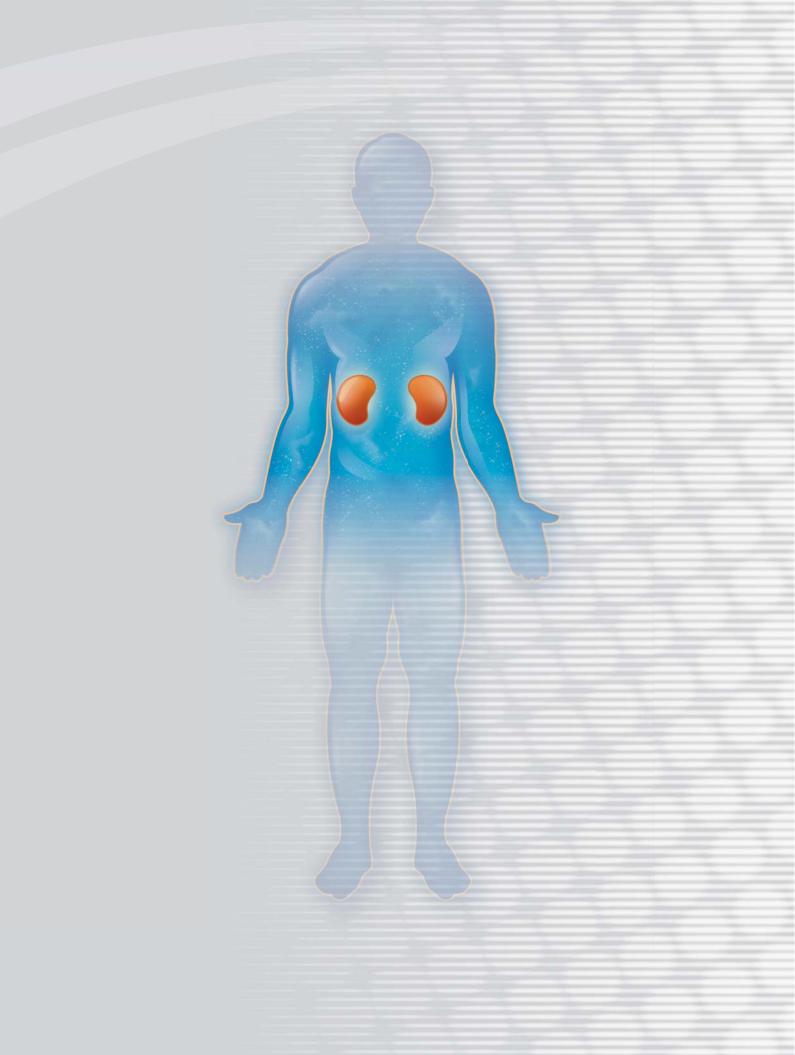


A University Health System & UT Health Science Center Partnership | San Antonio

A Patient's Guide to Kidney Transplant





A University Health System & UT Health Science Center Partnership | San Antonio

#### Kidney Transplant Patient Education Guide

Welcome to the University Transplant Center at University Hospital in partnership with the University of Texas Health Science Center at San Antonio (UTHSCSA). This guide will help to answer many of the questions you may have about kidney transplantation.

#### **Our Adult Kidney Program**

The Kidney Transplant Program was established in 1968. Our highly skilled transplant surgeons have performed over 1,000 kidney transplants. We have conducted many successful living donor kidney transplants and combined kidney/pancreas transplants in adults. Our patient and graft survival rates at one year and beyond are outstanding.

Please refer to the Scientific Registry for Transplant Recipients for our most current outcomes at www.SRTR.org.

## The Kidneys

The kidneys are located on either side of the spine near your waistline. They are about the size of your fist and are bean-shaped.

#### The Kidneys

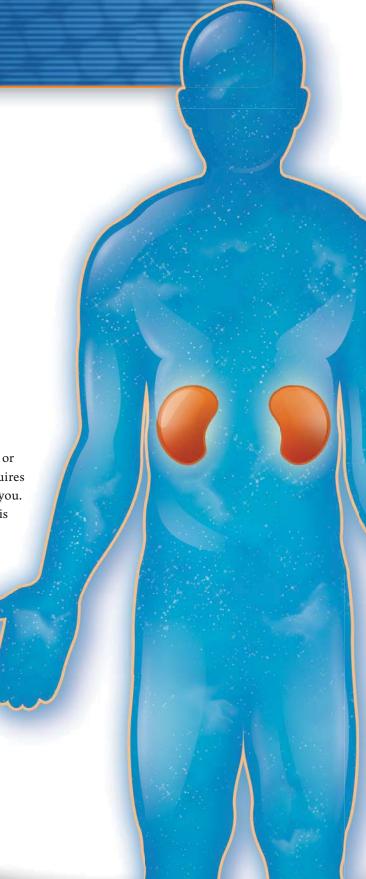
- Remove waste products
- · Regulate total body fluid by balancing water and salt
- Help make strong bones and red blood cells
- Control the amount of potassium, calcium, magnesium and phosphorus in the blood

