A Patient Guide to Kidney Transplantation
This booklet has been prepared to provide you with basic information about kidney transplantation at Temple University Hospital, the risks and benefits of transplantation, and what happens before, during and after surgery.

Please read the information in this booklet and share it with your family. The Glossary may help you to understand some of the medical terms used throughout the text. Feel free to ask your physician or one of the transplant coordinators any questions you may have. The transplant coordinators can be reached at 215-707-8889.
Kidney (Renal) Transplantation

Kidney transplantation is a treatment for patients with end-stage renal disease (ESRD). There are two treatment options available: dialysis or transplantation. Although dialysis is a lifesaving procedure, it involves dependence either on a hemodialysis machine or on peritoneal dialysis exchanges. For some patients the quality of life on dialysis is unsatisfactory.

Many people therefore choose transplantation rather than dialysis because it allows greater independence, which can lead to a more normal lifestyle. Also, research suggests that transplantation offers superior patient survival when compared to dialysis.

Risks Associated with Transplantation

Transplantation has risks as well as benefits. Some of the risks of transplantation include surgical complications, infection, rejection of the transplanted organ, and side effects related to the anti-rejection medications. These medications may increase your risk of the infection and may cause high blood pressure, high cholesterol, ulcer disease, malignancy and/or diabetes. The risks associated with transplantation will be discussed later in this booklet, and will be explained to you and your family by the transplant doctors.

The Transplant Team

During your evaluation for transplantation, you will meet many health care professionals who are part of the transplant team. The roles of each are described here.

Transplant Surgeons are doctors who specialize in the field of transplantation. They will perform a physical examination during your evaluation and will be available to answer any questions you may have. The transplant surgeons will perform your operation and manage your anti-rejection medications. They will continue to participate in your follow up care along with your transplant nephrologist and referring physician after your discharge.
Transplant Nephrologists are doctors who are trained in caring for patients with kidney disease and transplantation. They too will examine and interview you during your transplant evaluation in order to determine your suitability for transplant. They will also participate in your care while you are hospitalized for your transplant.

During your hospital stay, you will meet the residents on the transplant service. They are doctors who have finished medical school and are going through additional specialized training. They work directly with the attending transplant surgeons and nephrologists and will see you each day to follow your progress.

Your Transplant Coordinator is a registered nurse experienced in the field of transplantation. The coordinator will meet with you during your evaluation and will be available to address your concerns and answer any questions you may have. The transplant coordinator will assist you through the evaluation and activation process and follow you closely after your surgery. Your coordinator will work with you, your local physician, and the other members of the transplant team to provide you with support, information, and individualized care.

Transplant Social Workers have experience in helping patients and families address financial and emotional concerns associated with dialysis and transplantation. They can provide help and information about medication coverage, insurance issues, temporary housing, community services, and vocational rehabilitation. The social worker will be available after your transplant to assist with discharge planning.

A Transplant Financial Coordinator is a specialist who is knowledgeable in the area of insurance coverage. The financial coordinator is responsible for verifying your health insurance benefits and confirming your eligibility for transplant evaluation at Temple University. They will review your benefits and provide you with information about any co-payments and deductibles. The financial coordinator will be available to answer any questions or concerns you may have regarding your insurance coverage.
The Day of Evaluation

Prior to your evaluation, please complete the medical history questionnaire. Please bring the completed questionnaire with you, along with a list of the medications you are currently taking. In addition, be sure to bring any medications that you will need to take the day of your evaluation.

If you are on hemodialysis, please inform your dialysis unit of your evaluation appointment. If your appointment falls on a regularly scheduled dialysis day and you are unable to adjust your dialysis schedule, please let us know two weeks prior to your evaluation appointment. We will be happy to assist you in making alternative arrangements.

If you are on continuous ambulatory peritoneal dialysis (CAPD), please bring all of the supplies you will need for the day. CAPD equipment and supplies are not available in the clinic. Tell the transplant coordinator if you need to perform an exchange and an area can be provided.

Your transplant evaluation appointment will last approximately eight hours. Please make your travel arrangements accordingly, as we will be unable to modify your schedule on the day of the appointment.

