, blood pressure, and blood sugar (if this applies to you) every day. Record these in your log book and bring it with you to clinic appointments.
• Complete your lab work on time.
• Take all of your medications exactly as prescribed by your transplant doctor.
• Check with your transplant team before you take any medications, even those you can buy over the counter.

If you are being followed by the LLUMC transplant doctors, you can call the team at the outpatient clinic during working hours, Monday through Friday at 909-558-4252. After working hours call the hospital operator at 909-558-4000 and ask for the kidney transplant surgeon on call.

**Discharge Medications**
The nursing staff, transplant pharmacist, or post transplant coordinator will teach you about the medications you will be taking when you go home. Arrangements will be made with your pharmacy to get your medications before you go home.
Medications

You are responsible for taking the medications that the doctor has ordered. You will be taught about your medications before you go home from the hospital. Talk to your doctor, pharmacist, and/or transplant coordinator if you have any questions about the following:

• The name of each medication and the reason you are taking it
• When, how much, and how long you are to take each medication
• The main side effects of each medication
• What to do if you forget to take a dose
• When to order more medication so you don’t run out
• How to order your medications
• What you should avoid while you are taking your medications (such as drinking alcohol)
• What medications you should not take in combination
• What medications must be taken on an empty stomach

When you go home you will keep taking most of the medications that were started in the hospital after your transplant surgery. This includes immunosuppressant medications. These are medications that help prevent rejection of your new organ. You will probably have to take one or more of these medications for the rest of your life.

Remember
• Never stop taking your medication or change the amount you take without checking with your doctor.
• After you receive your transplant you will be responsible for your medication co-pay (if you have a co-pay). You will be required to pay this to the pharmacy that will be filling your prescriptions before you are discharged from the hospital.

General Guidelines For Storing Your Medications
• Keep all of your medications in the original container.
• Make sure the cap is on tightly.
• Store the medication containers in a cool (<80º F), dry place away from direct sunlight.
• Do not store medications in the bathroom - moisture can cause medications to lose their strength.

Important Medication Tips

• Take Prograf® on an empty stomach.
• Take your Prograf® or Cyclosporine doses 12 hours apart.
• Take Prograf® or Cyclosporine AFTER the lab draws blood for a level.
• Bring the medication with you and take it after your blood has been drawn.

Notify The Transplant Team If:
• You are not able to take your medications by mouth because you are sick.
• You think the directions on the label may be different than what you were told.
• You need to take aspirin, Tylenol® (acetaminophen), other pain pills, cold medications, any over-the-counter medications, or medicines from a health food store.
• You are having a reaction to your medications.

Antirejection Medications

CYCLOSPORINE

Cyclosporine is used to help prevent rejection of a transplanted organ(s). It decreases the amount of fighting cells in your immune system, so they won’t attack your transplanted organ(s). It is used for long-term (perhaps lifetime) immunosuppression.

How to take this Medication
• Sandimmune® brand of Cyclosporine and Neoral® brand of Cyclosporine ARE NOT INTERCHANGEABLE. You must not change brands without directions from your doctor.
• Capsules: 25mg and 100 mg. Liquid: 100 mg per ml.
• If you take Cyclosporine two times a day, doses should be 12 hours apart. You may be given intravenous Cyclosporine for the first few days after your transplant.

• If you are taking the liquid form of Sandimmune®, you may want to mix it with milk, chocolate milk, or orange juice. This may help it taste better. Mix it with room-temperature liquid in a glass or hard plastic container and stir it with a metal spoon. DO NOT USE A STYROFOAM CONTAINER, BECAUSE THE MEDICATION WILL STICK TO THE SIDE OF THE CONTAINER.

• If you are taking liquid Neoral®, you may take it straight from the measuring syringe without mixing.

• Your transplant team will decide the proper dose for you based on your weight, the level of the medication in your blood, laboratory tests, and the possible side effects of the Cyclosporine.

Important to Know

• Report any vomiting or diarrhea to your doctor because it may lower your Cyclosporine level. This may cause a rejection episode. Cyclosporine is usually taken with other immunosuppressants, such as a Prednisone, Rapamune®, or Cellcept®.

• You will have frequent laboratory tests to check your blood level of Cyclosporine.

• Take your morning dose of Cyclosporine after your blood has been drawn on the days your Cyclosporine blood level is checked.

• Store your Cyclosporine at room temperature. DO NOT leave Cyclosporine in a car, a refrigerator, a bathroom medicine cabinet, or a place that is exposed to direct light. Good places to store this drug include the kitchen or your bedroom; away from heat, cold, moisture, and children.

• An open bottle of Cyclosporine is good for 60 days. You should not remove a capsule from a foil pouch until you are ready to use it.

• Other medications may change your blood level of Cyclosporine. Check with your transplant team before starting any new medications. This includes anything you buy with or without a prescription.

• There can be problems if you take Cyclosporine while you are pregnant or breast feeding. The medication can affect you, your fetus, or your infant. You must tell your transplant team IMMEDIATELY if you think you are pregnant.

