

***Kidney Transplant  
Patient Education Handbook***



***Charles O. Strickler Transplant Center  
Charlottesville, Virginia***



## ***Kidney Transplantation***

### **Introduction**

Welcome to the Charles O. Strickler Transplant Program at the University of Virginia. This handbook was prepared to give you basic information about kidney failure and to introduce you to one of the treatment options available to you, kidney transplantation.

End-stage renal disease (ESRD) describes patients who have irreversible failure of their kidneys. The kidneys are life-sustaining organs and are responsible for many functions within the body. There are many causes of ESRD, each leaving patients with difficult choices. Dialysis, whether it is hemodialysis or peritoneal dialysis, can replace some functions of your own kidneys but not all. Kidney transplantation is therefore often considered the best treatment option for ESRD and the option that will most likely return you to the lifestyle you enjoyed prior to losing kidney function.

There are risks associated with kidney transplant. We feel it is essential for you to be well informed about the potential risks and benefits involved in transplantation. With this knowledge you and your family can make decisions that are most appropriate for you. The Transplant Team at the University of Virginia is here to assist you and guide you through the process.

### **The Transplant Team**

#### Transplant Surgeons

Dr. Kenneth Brayman  
Dr. Timothy Pruett  
Dr. Hilary Sanfey  
Dr. Robert Sawyer

#### Transplant Nephrologists

Dr. Ross Isaacs  
Dr. Peter Lobo

#### Kidney Transplant Coordinators

Brandy Yowell, RN  
Winsor Simmons, RN, CCTC  
Anita Sites, RN

Carol Lawson, RN  
Barbara Shephard, RN, CCTC

### Clinical Social Worker

Art Pearson, MSW

### Financial Coordinator

Howard Snoddy

### Support Team

Melissa Collins, Administrative Assistant

Kellie Williams, Clinic Manager

Frances Long, LPN, Clinic Nurse

### Transplant Office Access

Telephone: 1-800-543-8814 (Toll Free) (434) 924-8604 (Local Residents)

FAX: 434-924-0017

Hours: Monday-Friday 8:00AM-4:30 PM

## **History of Kidney Transplantation**

Physicians began experimentation in kidney transplantation in the early 1900s. In 1954 the first successful kidney transplant was performed. The donor and recipient were identical twins. At the University of Virginia, kidney transplantation began in 1967 with over 1000 patients having had their kidney transplant surgery here. Approximately 75 patients have kidney transplants performed each year.

## **Where do Kidneys Come From**

Kidneys for transplantation can come from two different sources, either from a deceased donor or a living donor. A deceased donor is someone who has undergone a catastrophic injury to his or her brain, for example from a car accident or a stroke. The deceased donor is a previously healthy person who has suffered brain death despite advanced life support. All thinking portions of the person's brain, as well as the brainstem, have been destroyed. When an individual meets strict clinical criteria establishing brain death, the next of kin is approached regarding organ donation.

Living donors are another option for kidney transplant. A living donor may be someone related to you, for example a sister donating to her brother, a parent giving to a child, or an uncle donating to his niece. A living donor may also be someone unrelated to you, for example a husband donating to his wife or friend donating to friend. The individual needs to have a blood type compatible with yours. If no blood type compatible donors are identified, we may still be able to move forward with transplant using a special protocol.

Due to the large number of persons waiting for kidney transplant and the shortage of donor organs available, we encourage you to explore the option of living donor transplant if it is available to you. Living donors go through a thorough evaluation to assure that they are healthy and that they have two excellent kidneys. One kidney can perform the function of two if it is a healthy one. There is an educational handbook with detailed information regarding ***Living Kidney Donation*** that will be provided to you if you choose to investigate this option.

### **The Evaluation Process**

You have been referred to the University of Virginia for evaluation for kidney transplant. In most cases your local kidney doctor or dialysis unit has referred you. Prior to your appointment, we ask that your medical information and recent diagnostic testing be forwarded to us. We will review this in order to prepare for your clinic visit.

On the day of your appointment, we ask that you arrive 30 minutes early for registration in the Transplant Clinic. Please plan to spend between three and five hours with us. During that time you will meet with the Transplant Nurse Coordinator who will teach a class about transplantation. You will be in a group with others who are interested in transplant. After class, you will meet individually with the Nephrologist, the Social Worker, the Transplant Nurse Coordinator and the Financial Coordinator.