#### Why do people need kidney transplants?

Some diseases can damage the kidneys. If the damage is severe or continues for a long time, you may have kidney failure that requires dialysis or soon will. A kidney transplant may be an option for you. A successful transplant would allow you to stop needing dialysis or avoid dialysis altogether.

#### **Common Causes of Kidney Failure**

- Diabetes
- High blood pressure
- Chronic inflammation in the kidney (glomerulonephritis)
- · Polycystic kidney disease
- Recurrent infections
- Chronic obstruction blockage of the flow of urine



#### Signs of Kidney Disease

- Fluid retention
- Shortness of breath
- Mental confusion
- Abnormal blood or urine test results (often occur before any other signs or symptoms)
- Headache
- High blood pressure
- Fatigue

**Treatment Options** 

- I. Dialysis
  - Hemodialysis
  - Peritoneal dialysis

#### II. Transplant

- · Living donor
  - Related, Unrelated and Altruistic
  - Paired donation
- · Deceased donor
  - Expanded criteria donor (ECD)
  - Donation after cardiac death (DCD)
  - Hepatitis C positive donor
- · "High risk" donor

Please note that transplantation is a treatment option and will not necessarily cure the underlying cause of kidney failure.



## The Transplant Team

The Transplant Team is a group of healthcare professionals who are here to assist you before and after your transplant. However, the most important decision maker is YOU.

#### **Transplant Nephrologist**

During your evaluation, you will meet the transplant Nephrologist, a kidney doctor who specializes in transplant. The Nephrologist will review your medical history and examine you and help to determine if you are a candidate for transplantation.

#### **Transplant Surgeons**

One of your first appointments will be with a Transplant Surgeon, who may perform your kidney transplant surgery.

#### **Transplant Nurse Practitioners and Physician Assistants**

These healthcare professionals work closely with the Nephrologist and Surgeons to evaluate your health both before and after your transplant.



#### **Transplant Nurse Coordinators**

The Transplant Nurse Coordinators are registered nurses.

- The Pre-Transplant Coordinators are responsible for setting up your transplant evaluation and keeping you informed of your progress toward transplantation.
- The Discharge Coordinators will provide additional education and support while you are in the hospital.
- Post-Transplant Coordinators are responsible for your care in the Clinic, as well as yearly follow-up care.

#### **Dietitians**

Our Dietitians are available throughout the transplant process to provide nutritional advice to help you remain as healthy as possible. What you eat and drink is very important to your overall health and healing. You may meet with them during clinic visits or when in the hospital. Your transplant clinician will refer you for dietary consult as needed.

#### **Transplant Clinic**

After your transplant, our Clinic Nurses and staff will oversee your care throughout the transplant process.

#### **Transplant Social Workers**

You will meet one or more of our Social Workers during the evaluation process. They can assist you with any non-medical issues before and after your transplant. They can also give you important information regarding Medicaid, Medicare and other insurance questions.

#### **Transplant Financial Coordinators**

Financial Coordinators will help you obtain preauthorization for your evaluation exams, kidney transplant surgery, and follow-up care. They can also answer any questions you may have regarding your healthcare coverage.

#### **Transplant Pharmacists**

The Transplant Pharmacists specialize in filling the prescriptions you will need after your transplant. They are available to answer questions about your medications. Our on-site pharmacy carries the transplant medications that you will need.

## Your Primary Care Physician (PCP) or Primary Nephrologist

In most cases, we expect you to continue keeping appointments with your personal doctors before and after your kidney transplant. Your primary doctors are a very important part of your healthcare team and should be your point of care for any non-transplant related health issues, such as arthritis, back problems, diabetes, and the common cold. After your transplant medications have been adjusted, your primary doctor will manage your non-transplant related healthcare. We will be available if you or your doctors have any questions regarding your health.