Main Side Effects

The most common side effects of Cyclosporine are:

• Headache
• Abnormal kidney function
• High potassium levels, low magnesium levels
• Swelling or overgrowth of the gums
• Increased cholesterol levels
• Nausea
• Increased blood sugar
• Hand tremors
• High blood pressure
• Excess hair growth
• Sleep disturbances
• Abnormal liver function
• Acne
• Infection

Tell a member of the transplant team if you have any of these side effects.

PROGRAF® (FK 506, tacrolimus)

Prograf® is used to prevent or treat organ rejection in people who have had transplants. It is used for long-term (perhaps lifetime) immunosuppression.

How to take this Medication

• Capsules: 0.5 mg, 1 mg, and 5 mg
• If you take Prograf® two times a day, the doses should be 12 hours apart.
• Prograf® must be taken on an empty stomach. This can be one hour before or two hours after eating.
• Your transplant team will determine the amount of medication you should take based on your weight, the amount of medication in your blood, other laboratory tests, and the possible side effects of Prograf®.

Important to Know
• Prograf® is usually taken with other immunosuppressants, such as Rapamune®, Prednisone, or CellCept®.
• You will have frequent laboratory tests to check your blood level of immunosuppression while you are taking Prograf®.
• Take your morning dose of Prograf® after your blood has been drawn on the days your blood level is checked.
• Other medications may change your blood level of Prograf®. Check with your transplant team before starting or stopping any medications. This includes any medications you buy with or without a prescription.
• There can be problems if you take Prograf® while you are pregnant or breast feeding. The medication can affect you, your fetus, or your infant. You must tell your transplant team IMMEDIATELY if you think you are pregnant.
• The transplant team will decide whether you should take Prograf® or Cyclosporine. They will make this decision based on what side effects you have or if you experience an episode of rejection.

Main Side Effects
The most common side effects of Prograf® are:
• Headache
• Diarrhea
• High blood sugar
• Decreased magnesium levels
• Hair loss
• Numbness/tingling of hands or feet
• Infection
Tell a member of the transplant team if you have any of these side effects.

PREDNISONE (Deltasone®)
Prednisone is a corticosteroid that helps prevent or treat rejection of the transplanted organ(s). It may be used for long-term (perhaps lifetime) immunosuppression, or in higher doses, for treatment of rejection.

How to take this Medication
• Tablets come in different strengths (such as 2.5 mg, 5 mg, 10 mg, or 20 mg). Your transplant team will decide which tablet strength you should take.
• You must take Prednisone with food.
• Prednisone does not mix with Carafate® (an anti-ulcer medication) or antacids. You must take these medications either one hour before or one hour after your Prednisone.
• If you take Prednisone only once a day, take it in the morning.
• The transplant team will decide the amount of medication you should take based on your weight, how well your transplant is working, and the length of time since your transplant.
• Your dose will be decreased slowly.
• Do not stop taking the Prednisone without your doctor’s advice because this could make you very sick.

Important to Know
• There can be problems if you take Prednisone while you are pregnant or breast feeding. The medication can affect you, your fetus, or your infant. You must tell your transplant team IMMEDIATELY if you think you are pregnant.
• For the first few days after surgery and during a rejection episode, you will get high doses of intravenous corticosteroids (Solu-Medrol®). Some common side effects of high doses can be wild dreams (hallucinations), anxiety, and paranoia. If you have any these side effects, please tell the transplant team. They can give you other medications to manage these effects.

Main Side Effects
Many of the side effects are related to the amount of medication you are taking. The most common side effects are:
• High blood pressure
• Sun sensitivity
• Fluid and sodium (salt) retention
• Stomach ulcers
• Muscle weakness
• Acne
• Bone disease
• Hormone problems
• Delayed wound healing
• Anxiety
• Mood swings
• Glaucoma
• Cataracts
• Decreased growth in children
• Weight gain
• Infection

Tell a transplant team member if you have any of these side effects.

**RAPAMUNE® (sirolimus)**

Rapamune® is given with other immunosuppressants to help prevent rejection of your new organ(s). It may be used for long-term (perhaps lifetime) immunosuppression.

**How to take this Medication**
• Tablets: 1 mg. Liquid: 1 mg/ml.
• Your transplant team will decide the proper dose for you based on your blood level and white blood cell count.

**Important to know**
• Rapamune® may lower your white blood cell and platelet counts. Notify the transplant team about any problems with bruising or bleeding that you may have.
• There can be problems if you take Rapamune® while you are pregnant or breast feeding. The medication can affect you, your fetus, or your infant. You must tell your transplant team IMMEDIATELY if you think you are pregnant.
• You will have laboratory tests to check your blood level of Rapamune®.
• Take your dose of Rapamune® after your blood has been drawn on the days your blood level is checked.
• Other medications may change your blood level of Rapamune®. Check with your transplant team before starting or stopping any medications. This includes any medications you buy without a prescription.

**Main Side Effects**
The most common side effects of Rapamune® are:
• Reduced white blood cell count
• Reduced platelet count
• Infection
• Increased cholesterol and/or triglycerides

Tell a transplant team member if you have any of these side effects.

**CELLCEPT® (mycophenolate mofetil)**

Cellcept® is given to you with other immunosuppressants to help prevent rejection of your new organ(s). It may be used for long-term (perhaps lifetime) immunosuppression.