Your evaluation may require diagnostic testing at Temple University Hospital.

During your evaluation you may have the following procedures:

Electrocardiogram (EKG or ECG) – This test records your heart’s electrical activity.

Chest x-ray – This x-ray allows your doctors to look at your lungs and heart.

Blood work — Your evaluation will include a blood test to determine your blood type. You can receive a kidney only from a donor with a compatible blood type. Another blood test checks your antibody level on a scale from 1 to 100. The lower your level, the easier it is to match you to a donor kidney. HLA (Human Leukocyte Antigens) will also be identified. The HLA antigens are specific genetic makers that are inherited from your parents and identify the cells as your own. This information is necessary when a donor organ becomes available. Additional blood work will also be drawn to help identify any past or current viruses you may have.

Skin test – You will receive three small injections in your arm to check for past exposure to tuberculosis. This test must be read by a nurse or doctor 48 to 72 hours after it is given. Please have the results sent or faxed to our office.
After the Evaluation

The doctors who see you in the evaluation clinic will decide which additional tests you may need. Not all candidates need the same tests. Some of the necessary testing may include the following examinations:

**Ultrasound** – This test uses high-frequency sound waves to obtain a picture of your kidneys and gall bladder.

**Dental exam** – You are required to see your dentist prior to transplantation to be sure that you have no oral (mouth) infections. Any major dental work should be completed prior to activation on the transplant list. This booklet provides exam guidelines and instructions for you to take to your dentist.

**Urine culture** – This requires a collection of urine to check for infection.

**For women** – Women need to have a routine gynecological exam including a pap test prior to transplantation to check for abnormalities. A mammogram is required for women who are age 35 or older.

**For men** – Men age 40 or older are required to have a prostate specific antigen (PSA) blood test.

Any additional required testing should be arranged through your referring doctor or your primary care physician, and the results should be forwarded to the transplant office. All correspondence should be addressed to:

Temple University Abdominal Transplant Center
3322 North Broad Street
Philadelphia, PA 19140
Fax: 215-707-8894

After the results of your evaluation are available and additional tests have been completed, your case will be presented to the Transplant Committee. This committee will review your evaluation and proceed with the listing process. If you are found not to be a candidate for kidney transplant, you and your doctor will be notified.

If you are found to be an acceptable candidate, the transplant financial coordinator will obtain preauthorization for the transplant from your health insurance carrier. This preauthorization is required prior to your activation on the transplant waiting list. It may therefore be several weeks before you and your physician receive notification of the activation.
Living Donation

Some candidates for kidney transplantation may have a relative, spouse, or close friend interested in donating a kidney. This is called living donation. The potential donor may be considered if he or she is 18 years of age and has a blood type compatible with yours (though not necessarily the same blood group as yours). A number of tests, including a crossmatch, will be performed to determine if the potential donor is able to donate a kidney.

Becoming a living donor involves these steps:
- AB (blood type)
- Crossmatch (blood test)
- Appointment in evaluation clinic
- EKG
- CXR
- Ultrasound of kidneys
- Blood tests
- Physical exam
- Social service evaluation
- Completion of any additional required testing
- Presentation of donor to transplant committee
- CT Angiography and preadmission testing
- Admission for surgery

Donating a kidney is not without risks. These risks, as well as benefits, will be discussed at the time of the donor’s evaluation. Contact your transplant coordinator for more information about living donation.
Cadaveric Transplantation

The candidate is placed on the cadaveric transplant waiting list if a living kidney donor is not available. Pertinent candidate information is provided to United Network for Organ Sharing (UNOS) at the time a patient is activated on the transplant list. This information includes blood type, HLA, antibody level, age, and activation date. When a possible donor is identified, laboratory studies are performed to determine the donor’s blood type and HLA. This donor information is entered into the UNOS computer system and is compared with all patients of the same blood type listed for transplantation. A computerized list of candidates is generated, with points given to each candidate based upon HLA matching, waiting time, and antibody level. Candidates are identified, and a cross match (blood test) is performed between the donor and potential transplant candidate to assure compatibility. All other things being equal, the patient at the top of the list (remember, a different list is generated for each kidney) is offered the organ. It is impossible to predict how long you will be on the waiting list. The average waiting time in Philadelphia is 3-5 years.