#### Family and Friends

Transplantation is not for "loners." The fact is that you cannot go through this process alone. Everyone will come to a point where he or she needs help and encouragement to make the journey. A strong support system produces the best outcome. This means you must have family or friends who are willing and available to drive you to and from your appointments, and take care of you before and after your transplant.

#### You

The most important part of this process is YOU. The success of your transplant is directly related to your compliance with the medications, clinic visits, and adherence to the rules set up by the Transplant Team. You must maintain a nutritious diet and keep a routine exercise program tailored to your physical abilities. Receiving a kidney transplant is a lifetime commitment.

## **Pre-Transplant Evaluation**

#### Your nephrologist initiates the transplantation process by referring you to our program for a kidney transplant.

The process continues with a patient evaluation to determine if you are a good candidate for transplantation. Throughout this evaluation, you'll find yourself taking many tests. These tests will help determine if transplantation is truly the best and safest option for you. During this process, your transplant coordinator will also discuss the option of living donation.

#### **Transplant Evaluation Exams**

- Physical exam and complete medical and surgical history.
- Social Work Assessment To discuss and determine your family/friend support before and after your transplant and to identify any additional resources that will be needed.
- Electrocardiogram (EKG or ECG) Evaluates the electrical system of the heart that controls rate and rhythm, and may reveal heart damage that was previously undetected.
- Echocardiogram An ultrasound of the heart that will show how well your heart "pumps."
- Cardiac Stress Test Shows how well your heart works under stress.
- Chest x-ray Determines the health of your lungs and lower respiratory tract and makes sure you don't have any old infections that would get worse after transplant.
- Colonoscopy A screening test for recipients age 50+. It reveals any abnormal condition of the colon.
- Bladder Studies An x-ray and/or camera examination of your bladder.
- Dental Evaluation Your dentist must tell us that your teeth and gums are healthy before transplantation. You will also need to be checked by your dentist every year while you are waiting for your transplant.
- Blood Tests Your blood count, blood and tissue type, blood chemistries, and immune system function will all be checked.
- Panel Reactive Antibody (PRA) A way of determining whether you have antibodies that would cause you to reject certain kidneys.
- Tissue Typing This test is used to find a matching organ.
- Nutrition Assessment A dietitian will be available throughout the evaluation process as well as post transplant.

#### **Females**

- Mammogram An x-ray which can detect signs of breast cancer.
- Pap smear Cells from a woman's cervix analyzed for signs of cancer.

#### Males

• Prostate Specific Antigen – Blood test to screen for prostate cancer in men over age 40.

#### **What Happens Next?**

- When your pre-transplant evaluation is complete and results are received, the selection committee meets to determine if you are ready to be placed on the list.
- Your transplant coordinator will contact you by phone and/or correspondence to inform you that you have been placed on the list. ONLY after you receive such correspondence are you officially on the transplant list.
- You have the option to be listed at other centers (multiple listing).
- Any potential living donors can begin their screening process at this time.
- Patients have the option to refuse transplantation at any time.



Cathy Gutierrez Kidney Transplant Recipient 2005

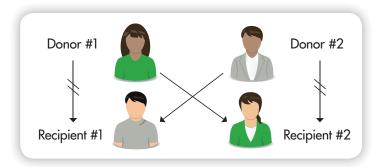
## Living Donation

#### A living donation is the quickest way to transplantation.

A family member, friend or other unrelated person may be able to donate one of their kidneys to you. Of all potential donors, living donors are the better option. If you have a potential living donor, please ask your Transplant Nurse Coordinator for further information about this option.

#### Your living donor does not need to be an exact match.

If your potential donor is tested and is incompatible (not an exact match), you can still get a transplant through a paired donor exchange. Other donor-recipient pairs are in the same situation. We can help arrange an exchange in which your donor gives his or her kidney to an unrelated, compatible recipient, and you receive a kidney from another living donor who is the right match for you. Sometimes, more than two compatible pairs can be matched. This results in more than two life-saving transplants.



To learn more about our living donor program, visit www.UniversityTransplantCenter.com/LivingDonor.



#### Waiting for a Transplant

The waiting list is a national computerized network. This list is managed by United Network for Organ Sharing (UNOS). UNOS is supervised by the federal government to help ensure that patients receive healthy organs as they become available.

You may contact them at (888) 894-6361 or visit their website at www.TransplantLiving.org or www.TransplantesYVida.org for Spanish information.