**How to take this Medication**
• Capsules: 250 mg. Tablets: 500 mg.
• If you take Cellcept® two times a day, doses should be 12 hours apart.
• Your transplant team will decide the amount of medication you should take based on your weight, your white blood cell count, and the possible side effects.
• You may take Cellcept® with or without food.

**Important to Know**
• Cellcept® may lower your white blood cell count.
• There can be problems if you become pregnant while taking Cellcept® and for six (6) weeks after you stop taking it. It can affect you, your fetus, or your infant. You must tell a member of the transplant team IMMEDIATELY if you think you are pregnant.

**Main Side Effects**
The most common side effects of Cellcept® are:
• Diarrhea
• Nausea
• Vomiting
• Reduced white blood cell count
• Infection

Tell a member of the transplant team if you have any of these side effects.

**ORTHOCLONE OKT3® (monomurab-CD3)**

OKT3® may be given to you during your transplant surgery or right after the transplant to prevent rejection. It may also be used to treat rejection.

**How to take this Medication**
• This medication is given only in the intravenous (IV) form. It is usually given once a day for 7-14 days. It only takes a short time (30 seconds-1 minute) to be given.
• To decrease the side effects, you will take Tylenol® and/or Benadryl® before treatment with OKT3®. You will take these medications before the first 3-4 doses.
- Your transplant team will decide the proper dosage for you based on your weight, how your transplant has been working, your white blood cell and platelet counts, and the possible side effects of OKT3®.
- You may be able to get your OKT3® as an outpatient after you have had your third dose.

**Important to Know**
- Your transplant team may change the dosages of your other immunosuppressive medications while you are being treated with OKT3®.
- There can be problems if you are getting OKT3® while you are pregnant or breast feeding. The medication can affect you, your fetus, or your infant. You must tell your transplant team IMMEDIATELY if you think you are pregnant.

**Main Side Effects**
The most uncomfortable side effects usually only happen during the first few doses. The most common side effects of OKT3® are:
- Wheezing
- Fast heart beat
- A hard time breathing
- Muscle stiffness
- Chest pain
- High or low blood pressure
- Fever
- Headache
- Chills
- Tremor
- Nausea
- Diarrhea
- Vomiting

Tell a member of the transplant team if you are having any of these side effects.

**Thymoglobulin or ATGAM® (antithymocyte globulin)**
Atgam® or Thymoglobulin may be given to you right after your transplant to prevent rejection. It may also be used to treat rejection. It lowers your body’s immune response.

**How to take this Medication**
- This medication is given only in the intravenous (IV) form. It is given over four to six hours. It is given through a central venous line.

- To lower the side effects, you may get Tylenol® or Benadryl® before you receive a dose of Atgam® or Thymoglobulin.
- Your transplant team will decide the proper dosage for you based on your weight, how your transplant is working, your white blood cell count, and the possible side effects of Atgam® or Thymoglobulin.

**Important to Know**
- Your transplant team may change the dosages of your other medications while you are being treated with Atgam®.
- There can be problems if you are getting Atgam® while you are pregnant or breast feeding. The medication can affect you, your fetus, or your infant. You must tell a member of the transplant team IMMEDIATELY if you think you are pregnant.

**Main Side Effects**
The most common side effects of Thymoglobulin or Atgam® are:
- A hard time breathing
- Muscle aches
- Fever
- Abnormal kidney function
- Chills
- Low platelet or white blood count
- Rash
- Diarrhea
- Nausea
- Infection

Tell a member of the transplant team if you are having any of these side effects.

**SOLU-MEDROL® (methylprednisolone)**
Solu-medrol® is a corticosteroid that helps prevent or treat rejection of a transplanted organ(s).

**How to take this Medication**
- This medication is only given intravenously (IV). It will be given over 10-30 minutes.
- The transplant team will decide the amount of medication you will be given based on your weight, how well your transplant is working, and the length of time since your transplant.
- The dose is decreased slowly (over several days). You will be switched to Prednisone when the dose is low enough and you can swallow tablets.
Important to Know
• There can be problems if you take Solu-medrol® or Prednisone while you are pregnant, or breast feeding. The medication can affect you, your fetus, or your infant. You must tell a member of the transplant team IMMEDIATELY if you think you are pregnant.
• You will be given high doses of Solu-medrol® for the first few days after surgery and during a rejection episode. Some common side effects when you are given high doses are wild dreams (hallucinations), anxiety, and paranoia. If you have any of these side effects, please tell a member of the transplant team. They can give you other medications to help lessen these side effects.

Main Side Effects
The main side effects of Solu-medrol® are the same as for Prednisone. Other side effects from Solu-medrol® may be:
• Vision changes (decreased or blurred)
• Restlessness
• Trouble sleeping
• Increased appetite
Tell a member of the transplant team if you have any of these side effects.

Antibacterial Medications

**Septra DS®, Bactrim®, Cotrim® (trimethoprim/sulfamethoxazole, or TMP/SMX), Cipro® (ciprofloxacin), Pentam® (Pentamidine), Dapsone**

The medications you take for immunosuppression also lower the normal ability of your body to fight bacteria. This means you have a higher risk of getting infections. Your doctor may prescribe one or more drugs to protect you from infections or to treat infections.