Currently, UNOS guidelines stipulate that donor organs be distributed first on a local level. This means that any candidate on the waiting list at a transplant center in our area will be considered first for donor organs obtained locally. In the unlikely event that a suitable candidate is not identified for transplantation, the organs will be offered, according to UNOS policy, regionally and then nationally. UNOS guidelines also designate that a perfect antigen matched kidney (zero antigen mismatch) be offered nationally for a specific patient on the transplant waiting list.

While on the Waiting List

Once you are accepted as a transplant candidate and are activated on the waiting list, it is very important that we are able to contact you at all times. Please give your transplant coordinator the names and phone numbers of at least two reliable contact people who will be able to contact you if we cannot reach you at home. Please let us know how to reach you if you are going on vacation or will be out of town.

While you are on the transplant waiting list, it is important that you send a monthly blood sample to our tissue-typing laboratory. This blood sample is used by the laboratory to determine your compatibility with available donors. If we do not receive this monthly sample, you cannot be considered for a transplant. The blood sample may be drawn at your local physician’s office, dialysis unit, or laboratory.
The Transplant

When a suitable organ becomes available for you, the transplant coordinator will contact your referring physician to obtain medical clearance. Once medical clearance has been received, the coordinator will contact you for additional information and will also provide you with instructions. The transplant coordinator who contacts you will also let the hospital know you will be arriving.

When you are admitted to the hospital several doctors will examine you prior to surgery. A chest x-ray, EKG and laboratory testing will be performed. If necessary, you will be dialyzed before the transplant.

The kidney transplant operation lasts approximately three to four hours. The new kidney is usually placed in the lower right or lower left side of your abdomen. Your own kidneys are not usually removed during the transplant.
After the Operation

After the kidney transplant operation, you will go to the Recovery Room until your condition has stabilized. There you can be more closely monitored for subtle changes in your condition. All patients are transferred to a room on the transplant unit once the transplant team feels it is appropriate.

While you are in the hospital, you will learn about the immunosuppressive medications that you will be taking to prevent rejection of your transplant. You will be given information on how to care for yourself after transplantation. You are encouraged to share the information with your family. The transplant team will be available to answer any questions you may have.

Possible Complications after Transplantation

Delayed Graft Function (DGF) – There are times when a transplanted kidney may not initially function. This is known as delayed graft function (DGF). Dialysis may be necessary while the transplanted kidney is not working. It is difficult to predict how long you may require dialysis.

Rejection – Your immune system recognizes your transplant as foreign and attempts to attack it through a process known as rejection. Many patients may have one or more episodes of rejection. If rejection is diagnosed and treated early, it can usually be reversed.

Cytomegalovirus (CMV) – A frequent cause of infection in transplant recipients is CMV. Patients usually report flu-like symptoms, which may include fatigue, fever, loss of appetite, and stomach upset. When CMV is suspected, a blood test is performed to determine if the infection is present. Initial treatment for CMV consists of intravenous antiviral medication. Oral medication will also be necessary even after follow-up blood tests become negative.

Epstein Barr Virus (EBV) – This infection can present as mononucleosis, or of greater concern, as a lymphoproliferative disorder.

Post-Transplant Lymphoproliferative Disorder (PTLD) – is a cancer-like condition that occurs in a small percentage of transplant recipients. For many patients, regression of the disease usually occurs after the reduction or discontinuation of immunosuppression and the use of antiviral medications.

Post Transplant Diabetes Mellitus (PTDM) – Occasionally, a patient may develop diabetes after transplantation. This is related to the anti-rejection medications that you will be taking. This type of diabetes is usually but not always temporary and may resolve as your immunosuppression is decreased. Oral medications or insulin may be required to treat the elevated blood sugar levels.
Follow-up Care

When you are discharged from the hospital, you will need to schedule an appointment for your first outpatient clinic visit. During your clinic visit, the transplant coordinator will check your blood pressure, temperature, and weight. The coordinator will assess your medical condition and answer any questions you may have.

The transplant physicians will review your list of medications and laboratory test results, and evaluate your progress. Adjustments in your immunosuppressive (anti-rejection) or other medications may be made at the time. The transplant pharmacist will also be available for consultation.