Several factors are considered when determining who will receive the available kidneys:

- Blood Type Every person is a blood type A, B, AB, or O. For deceased donors, the blood type must be the same. For living donors, the blood types must be compatible.
- Tissue Type Genetic matching to determine which donors are appropriate for you. If a perfect match is not available, the kidneys are allocated based on the closest match and time on the waiting list.
- Cross Match A test which makes sure you don't have antibodies in your blood that would cause you to reject certain donor kidneys very quickly.

#### **Average Wait Times by Blood Type**

- O: 5 7 year wait
- A: 3 5 year wait
- B: 5 7 year wait
- AB: 2 4 year wait

#### While on the waiting list

- Attend our pre-transplant class (a schedule will be given to you).
- Stay as healthy as you can.
- Keep in touch with the transplant team.
- Notify us of any changes in telephone, address or insurance.



<sup>\*</sup> Mandatory National Sharing – Zero mismatch can happen anytime.

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## Self-Care While Waiting

#### **Nutrition**

Patients who are better nourished generally have fewer complications, spend less time on the ventilator in the Intensive Care Unit after surgery, and have a shorter recovery time. In addition, good nutrition combined with an exercise program helps you maintain a reasonable quality of life during the waiting period. It's recommended that all patients follow a low-salt diet to help prevent fluid from building up. You may also need to adjust your energy level and protein intake to prevent undesirable weight changes or muscle loss. The Transplant Dietitian is available to help assess your food habits and suggest strategies for symptom management together with general nutritional advice.

#### **Exercise**

Physical fitness is very important as you wait for your kidney transplant. It is difficult to remain active when you're feeling poorly, but this must remain a priority. Patients who are in better condition generally have shorter recovery times and fewer complications following surgery.

"Working out" at a gym may be unrealistic. Light exercises, such as lifting cans of soup or small weights, are good ways to get exercise done at home. While on the waiting list, walking is the best exercise to maintain your health and fitness. You can start by going for a 5-10 minute walk outside or in a nearby mall. Aim to increase the time you spend walking by one minute every day you walk. Your ultimate goal is to walk for 30 minutes, three times each week. Try to walk at a pace that gets you slightly short of breath, but still able to talk. This level of activity is generally safe for people with health problems, including heart and kidney disease.

Don't walk immediately following a big meal, or on days that are extremely cold, hot or humid. Stop exercising if you feel dizzy, nauseated, or unusually short of breath. Maintaining your physical health is important before transplantation. You'll benefit physically and mentally by keeping your body in good shape. Try your best to fit exercise into your daily routine by getting your family and friends to join you. Perseverance now will pay off later. Please remember you must consult your healthcare provider before starting any new exercise program.



#### **Contacting the Transplant Team**

Despite the uncertainty of the waiting period, we encourage you to lead as normal a life as possible. Your Transplant Nurse Coordinator is available if you have any questions or concerns. You may, however, contact any member of the Transplant Team at any time. Continue to see your local doctor or specialist who can also communicate with our Transplant Team in order to provide you with the best care.

Please remember that you or a family member must inform your Transplant Nurse Coordinator or Transplant Team of any admission or discharge from the hospital. The waiting period during the transplant process can be a difficult time. Clear, direct, and honest communication among all family members will help reduce frustration and tension. If you or your family experience significant difficulty with coping during the waiting period, please seek help from a local, qualified health professional or contact the Transplant Team's Social Worker.

#### **Contacting your Coordinator**

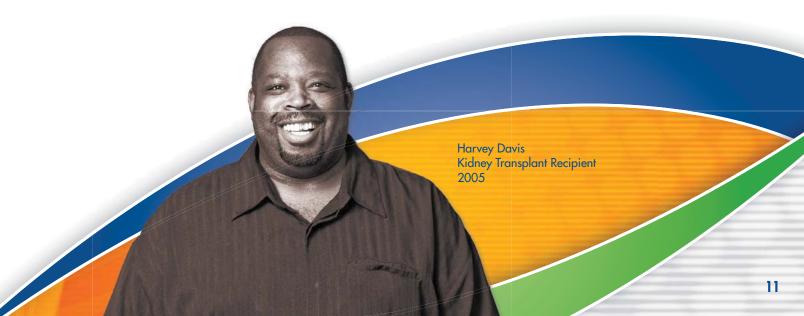
Call (210) 567-5777

The administrative staff in the Transplant Office will answer all calls for the Transplant Nurse Coordinators between 8 a.m. and 5 p.m., Monday through Friday, except holidays. The Transplant Nurse Coordinators will answer these calls at their earliest convenience, usually the same day that you call.