For each type of infection there may be several drugs that will work. The medications listed here are most commonly prescribed by the transplant team.

**Septra DS®**

Septra DS® is a sulfa antibiotic used to prevent and treat pneumocystis pneumonia (PCP) and other infections. The risk of this kind of pneumonia is higher for transplant patients because they are taking immunosuppressants.

*Note: Be sure to tell a member of the transplant team if you have an allergy to sulfa products.*

**How to take this Medication**
• This medication is taken by mouth and comes in a tablet or a liquid form.
• Your transplant team will decide the proper dosage and length of time for you to take Septra DS® (usually six months - one year).
• Take this medication with a full glass of water.

Important to Know
• Patients who have an allergy to sulfa antibiotics will be given a breathing treatment with a drug called Pentamidine every month for at least six (6) months or a daily dose of Dapsone.
• There can be problems if you are taking Septra DS® while you are pregnant or breast feeding. This medication can affect you, your fetus, or your infant. You must tell a member of the transplant team IMMEDIATELY if you think you are pregnant.
• Septra DS® causes sun sensitivity. Always wear SPF 15 sunscreen to protect yourself from skin cancers.

Main Side Effects
The main side effects of Septra DS® are:
• Low white blood cell count
• Vomiting
• Itching
• Nausea
• Rash
• Loss of appetite
Tell a member of the transplant team if you are having any of these side effects.

**CIPRO® (ciprofloxacin)**

CIPRO® is a quinolone antibiotic used to treat or prevent bacterial infections.

**How to take this Medication**
• This medication is taken by mouth and comes in tablet form.
• Your transplant team will decide the proper dosage and length of time for you to take Cipro® (usually 1-3 weeks).
• This medication can be taken on either a full or empty stomach. Take the tablet with lots of fluid - at least one full glass of water with each dose.
• Do not take this medication with milk, yogurt, antacids, calcium, or Carafate® (sucralfate).

Important to Know
• Do not take this medication if you have had an allergic reaction to ciprofloxacin or other quinolone-type antibiotics, like norfloxacin, ofloxacin, or nalidixic acid.
• There can be problems if you are taking Cipro® while you are pregnant or breast feeding. This medication can affect you, your fetus, or your infant. You must tell a member of the transplant team IMMEDIATELY if you think you are pregnant.

Main Side Effects
The most common side effects of Cipro® are:
• Nausea
• Dizziness
• Diarrhea
• Headache
• Stomach discomfort
• Lightheadedness

Side effects that happen less frequently are:
• Agitation
• Painful or stiff joints
• Shakiness
• Greater sensitivity to sunlight
• Confusion
• Hallucinations

Tell a member of the transplant team if you are having any of these side effects.

Antifungal Medications

Mycelex Troche® (clotrimazole), Nystatin (Nilstat®), Diflucan® (fluconazole)

Your immune system has less ability to fight infection while you are taking immunosuppressive medications and you have a greater chance of getting a serious fungal infection. The antifungal medications are used to treat or prevent these fungal infections. Examples of fungal infections are thrush (white tongue) or vaginal yeast infection.

How to take these Medications
• Mycelex Troche® (clotrimazole) lozenge - dissolved in your mouth until gone.
• Nystatin Suspension (Nilstat®) - swish in your mouth and swallow.
  - The liquid or lozenge should be taken after meals and other medications to allow them to work in your mouth. They are usually taken for three to six months after your transplant, during a rejection episode, and when you are taking antibiotics.

• Vaginal suppository or cream - use as directed.
• Diflucan® - swallow.

Your transplant team will decide the proper dosage and how long you will take these antifungal medications.

Important to Know
• Look at your tongue every day. If you have a white coating on your tongue call the transplant team.
• There can be problems if you are taking any of these antifungal medications while you are pregnant or breastfeeding. These medications can affect you, your fetus, or your infant. You must tell a member of the transplant team IMMEDIATELY if you think you are pregnant.

Main Side Effects
The most common side effects of the antifungal medications are:
• Nausea
• Diarrhea
• Vomiting
• A metallic taste in your mouth

Tell a member of the transplant team if you are having any of these side effects.

Antiviral Medications

ACYCLOVIR (Zovirax®)

Acyclovir is used to treat or prevent herpes viral infections. You have more risk for getting this infection because you are immunosuppressed. It may also be used to treat herpes simplex and shingles. This medication will not get rid of the herpes viruses. It will help to heal the sores and decrease the pain.

How to take this Medication
• Capsules: 200mg. Tablets: 400 and 800 mg. Liquid: 200 mg per 5 ml. Ointment.
• If you are taking Acyclovir by mouth, you should take it with food so it won’t upset your stomach.
• Your transplant team will decide the proper dosage and how long you will need to take this medication.

Important to Know
• There can be problems if you are taking Acyclovir while you are pregnant or breast feeding. The medication can affect you, your fetus, or your infant. You must tell a member of the transplant team IMMEDIATELY if you think you are pregnant.
If you have an active herpes infection:

• Keep the affected area as clean and dry as possible.
• Wear loose-fitting clothes to avoid irritating the infected area and spreading the virus.
• Acyclovir will not prevent you from spreading herpes to others.
• It is best not to have sex if either partner has any symptoms of genital herpes. Condoms may help prevent the spread of genital herpes, but vaginal jellies and diaphragms will not.
• Avoid kissing or having sex with someone who has a cold sore (on the genitals or on the mouth).