The frequency of your clinic visits should decrease within a few months, and you will be referred to your local physician for much of your long-term care. We will continue to follow your progress along with your local doctor. You will be required to have lab work done periodically (more frequently at first) as long as your transplanted organ is functioning.

Medications after Transplantation

Your transplant physician will prescribe immunosuppressive medications that you must take daily for the rest of your life to keep your body from rejecting the new transplant. These medications may include tacrolimus (Prograf®, cyclosporine (Neoral®, or Gengraf®), prednisone, mycophenolate mofetil (Cellcept®, sirolimus (Rapamune®, anti-thymocyte globulin (Thymoglobulin®), daclizumab (Zenapax®), or basiliximab (Simulect®). These medications and their side effects are described on the following pages. It is important to remember that not everyone experiences side effects of these medications. Most of the side effects that occur can be reduced or relieved by adjustment in the dosing of the drugs by your physician.

You must never change the dosage of, or stop taking, your immunosuppressive medications without specific instructions from your transplant team.
Tacrolimus (Prograf®)

Tacrolimus (Prograf®) - is one of the medications used to prevent rejection of your transplanted organ. You will be required to take this medication as long as you have a functioning transplant. Some of the side effects may include:

- Insomnia (difficulty sleeping)
- Tremors
- Increased risk of infection
- Changes in kidney function
- Burning or tingling of the hand and feet
- Headaches
- High blood sugar
- Hair loss
- Elevated potassium level

Cyclosporine (Neoral® or Gengraf®)

Cyclosporine (Sandimmune® or Neoral® or Gengraf®) is another medication used in combination with other drugs to help your body accept your new transplant. You will be prescribed either Tacrolimus or Cyclosporine. The side effects of Cyclosporine may include:

- Increased hair growth, usually on the arms and face
- Swollen or inflamed gums
- Sweating or “hot flashes”
- Tingling of the hands and feet
- Tremors
- Runny nose
- Increased risk of infection
- High blood pressure
- High blood sugar
**Prednisone (Deltasone®)**
Prednisone (Deltasone®) is used in transplant recipients to prevent or treat rejection. It is a steroid that is similar to a hormone produced by your body. Side effects may include:
- Mood swings
- Increased appetite
- Changes in vision
- High blood sugar
- Stomach irritation
- Fluid retention
- Increased risk of infection
- Weight gain
- Acne
- High blood pressure
- Joint destruction/bone thinning
- Growth retardation

**Mycophenolate Mofetil (Cellcept®)**
Mycophenolate Mofetil (Cellcept®) is used in combination with other immunosuppressive medications to prevent rejection of your new transplant. Side effects may include:
- Decrease in white blood cells or platelets
- Loss of appetite
- Stomach pain
- Nausea/vomiting
- Diarrhea
- Increased risk of infection
Sirolimus (Rapanune®)
Sirolimus (Rapanune®) is indicated for the prevention of organ rejection, and it works together with other medications that you are taking. Side effects may include:
- Diarrhea
- Hypertension
- High cholesterol and triglyceride levels
- Decreased platelets
- Joint pain
- Rash/acne
- Increased risk of infection
- Low potassium

Anti-thymocyte Globulin (Thymoglobulin®)
Anti-thymocyte Globulin (Thymoglobulin®) is an immunosuppressive medication that is given in conjunction with steroids and other anti-rejection medications only while you are in the hospital. Thymoglobulin is an intravenous medication that is usually used to treat a rejection that is resistant to conventional therapy. The therapy is administered daily for approximately seven to fourteen days. Most side effects are temporary and may include:
- Chills/fever
- Pain
- Headache decreased white blood cell count
- Decreased platelet count
- Nausea
- Abdominal pain
- Diarrhea
- Shortness of breath
- Increased heart rate
- Elevated potassium
- Increased risk of infection
Daclizumab (Zenapax® or Basiliximab (Simulect®))
Daclizumab (Zenapax® or Basiliximab (Simulect®)) is used to prevent rejection by suppressing your immune system and given only while you are in the hospital. Side effects are uncommon, but may include:

- Upset stomach
- Edema
- Tremors
- Headaches
- Dizziness
- Chest pain
- Changes in blood pressure
- Rapid heart rate
- Urinary hesitancy
- Night sweats
- Muscle pain/cramping
- Blurred vision

Please notify your transplant coordinator if you experience any of these side effects. Your transplant surgeon will follow you closely and will make changes in your medications as needed.