At the end of your initial appointment, you should have a good idea of what risks and benefits are associated with kidney transplant, whether it is a good option for you and how the remainder of your evaluation will proceed. At any time either before or after your clinic appointment, please feel free to contact us with any questions or concerns. We are here to help you.

### **Evaluation of the Kidney Transplant Recipient**

Not every patient with end stage renal failure is a suitable candidate for kidney transplantation. The age requirement for a potential candidate is flexible. A patient may be considered an excellent candidate and be over the age of 65. The selection decision is more dependent upon a patient's physical condition rather than their age. Each case is evaluated individually. There are some factors that exclude patients from receiving a transplant. Such factors include chronic infection, liver disease, extensive vascular disease, morbid obesity, severe respiratory disease, cancer, and active substance abuse (including alcohol). A thorough evaluation is essential to clearly identify risks associated with transplantation. We will also help you and your local doctor correct or stabilize conditions that may lead to complications following transplant.

The routine evaluation for any potential kidney recipient includes the following diagnostic tests:

- Blood tests: Complete Blood Count (CBC), Chemistry tests, Coagulation tests, Blood and Tissue Typing, Hepatitis testing and Viral Screening tests including CMV, EBV, VZV and HIV.
- Chest x-ray.
- Cardiac evaluation: EKG and other diagnostic tests the Transplant Nephrologist feels are necessary, which may include an Echocardiogram, Exercise Stress Test, and/or Myocardial Perfusion Study. A cardiac catheterization may be necessary for some patients.
- Dental evaluation.
- Stool Hemoccult cards.
- PAP smear and Mammogram (for women 40 or older).
- Vaccinations for Pneumonia and Hepatitis B.
- Anergy Panel including TB skin test.
- Social Work Evaluation.

We also may ask that you see a psychiatrist if you have a history of non-compliance with dialysis or substance abuse. After your clinic appointment the nurse coordinator will send a letter to you, your referring doctor and your dialysis unit indicating what tests are necessary to complete your evaluation for kidney transplant. The tests can be performed locally or at the University of Virginia if you or your doctor prefer. The Kidney Program's administrative assistant can help you in scheduling tests. Working closely with the Transplant team and your local doctor will help your evaluation go smoothly.

### **Evaluation of the Living Donor**

A living kidney donor must go through a thorough evaluation to ensure that kidney donation is safe for him/her. Blood tests are done to determine his/her blood type, blood chemistries, viral studies and blood count. If the donor and recipient have compatible blood types, tissue typing is obtained. Here are the blood types and which are compatible:

<b>Donor</b>		<b>Recipient</b>
O	→	O
A or O	→	A
B or O	→	B
A, B, O, or AB	→	AB

The Rh factor, negative (-) or positive (+), is not important for organ transplants.

Each of us inherits certain genetic markers from our parents. Tissue typing determines how closely one's markers match those of someone else. For instance, you and a sibling may have all six markers match, or only half will match or none will match. These results are obtained through a blood test.

A living kidney donor must also have their urine tested. A urinalysis is obtained to look for the normal microscopic components of urine and to look for bacteria. A 24-hour urine collection is also analyzed for creatinine and protein. A chest X-ray and EKG are done to determine if the donor's heart and lungs are normal. A renal ultrasound is completed to make certain that the donor has two kidneys. The final test is the CT scan or MRI of the kidneys. This is done to closely examine the blood vessels to and from the kidneys. It provides valuable information the surgeons require when removing the donor's kidney.

All expenses associated with living kidney donation are paid through a special account and eventually are billed to the recipient's insurance. There is no compensation to the donor for time lost from work or costs incurred coming to and from the transplant center. Hospitalization for surgery and treatment of any complication arising directly from the donor's surgery are covered.

If you have a potential living donor, he/she must contact the transplant office or attend your clinic appointment with you. We will not call donors to solicit their interest.

### **Evaluation of the Deceased Donor**

The evaluation of a deceased donor begins when brain death is declared and the donor's family gives consent for organ donation. Chemistry tests are done to determine if the kidneys are functioning normally. Blood typing and tissue typing are also completed. The donor is tested for hepatitis, HIV and other viruses. The donor family is interviewed to determine if the donor exhibited any high-risk behavior that would make infection with hepatitis B or HIV likely.

If the kidneys are found to be suitable for donation, the donor is taken to the operating room where the kidneys are removed. Once removed, the kidneys are placed on ice and in a nutrient rich solution that helps to preserve their function. The kidney is transported to the location where the recipient operation will occur. Every effort is made to transplant the kidney(s) within 36 hours of being removed from the donor. Generally the longer the kidney has been out of a donor the more slowly normal function will recur in the recipient.