Main Side Effects
The most common side effects of acyclovir are:

- Nausea
- Rash
- Vomiting
- Diarrhea
- Headache
- Dizziness

Tell a member of the transplant team if you are having any of these side effects.

GANCICLOVIR (Cytovene®), VALGANCICLOVIR (Valcyte®)

Ganciclovir or valganciclovir is used to prevent or treat CMV (cytomegalovirus) infection.

How to take this Medication

- Ganciclovir is given intravenously (IV) or orally (250 mg & 500 mg capsules).
- Valganciclovir is given orally (450 mg tablet).
- Your transplant team will decide the proper dosage and the length of time you will be given Ganciclovir or Valganciclovir.
- Drink lots of fluids while you are taking this medication. The transplant team will tell you how much you should drink. The capsules must be taken with food.

Important to Know

- Ganciclovir or Valganciclovir may lower your white blood cell count. This could put you at higher risk for infection.
- Men and women must practice birth control methods to prevent pregnancy. There is a high risk of birth defects in babies conceived while a parent is on Ganciclovir or Valganciclovir.
- There can be problems if you are taking Ganciclovir or Valganciclovir while you are pregnant or breast feeding. The medication can affect you, your fetus, or your infant. You must tell your transplant team IMMEDIATELY if you think you are pregnant.

Main Side Effects
The most common side effects of Ganciclovir or Valganciclovir are:

- Low white blood cell count
- Low platelet count
- Abnormal kidney function
- Fever
- Rash
- Headaches
- Confusion

Tell a member of the transplant team if you are having any of these side effects.

Antiulcer Medications

Pepcid® (famotidine), Zantac® (ranitidine), Prilosec® (omeprazole), Protonix® (pantoprazole), Prevacid® (lansoprazole)

This medication is used to prevent and sometimes treat ulcers of the stomach or GI tract.

How to take this Medication

- It is important that you follow directions given to you by the transplant team when taking any of the antiulcers medications. The transplant team will decide the proper medication dosage, when to take it, and how long you will need to take the medication.

Important to Know

- Some of the antiulcer medications interfere with other medications.
- There can be problems if you take these medications while you are pregnant or breast feeding. These medications can affect you, your fetus, or your infant. You must tell a member of the transplant team IMMEDIATELY if you think you are pregnant.

Main Side Effects
The main side effects of the antiulcer medications are:

- Headache
- Nausea
- Intestinal Gas
- Diarrhea or constipation
Now is a good time for you to think about making changes in the way you eat and exercise to help keep you healthy. It is important for you to eat a healthy diet, exercise regularly, and take your medicines. The medicines you take to suppress your immune system after transplant have side effects that are related to your diet and nutrition. Some of these side effects are:

- Increased blood cholesterol and triglyceride levels
- Weight gain
- High blood pressure
- Increased blood sugar levels

Follow the diet and nutrition information given to you after your surgery.

- Eat foods low in salt, sugar, and fat.
- Eat foods that are high in fiber.
- Follow the food guidelines (the “food pyramid”)

Take good care of your heart.

- Eat a balanced diet.
- Start an exercise program (talk with your doctor about this).

**Diet and Nutrition**

**Use Sparingly**

- Fats, Oils, & Sweets

**2-3 Servings**

- Milk, Yogurt, & Cheese Group

**2-3 Servings**

- Meat, Poultry, Fish, Dry Beans, Eggs, & Nuts Group

**3-5 Servings**

- Vegetable Group

**2-4 Servings**

- Fruit Group

**6-11 Servings**

- Bread, Cereal, Rice, & Pasta Group
• Before surgery, the transplant team requires that you stop smoking.
• Limit egg yolks to 2-3 per week; the yolk has all the fat. Most recipes can be made with egg whites or egg substitute.
• Use extra light or nonfat milk and other low fat dairy products. The lower the percentage of fat, the better!
• Choose the leanest varieties of meat and trim off the fat.
• Small portions of fried foods are allowed once in a while, not all the time.

**Good Main Dish choices**

• Skinless poultry, fish, beans - all cooked with very little fat.
• Read labels. You will discover foods that are high in saturated fat or cholesterol.
• Avoid foods that have lard, palm, and coconut oils in them.
• Choose fresh fruits, vegetables, legumes, and whole grains, such as whole wheat and oat bran. More fiber in your diet may help decrease cholesterol.
• Avoid simple sugars as found in desserts, pastries, candies, and sodas.

**Watch Your Weight!**

After transplant, unwanted weight gain often becomes a problem. This happens because the medication that you take can cause hunger. It also changes the way your body uses fat and sugar. Food may taste much better and this may make you eat more than necessary. Excessive weight gain can make complications, such as high blood pressure and increased blood sugars, worse.