For non-emergencies, during weekends, holidays, or after hours, call the Transplant Office at (210) 567-5777, and your call will be answered by our voicemail. Leave your name and telephone number where you can be reached. Try to be as specific as possible when you leave your message on the recorder. Your call will be returned within 24 hours or on the next business day.

#### In an Emergency - Call 911

In the event of a life-threatening emergency, such as chest pain, coma, breathing problems, or bleeding, call 911 and they will take you to the nearest hospital emergency room. You and your family can always ask the physicians in the emergency room to call the University Transplant Center. DO NOT try to drive to University Hospital in an emergency.



## **Getting the Call**

#### Receiving the call to come to the hospital for a transplant.

- A Transplant Nurse Coordinator will call you with specific instructions at the phone numbers you provided
- · Have a designated driver and a back up transportation plan to the hospital
- Bring health insurance information
- Do not have anything to eat or drink once you have been called to come into the hospital for a transplant unless instructed to by the Transplant Nurse Coordinator

#### What to bring

Pack a small suitcase or have a list ready of what you need to pack:

- Sleep wear, shoes/slippers, robe
- Personal hygiene items
- List of medications you currently take
- List of important conditions or surgery
- Important phone numbers/next of kin
- · Copy of directive or living will



#### What not to bring

- Money
- Credit cards
- Jewelry
- Flowers/plants/pets
- Fresh fruit/vegetables
- Children under 14 years of age
- A large suitcase
- Clothes

#### Once you arrive at the hospital, report to the Transplant Unit.

Several members of our Transplant Team will administer the following exams:

- Physical examination & evaluation review
- · Blood work
- Chest x-ray
- Electrocardiogram (EKG)
- IV to provide fluids and medicines
- Dialysis (if needed)
- · Final cross match

#### Your transplant could be cancelled if:

- You have any signs of infection.
- The donor kidney has any problems.
- A new medical problem exists. This is why it is important to inform our Center if you develop a new medical problem.
- Final cross match is positive (if you have antibodies against the particular donor kidney).

## Kidney Transplant Surgery

#### Your transplant

- You will be under general anesthesia.
- Surgery is 2 to 4 hours long.
- The transplant surgeon will make an incision (approximately 6 inches long) just above the groin on the right or left side.
- The artery and vein of the new kidney will be attached to one of your arteries and veins.
- The new kidney's ureter (the tube that carries urine to the bladder) will be attached to your bladder.

#### After your transplant

- You will wake up in the Transplant Intensive Care Unit.
- You will have some mild discomfort. You will receive medication to relieve your pain.
- In order to clear your lungs, the transplant staff will ask you to cough.
- Medications and fluid will be given to you through an IV for the first few days after your transplant.
- A catheter will be in place in your bladder to help you pass urine.
- Some patients require dialysis for a short time if the donor kidney does not work right away.
- · You will learn your medications and how to care for your transplanted kidney.
- The average time in the hospital after an uncomplicated kidney transplant is 5 to 6 days.

#### After you leave the hospital

- You will receive an appointment for your next visit in the Transplant Clinic and for a procedure to remove a tube in your bladder.
- We will follow you closely for the first few weeks.
- You should bring your medications and your Transplant Manual to ALL of your appointments.
- We will give you instructions for lab work or other tests that you might need. The purpose of these tests is to monitor your progress and identify complications as soon as possible.
- You will be seen in the clinic every week for the first month.
- The visits will gradually decrease over the next few months. After three months, you should return to your regular doctor for follow up care.

#### Returning to work

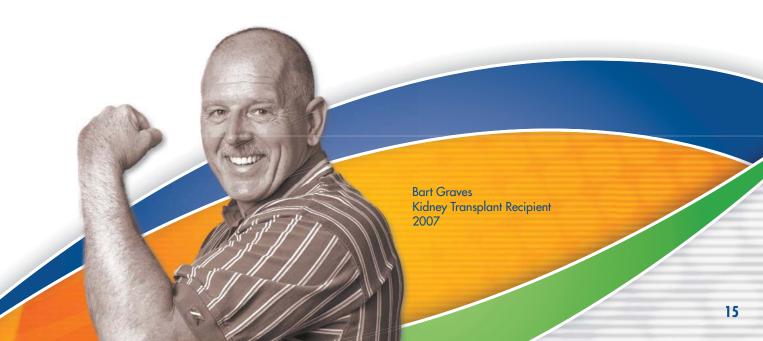
- Your health at the time of transplant and the type of job you have will determine how quickly you may return to work.
- Your Transplant Physician will let you know when you can resume your normal activities.
- Most patients return to work on a part-time basis then gradually work up to full-time.