### **Activation on the Kidney Transplant List**

Once you have been evaluated in the transplant clinic, your case will be discussed at Kidney Selection Conference. This is a multidisciplinary group that meets weekly. The group consists of the Transplant Surgeons, Transplant

Nephrologists, a Social Worker and Nurse Coordinators. You will be notified of the group's decision. If the decision is made to activate you on the **list**, information is provided to UNOS. UNOS, which stands for the United Network for Organ Sharing, is a federally regulated, private organization. They maintain the computer registry where all organ transplant candidates are listed. UNOS is responsible for establishing the policies that the transplant centers must follow and ensures that the sharing of organs is fair to all individuals.

Your name will be placed on the list along with your blood type and the antigens that were identified as part of your blood tests. Occasionally a kidney may become available for a recipient that matches at all six antigens. This kidney will then be offered to that individual regardless of their location in the country. This is done because an identically matched kidney may last longer and be less likely to be rejected.

While active on the kidney transplant list, you will need to send us a sample of your blood each month. With this blood we are able to determine your PRA (performed antibody level) and perform a preliminary crossmatch with potential donors that become available.

The waiting period for a transplant is a difficult time for most patients. You can anticipate a waiting time of approximately five years for a deceased donor kidney transplant. During that time you need to be prepared to accept a kidney should one become available. While active on the transplant list, we will need to be able to reach you at all times. We will ask you for phone numbers of family or friends who could assist in helping us to locate you. There is a feature now available on phones called call intercept. If you have call intercept, you must either provide us with the code or discontinue the feature once you are on the waiting list. It is extremely important that our office be able to contact you at any given time, which can be difficult with the call intercept service. You may also obtain a pager. Our department does not provide pagers, but you are welcome to obtain one on your own and inform us of how to reach you on it.

When a kidney becomes available for you, the nurse coordinator must make contact with you within one hour, or the kidney will be offered to the next person on the list. You will need to come to the hospital immediately. It may be necessary for you to be dialyzed prior to surgery. If you are active on the list, it is assumed that you are ready and willing to accept a kidney. If you change your mind about this, or become ill, please contact us so that we may change your status to inactive (Status 7) on the transplant list. You will continue to accumulate waiting time while in an inactive status.

## Crossmatch

Just prior to both a living donor transplant and a deceased donor transplant, a critical blood test called a **crossmatch** will be performed. A sample of your blood will be mixed with white blood cells from the potential donor to determine the presence of cytotoxic antibodies to the donor's antigens. If this test is "positive", indicating the presence of antibodies to the donor within your blood, a transplant from that donor cannot be done. Your body would quickly try to reject the kidney. This can be very disappointing for the living kidney donor and recipient when the transplant surgery has been scheduled and it must be cancelled due to positive crossmatch. You will be told at what point the crossmatch can be repeated and when the surgery may be rescheduled.

## Kidney Transplant: Surgical Procedure

When it is determined that the crossmatch is negative and that there are not any other concerning medical issues with the recipient, he/she will be taken to the operating room. The surgical procedure lasts approximately four hours. The kidney is placed in either the right or left lower abdomen near the hipbone. An incision, approximately 10 inches in length, is made in the lower abdomen. The renal artery and vein are connected to the hypogastric or iliac artery and vein. After blood flow is established, the donor ureter is implanted on the recipient bladder. The recipient's native kidneys, or his/her own kidneys, will remain in place unless they are causing problems or are infected. The recipient is then taken to the Post Anesthesia Care Unit (PACU) or recovery room. From there, the patient is admitted to the transplant unit, 5-West. Some patients may need to be admitted to the Surgical Intensive Care Unit (SICU) after surgery before going to 5-West.

## Immunosuppressive Medicine

While in the hospital after receiving a kidney transplant, it will be very important for you to learn about the medications you will be on. The success of your kidney transplant is dependent on how effectively we are able to suppress your immune system. In order to prevent your body from rejecting your transplanted kidney, we need to alter your immune system through the use of immunosuppressive drugs. **If you stop taking your medicines after transplant, you will reject your kidney.** It is critical that you realize this BEFORE you undergo transplant. You are making a commitment to life-long immunosuppression. These medications have side effects that you should be aware of as you decide whether transplant is a good option for you.