• Eat meals at regular times every day to avoid problems with hunger and unnecessary snacking.
• Eat smaller portions and avoid seconds.
• Instead of adding fat to foods, add flavors! Try fat free buttery flavored powders and fat free salad dressings.
• Eat out at restaurants that offer low fat versions of regularly high fat foods.

**Exercise**

Start with short walks around your house or in the park once or twice a day. Ask a friend or family member to go with you. Gradually work up to 30 minutes a day, three to four times a week. You may choose other forms of exercise but consult your physician first. Physical activity helps burn calories, control weight, and reduce cholesterol. It can help you feel stronger and more relaxed. If you need a snack, choose low calorie items like fresh fruit, carrot or celery sticks, diet soda, or foods that are sugar free and fat free. Eat what you should, not what you could. It is up to you to control your weight.

**Other Concerns**

• **Potassium**: Cyclosporine® and Prograf® can sometimes cause your blood levels of potassium to be high. Increased blood potassium can be dangerous. During this time, avoid potassium-rich foods, (oranges, asparagus, apricots, milk, artichokes, bananas, salt substitutes, avocados, cantaloupe, and bran).

• **Sodium**: Prednisone may cause your body to retain sodium and fluid. This can lead to high blood pressure. Avoid foods high in salt (sodium). Season your food with other herbs and spices. Occasionally, you may use a small amount of salt in cooking. Do not add any more salt at the table.

• **Calcium and Phosphorus**: If you are unable to consume foods high in calcium and phosphorus (such as low or non fat milk and dairy products) you may need to take a calcium and/or a phosphorus supplement.
Clinic Visits

After your surgery you will be seen by the surgeon in the Transplantation Institute Clinic. This is on the lobby level of the Medical Center, Room 1405. This is the same place you saw the doctor before your transplant.

These visits are to check any problems that you may have, such as rejection or infection. They are also to make sure you are taking your medications correctly and that you are not having any side effects.

**Clinic telephone numbers:**
Appointments: 909-558-4252
Other needs: 909-558-8684

**Clinic hours:**
Monday - Thursday
8:00 am to 5:00 pm
Friday
8:00 am to 2:00 pm

- At first you will see the doctor two times a week until he is sure that you are stable. Your visits will decrease to once a week, when your lab values are stable and you are feeling good.
- If you are having problems, call the triage nurse and follow their advice.
- You need to have your blood drawn at the lab the day before you come to the clinic.
- The clinic nurse will call you in the evening on the day of your appointment. She will tell you about your lab results and any changes in your medication. It is important that you be available by phone between 4:00 and 5:00 p.m., or have an answering machine.
- If your telephone number changes, please call and tell the clinic staff.
- You can call and leave a message for the triage nurse any time, even after clinic hours. A call after hours will be answered the next day. If you have a fever or an urgent problem after hours, please call 909-558-4000 and ask to speak to the kidney transplant surgeon on call.
- Please bring your Transplant Patient Log Book with you to all clinic visits. The nurse and doctor will go over the medications and dosages with you. Any time there is a change in your medication, you will write it in your Log Book.

Your Primary Physician

The transplant surgeons will follow you in clinic after you are discharged from the hospital. They are in charge of your care until you are medically stable, which usually takes about six weeks. When you are stable your care will be transferred to your primary nephrologist. You will need to make an appointment to see your primary nephrologist within one week after you stop coming to the Transplant Clinic. This doctor will continue your medical care and see you routinely. He or she will check your lab work and your progress closely for the life of your transplant. You will need to schedule appointments with the Transplantation Institute at three, six, and nine months, then yearly to check on your progress.

Preventing Problems After Transplant

**Cancer Prevention**

Some of the medicines you take increase the chance of developing cancer. It is important to have regular check-ups with your doctor. Your doctor will do tests to detect signs of cancer. Women need to have a yearly PAP smear and mammogram. Men should have a PSA (prostate specific antigen) blood test done to screen for prostate cancer.

**Sun Exposure**

Transplant patients have an increased chance of developing skin and lip cancers. The medications you take after transplant make you more sensitive to the sun. We recommend that you wear sunscreen lotion (SPF 15 or higher) and lip balm every day, rain or shine, when you are outside. It is also a good idea to wear a hat and/or other protective clothing, like long sleeves and long pants. It is important for you to see a dermatologist if you have any changes or marks on your skin.

**Dental Care**

You must see a dentist regularly. You need to take antibiotics before you have any work done on your teeth (this includes cleaning). The antibiotics help prevent infection. You need to let your primary doctor know before you have any dental work done. He or she will give you a prescription for the antibiotics.

**Smoking**

The Surgeon General of the United States says that smoking is harmful to your health. You must stop smoking so you can be in the best health possible. We can help you find a stop-smoking program.
Routine Health Care
You need to check with the transplant surgeon before you take any new medications. This means prescription medications and ones that you buy over-the-counter. Also, check with the transplant doctors before you have any vaccinations.

Vaccination and Immunizations
Your vaccinations were updated before your transplant. It will be your responsibility to keep them up to date from now on. We recommend a tetanus vaccine every ten years. The shot to prevent pneumonia needs to be given every five years. We recommend that you speak with your primary doctor about the Hepatitis vaccines. We DO NOT recommend the flu vaccine within the first year after your transplant. After the first year, you should get a flu vaccine every year. For a week after you get the flu vaccine, your Prednisone dose should be increased. Please consult your doctor for the proper dose.