#### Medications after transplantation

The body tries to get rid of anything that it considers foreign. After your transplant your body will try to reject your transplanted kidney. In order to prevent rejection, we will give you immunosuppressive medications. These medications help the body control the cells that will try to reject your new kidney by lowering your immune system. This is the same system in your body that helps you to fight infection. Therefore, after transplant, especially in the early period, you will be more susceptible to infections. We will also give you medications that will help your body fight infections.

#### These are some of the medications you will take:

- Immunosuppressant or "anti-rejection" special medications that are designed to suppress (or lower) your immune system
- Steroids first line of defense for rejection. These medications will quickly be reduced to low doses
- Antibiotics help your body prevent bacterial and fungal infections
- Antiviral help your body prevent viral infections
- Antihypertensive these medications, although used to treat high blood pressure, will improve blood flow to your new kidney
- Diuretics help control fluid ("water pill")
- Vitamins and minerals
- · Medications to help prevent stomach ulcers
- Cholesterol-lowering agents



## Research

## Our Transplant Team is actively involved with research into new transplant techniques and new immunosuppressive medications.

Due to our large number of patients and high success rates, we actively participate in ongoing research studies to advance transplant patient care. After your transplant, one of our Research Nurses may ask you to participate in a voluntary study.

#### **Biorepository**

The Transplant Center makes a collection of tissue related to kidney and liver disease. The tissue is donated by patients. Most is simply taken from excess tissue removed during transplants, kidney or liver resections. You may be asked if you would like to donate samples to this collection known as a "biorepository" or "tissue bank."

#### **Contacting Your Donor Family**

University Transplant Center strongly encourages written correspondence between organ donor families and transplant recipients. All correspondence is anonymous and identities are kept confidential.

Transplant recipients may want to contact the donor family to express their sincere gratitude and to learn about their donor. However, this is a very personal decision and your decision alone.



### Resources

#### **United Network for Organ Sharing (UNOS)**

(888) 894-6361 www.UNOS.org

#### **National Kidney Foundation**

(800) 622-9010 www.Kidney.org

#### **American Diabetes Association**

(800) DIABETES (1-800-342-2383) www.Diabetes.org

#### **US Department of Health and Human Services**

Access to the Government's information on organ and tissue donation and transplantation www.OrganDonor.gov

#### Texas Organ Sharing Alliance (TOSA)

(210) 614-7030 www.TXOrganSharing.org

#### **Transplant Living**

A website with information and resources for transplant recipients www.TransplantLiving.org or www.TrasplantesYVida.org

#### RenalInfo

A website with support and resources for people with kidney disease **www.RenalInfo.com** 

#### The Scientific Registry of Transplant Recipients

www.SRTR.org

#### **State of Texas Kidney Foundation**

(210) 739-9778 www.txkidney.org

Notes



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#### **General Information**

#### **University Hospital**

4502 Medical Drive MS 18 San Antonio, Texas 78229

#### Office Telephone Numbers:

(210) 567-5777 or Toll free (888) 336-9633 Fax: (210) 358-0408, Alternate Fax: (210) 567-5122

#### Office Hours:

8 a.m. to 5 p.m.

Monday through Friday – Answered by a live person Closed on holidays and weekends – Answered by voice mail

www.UniversityTransplantCenter.com

#### **University Hospital Operator**

(210) 358-4000 4502 Medical Drive San Antonio, Texas 78229

#### University Hospital Transplant Clinic

4502 Medical Drive, 8th Floor San Antonio, Texas 78229

#### Clinic Telephone Number:

(210) 358-4500

#### Clinic Hours:

7 a.m. to 4 p.m. Monday through Friday Closed on holidays and weekends

#### **Useful Websites:**

www.UNOS.org
www.Kidney.org
www.Diabetes.org
www.RenalInfo.com
www.SRTR.org
www.ASTS.org
www.TransplantLiving.org or
www.TrasplantesYVida.org



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Referral Hotline: (210) 567-5777 or (888) 336-9633

Referral Fax: (210) 358-0408

Referral Address:
University Transplant Center
4502 Medical Dr., San Antonio, TX 78229
www.UniversityTransplantCenter.com