The following drugs are used in combination to prevent rejection. You will also find other medicines listed which you will need to take in conjunction with the anti-rejection drugs. The most frequent side effects are listed for each.

<b>PREDNISONE</b>	<b>PROGRAF</b>	<b>CELLCEPT</b>
1. Mood Swings	1. Tremors	1. Nausea
2. Stomach Ulcers	2. High Blood Pressure	2. Low White Blood Cell
3. Bone Loss	3. High Potassium levels	3. Vomiting
4. Muscle Weakening	4. Headache	4. Diarrhea
5. Diabetes	5. Diabetes	
6. Weight gain	6. Nausea	
7. Moon face		

Bactrim is used to prevent *pneumocystis pneumonia*, a rare lung infection that affects persons who are immunosuppressed. You will take this drug twice each week.

Nystatin or Mycelex are anti-fungal medicines that prevent the overgrowth of yeast in your mouth, which can occur because of immunosuppression. You will use this daily during the first three months after transplant.

Anti-ulcer medications are given to protect your stomach while you are taking prednisone.

Your doctor may feel that you need other medications to treat rejection or infection. Listed below are other medicines that may be prescribed.

Ganciclovir or Valganciclovir is used to prevent or treat CMV infections. It is available both intravenously and orally.

Acyclovir is used to prevent or treat herpes simplex or shingles. It is available both intravenously and orally.

You may also need to be on other medications to control blood pressure or to treat other medical problems you may have. The side effects that you experience will be most prominent in the first six months after transplant. As you progress after transplant we will be able to decrease your medications.

## **Rejection**

Rejection of an organ can occur after any kind of transplant. Fewer than 15% of patients who receive a kidney transplant will experience rejection. It is important to know that rejection is treatable. At the first sign of rejection, we will treat you with medicine to reverse it. You will be given steroids in a large dose initially. If treatment with steroids does not reverse the rejection, you may be given other very potent immunosuppressive drugs.

We will monitor you for rejection through your laboratory values. There are also physical symptoms to watch for. Those symptoms may include fever, high blood pressure, weight gain, decrease in urine output, swelling of arms and/or legs, general tiredness or aches, or pain over the transplanted kidney. If you notice any of these symptoms, you should contact the transplant office immediately. In many circumstances, we will notice rejection through your lab values before you feel symptoms. That is why it is critical that you adhere to the lab schedule that will be outlined for you at the time of your discharge from the hospital.

### **Follow-up Care After Kidney Transplant**

We will follow your lab values closely in order to help you maintain your transplanted kidney. You may have your lab work done at a local hospital. You will not need to come to the University of Virginia unless it is the most convenient for you. We will obtain the results of your lab tests and make any changes necessary in your immunosuppressive medicines. You will need to have blood drawn two times per week for the first two to three months post-transplant. The frequency decreases over the first year so that by your first anniversary after transplant, you will need to have labs drawn monthly.

We will need to see you in the Transplant Clinic one week after your discharge from the hospital and then one month after your transplant date. We will then see you every three months until your one-year anniversary. It will be important for you to see your referring doctor within one month of your transplant operation. He or she will be an important member of your healthcare team post-transplant. We will work closely with your doctor to ensure the success of your kidney transplant.

When you undergo kidney transplant it is assumed that you will follow the plan of care established by the Transplant Team. That means that you must have your labs drawn as directed and that you must return to the clinic for follow up. Please take this into consideration as you consider whether kidney transplant is right for you. Working together we can ensure that you receive the best care possible.

### **Financial Concerns**

Medicare covers most patients, who have End Stage Renal Disease and are on dialysis. Medicare will cover the costs involved with kidney transplant. Medicare also covers 80% of the cost of immunosuppressive medicines **only** for the first three years after transplant. If you have received Medicare as result of another qualifying disability or are eligible based on age, Medicare coverage will continue. **It is essential to explore the potential options for obtaining**

**transplant medications prior to undergoing kidney transplant.** Transplant medications are very expensive. Our Financial Coordinator and Kidney Transplant Social Worker will work with you during your evaluation to determine how you may be able to obtain medications after your Medicare coverage ends.

### **Summary**

Kidney transplantation is one treatment option available to persons with end stage renal disease. There are risks and benefits associated with kidney transplant. We look forward to seeing you through the transplant process if this is a good option for you. Please contact us with any questions you may have either before or after your clinic appointment. Our toll-free number is 1-(800)-543-8814 or (434)-924-8604.