Travel
Once you are feeling better and your lab work is stable, you may travel. Please talk to your doctor before you make travel plans. You may need to take special precautions. Remember to carry your medicines with you at all times. Do not check your medications into the baggage compartment. Take extra medications, in case you are delayed in returning.

Alcohol/Street Drug Use
We do not recommend drinking any type of alcohol. Alcohol will interfere with and can cause dangerous changes with your transplant medications. Do not use any street drugs. These could cause serious life threatening infections or death. Drugs prescribed by your doctor should be taken in the amount ordered.

Alternative Medicine/Herbal Medications
We do not recommend taking herbal or alternative medications. These may have drug interactions with your immunosuppressants.

Medic Alert Bracelets
We recommend you wear a medic alert bracelet. The clinic has order forms available. The bracelet should say who your doctor is, what type of transplant you have had, and that you are taking immunosuppressive medications.

Pets
You can have pets at home after your transplant. If you have birds or cats have someone else clean the cages or litter box. These may contain bacteria that can be harmful to you.

Resuming Activities
Once you are discharged from the hospital you may slowly begin your normal activities. Do not do any strenuous activities or abdominal exercises for at least six weeks. Do not lift anything over ten pounds for six weeks after the surgery. If you have any questions about your activity level, check with your doctor.

Returning to Work
You should be able to go back to work six to eight weeks after the transplant. If your job involves any lifting or strenuous work, you may need to take more time off. The clinic staff and your doctor will help you determine when you should return to work.

Birth Control
Talk to your doctor about birth control after your transplant. Women may be able to become pregnant after transplant and men may be able to father children. The chances of a successful pregnancy depends on the type of medication you are taking.

Pregnancy
It is risky to have a baby after transplant. Be sure to talk to your doctor about this before you get pregnant. He/she will help you plan for a successful pregnancy.
Kidney and kidney/pancreas transplants can be expensive and may place a strain on a family’s finances. Families can obtain help from several different organizations.

**Disability**
To see if you qualify for any disability insurance, contact the Social Security Administration at 1-800-772-1213, the Employment Development Department in your area, or your employer’s Human Resource Department.

**Fund Raising**
There are several companies that will assist you in raising the money you will need for your transplant and for the immunosuppressive medications you will be required to take after your transplant. Contact the financial coordinator for more information.

**Indigent Patients**
Families without medical coverage need to contact the Medi-Cal Field Office in their county. In the Inland Empire, the Medi-Cal Field Office can be contacted at 909-383-4192.

**Social Security Administration**
The Social Security Administration provides general financial assistance and medication grants to transplant patients. Supplemental Security Income (SSI) makes monthly payments to disabled individuals with few assets and low income. Social Security Disability Income (SSDI) provides assistance for individuals who are working and paying Social Security taxes. For more information contact Social Security at 1-800-772-1213.
Vocational Rehabilitation

If you have a disability that prevents you from working, you may be a candidate for vocational rehabilitation. The goal of rehabilitation is to prepare people with disabilities for work. It is important to enter rehabilitation as soon as you are released from the hospital in order to protect your disability coverage. In the Inland Empire, contact the Employment Development Department at 951-782-6650.

Loma Linda University Medical Center Transplantation Institute Kidney and Pancreas Support Group

Support group is held twice a month on the first Tuesday and first Wednesday of each month. Call 909-558-4000 ext. 81700 and ask a social worker for details.

National Kidney Foundation

17100 Ventura Blvd., Suite 222, Encino, CA 91316-04017 • 818-783-8153

Transplant Recipients International Organization (TRIO)

1735 I Street, NW, Suite 917, Washington, DC 20006-2461 • 202-293-0980

United Network for Organ Sharing (UNOS)

1100 Boulders Parkway, Suite 500, PO Box 13770 Richmond, VA 23225-8770 1-888-TX INFO1 (1-888-894-6361)
Glossary

**Acute Care Area** - An area of the hospital where a patient will go after their medical condition has improved and they no longer need intensive care.

**Acute Tubular Necrosis (ATN)** - Reversible kidney damage resulting in delayed kidney function. This can be caused by antirejection medications that prevent rejection or prolonged organ storage before transplant.

**Activated** - This means your name has been placed on the national UNOS waiting list.

**Angiogram** - A test used to determine if there are any blockages in the blood vessels leading to or from an organ such as the kidneys. To conduct the test, a dye is injected into a blood vessel, usually in the groin.

**Anemic** - Low red blood cell count.

**Antibody** - A protein substance made by the body’s immune system in response to a foreign substance, for example, a previous transplant, blood transfusion, pregnancy, virus, or bacteria.

**Antigen** - A foreign substance, or event (such as a transplant) that triggers an immune response. This response may be the production of antibodies.

**Bacteria** - Small organisms (germs) that can cause disease.

**Biopsy** - A procedure whereby a small piece of tissue from an organ, such as a kidney, is obtained by inserting a special needle through the abdominal wall. A biopsy is done to assess any damage to an organ.