Changes in Lifestyle after Transplantation

**Diet**
Nutrition is a very important part of your recovery after transplantation. A balanced diet containing a variety of foods is needed to get well and stay healthy. Most patients have very few dietary restrictions after transplantation. A dietitian will be available to assist you in the hospital or in the outpatient clinic with any dietary questions.

**Physical Activity**
There are some physical restrictions immediately after transplantation. For example, you may not lift, pull, or push heavy objects for several weeks. You may not resume your previous exercise program or athletic activities without first checking with your transplant surgeon. Driving is not permitted for at least six weeks after your surgery. You are encouraged to discuss any specific concerns with the transplant surgeon or transplant coordinator.
You may return to work or school when your doctors determine that you are well enough. A work release can be provided by your transplant surgeon upon your request.

**Sexual Activity and Pregnancy**

You may resume sexual activity after transplantation when you feel comfortable. Birth control options should be discussed with your doctor prior to resuming sexual activity. Please remember that female recipients of childbearing age generally resume their menstrual cycle after transplantation and can become pregnant. It is important to discuss your interest in becoming pregnant with your transplant surgeon and gynecologist. Transplant recipients have delivered healthy babies; however, their pregnancies are usually considered high risk.

**Insurance Coverage**

Please contact your insurance company to verify that your policy covers transplantation at our facility. If your insurance carrier requires you to obtain a referral from your primary care physician, please do so prior to your appointment. You will meet with a financial coordinator during your evaluation.

**Accommodations**

There are many hotels in the Philadelphia area that offer discounts to Temple University Hospital patients. Please refer to the enclosed pamphlets regarding information on accommodations, transportation, and parking.
If You Have Questions

Please ask your doctor, social worker or transplant coordinator any questions that you or your family may have about the information in this booklet. You may want to write your questions in the space below.

**Questions for the doctor:**

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Questions for the Transplant Coordinator:
Questions for the Social Worker:
Glossary

Allograft – the transplanted organ

Biopsy – a procedure performed under local anesthesia in which a needle is inserted under ultrasound guidance into the transplanted organ. A small sample of tissue is removed in order to evaluate the function of the transplant.

Cadaveric transplant – transplantation using an organ from a donor who has been declared brain-dead.

Crossmatch – a test performed prior to transplantation to evaluate the compatibility of a donor and recipient. If a crossmatch is negative, then the transplant can usually proceed.

Diabetes – a disease characterized by abnormal blood sugar levels.

Electrocardiogram (EKG) – test that records heart’s electrical activity.

End-stage renal disease – kidney disease which has declined to the point where dialysis or transplantation is necessary.

Human Leukocyte Antigen (HLA) – an individual’s genetic “fingerprint” defined by specific markers found on the surface of cells.

Immunosuppressive medication (anti-rejection) – medication that weakens the immune system to help prevent rejection of the transplanted organ.

Living donor – a person who donates a kidney to a close relative, a spouse, or a friend for transplantation.

Prophylactic – a preventative treatment.

Rejection – when the body’s immune system attacks the transplanted organ.

Renal – related to the kidney.

Residents and fellows – doctors who have completed medical school and are continuing more specialized training.

Transplant committee – members of the transplant team who meet to review candidates for transplantation. Included are transplant nephrologists, transplant surgeons, nurse coordinators, social workers, residents, and fellows.

Transplant coordinator – registered nurse experienced in working with patients who have received or are in need of a transplant.

Transplant nephrologist – doctor educated in treating patients with kidney disease and kidney transplantation.

Transplant surgeon – a doctor who performs transplant operations.

Ultrasound – an imaging test that uses sound waves.

United Network for Organ Sharing (UNOS) – an agency under contract with the U.S. Department of Health and Human Services that is responsible for overseeing the national organ allocation system.