**Blood Urea Nitrogen (BUN)** - A waste product from the blood that the kidney excretes in the urine. This blood test is checked to show how well the kidney is working.

**Blood Type** - There are four (4) types of blood: A, B, AB, & O. Every person has one of these types of blood.

**Central Venous Line (CVP)** - A central venous line is a special IV needle that is put into a big vein (usually in the neck or shoulder). This kind of IV can be used to draw blood, give medicine, and measure heart pressures. The central line will be put in during surgery. The nurse will change the dressing every other day and watch the site for infection. The central line is usually taken out by your nurse on the transplant unit before you go home.

**Cold Ischemic Time** - The amount of time the organ was out of the donor’s body, placed on ice and transplanted into a recipient.

**Compatible** - Likeness or similarity between donor and recipient blood type or organs.

**CMV Infection** - A viral infection caused by the cytomegalovirus. Signs of this infection include fever, tiredness, and low WBC count. Many patients need to be in the hospital to have this infection treated.

**Continuous Ambulatory Peritoneal Dialysis (CAPD)** - A type of dialysis that you do at home using fluid exchange through the abdomen.

**Corticosteroids** - A category of immunosuppressive medications that includes Prednisone and prednisolone.

**Creatinine** - A waste product from the blood that the kidney excretes in the urine. This blood test helps measure kidney function.

**Crossmatch** - A test in which donor and recipient blood samples are mixed together. A “positive” crossmatch shows that the donor and recipient are incompatible. A negative crossmatch shows there is no reaction between the donor and recipient. This means that the donor and recipient are compatible and the transplant may proceed.

**Continuous Cycling Peritoneal Dialysis (CCPD)** - A type of dialysis done at night while you sleep. A machine called a cycler is used.

**Diabetes** - A disease in which the body has high levels of sugar in the blood.

**Edema** - Excess fluid in body tissues; swelling of the ankles, for example, is a sign of edema.

**ESRD (End Stage Renal Disease)** - The condition of chronic failure of the kidney for which a person needs dialysis or transplant to survive.

**Electrolytes** - Substances such as potassium and sodium, that are found in the blood.

**Financial Evaluation** - A meeting with the financial coordinator to review your insurance coverage and financial status.
**Foley Catheter** - This is a tube that goes through your urethra into your bladder. It has a balloon on the end to keep it in your bladder. It is connected to a drainage bag on the other end. The Foley catheter will be placed during surgery. It is removed 4-5 days after surgery. The purpose of the Foley catheter is to make sure your bladder doesn't get too full and break the stitches where the ureter is connected.

**Hemodialysis** - A type of dialysis done at a dialysis center under medical supervision.

**Herpes** - A family of viruses that infect humans: herpes simplex causes lip and genital sores; herpes zoster causes shingles.

**Hypertension** - Another name for high blood pressure.

**Immune Response** - The body’s defense against things that are not normally a part of the body, such as bacteria, viruses, blood transfusions, or a transplanted organ.

**Immunosuppression** - Suppression of the immune response, usually through medications, so that the body will not reject a transplanted organ.

**Immunosuppressant** - Medications that are able to block the body’s immune response.

**Immunosuppressive Medications** - Medications that are able to block the body's immune response.

**Incentive Spirometer** - A piece of equipment that you will use to help exercise your breathing muscles and prevent pneumonia after surgery. This is part of your deep breathing exercises. The nurse will show you how to use it and how to deep breathe and cough.

**Incompatible** - No likeness or similarity between donor and recipient blood type or organs.

**Intravenous (IV)** - Medication or fluid given through a vein.

**Intensive Care Unit** - An area of the hospital where a patient will be monitored closely for a critical medical condition.

**Orally** - By mouth.

**Panel Reactive Antibody (PRA)** - A way of measuring how active your immune system is. When you make more antibodies, the PRA is high. It is harder to get transplanted when you have a high PRA.

**Rejection** - A condition that occurs when the body recognizes an antigen, such as a transplanted organ, as foreign and tries to attack it. Immunosuppressive medications are used to prevent or treat rejection.

**Platelet** - A small blood cell needed for normal blood clotting.

**Street Drugs** - Illegal drugs such as marijuana, speed, cocaine, heroin, crack, etc.

**Thromboguards** - Plastic leg wraps that fit around your legs from the ankle to the knee. They are connected to a machine that inflates and deflates them on a cyclical basis. This is to help the blood flow in your legs and prevent clots in your leg veins. You will be able to take these off when you get out of bed.

**Ted Hose** - Elastic stockings used to help the blood flow in your legs and prevent blood clots.

**Ureters** - Tubes that carry urine from the kidney to the bladder. There is one ureter for each kidney.

**Urethra** - The tube that drains urine from your bladder to the outside of your body.

**Tissue Typing** - When a sample of your blood is checked for your “genetic” makeup. This helps match you to a donor organ.

**Thrush** - A fungus infection in the mouth.

**Ultrasound** - A test done on the outside of your body to look at your organs. The probe, or doppler, placed on your skin uses sound waves to create a picture of your internal organs on a monitor.

**Virus** - A very small agent (germ) that causes infection.

**White Blood Cell** - Cells in the blood that fight infection; part of the immune system.
Many strengths.
One mission.
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