

## Transplants at University Hospital

In 1964, a team of surgeons at Michigan Medicine (MM) performed the first kidney transplant operation in Michigan. Our transplant surgeons do between 200 and 250 kidney transplants a year. This makes the MM team among the most experienced in the nation. Our kidney transplant team includes transplant surgeons, urologists, nephrologists (kidney doctors), physician assistants, nurse practitioners, nurses, transplant coordinators, social workers, psychologists, dietitians, pathologists, pharmacists and other specialized support staff. These professionals can help you have the best possible kidney transplant experience. In addition to an expert transplant team, MM also has the most comprehensive medical facility in the state.

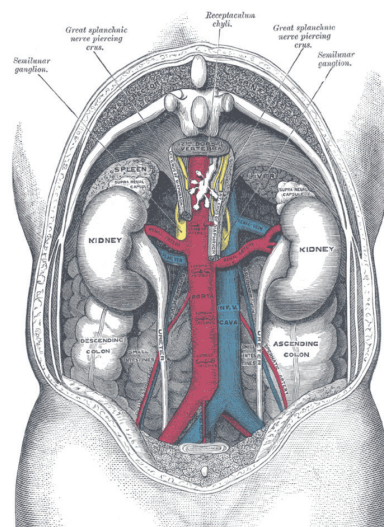
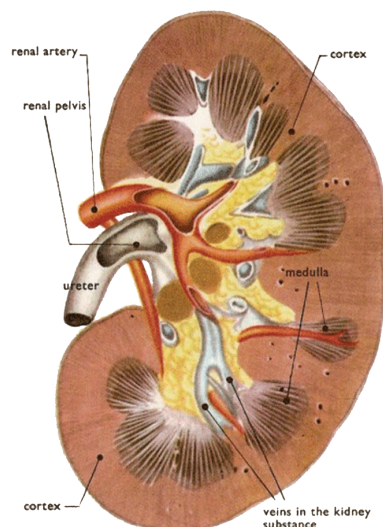
## Kidneys

### *Normal Kidneys*

Kidneys filter waste products and excess water from your blood. They also make hormones that control your blood pressure and red blood cell count. They keep the water, salt and acid levels in your body balanced. Most people have two kidneys that are located toward the back and under the rib cage, where they are protected. There is one on each side of the spine.

Kidneys produce urine that carries waste products out of your body. Each kidney is attached to a **ureter**, a tube-like structure. The urine travels through the ureter and empties into a bag-like organ called a **bladder**. The bladder can stretch to hold urine until it is full. It then signals your brain that you need to urinate. The urine leaves your body through a tube called the **urethra**. This tube exits through the penis in men and in front of the vagina in women.

### *Kidney Failure Leading to Transplantation*



When your kidneys are unable to perform their normal functions you have kidney failure, also known as renal failure. Some of the primary causes of end stage kidney failure include:

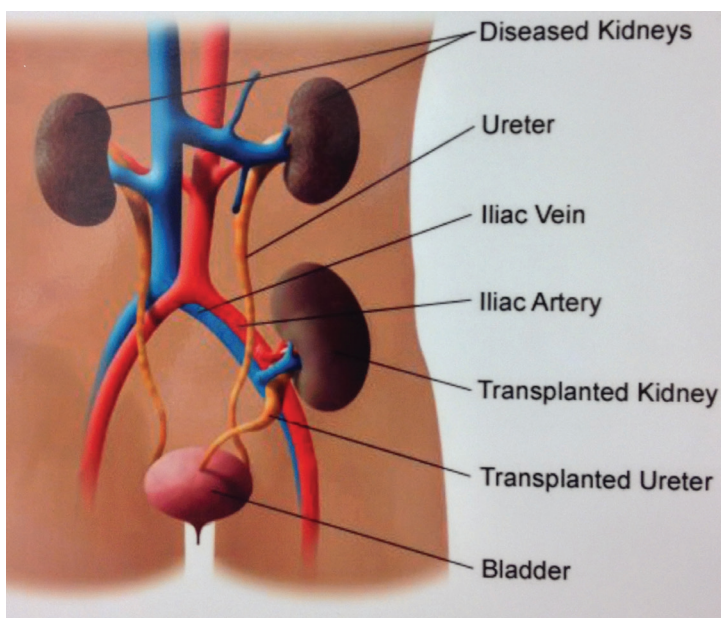
- Diabetes mellitus
- Hypertension
- Glomerulonephritis
- Hereditary diseases like polycystic kidney disease or Alport's syndrome
- Metabolic diseases or inborn errors of metabolism like oxalosis or cystinosis
- Obstructive uropathy
- Medication toxicities
- Multisystem diseases like vasculitis, amyloidosis or systemic lupus erythematosus
- Congenital malformations including vesical ureteral reflux, hypoplasia or dysplasia
- Other forms of irreversible acquired renal failure



Diseased kidneys do not do a good job of filtering toxins or removing water from the body. To stay healthy, people with diseased kidneys will need dialysis or a kidney transplant. Kidney transplantation improves the length and quality of life of people whose own kidneys have failed.

### *The Kidney Transplant*

Your transplanted kidney will be placed in your pelvis above the groin area. Your native kidneys do not normally need to be removed and therefore remain in your body. The incision for a kidney transplant is approximately four to 12 inches long and is located on the lower abdomen on the right or left side. The operation usually lasts two to four hours. After the transplanted kidney is connected to your blood supply, the transplanted kidney usually begins to make urine. The



transplanted ureter is attached to your bladder. As the new kidney begins to work filtering waste products from your body, you will begin to feel better.

### *Kidneys for Transplantation – Where Do They Come From?*

All kidneys available for transplantation are a result of a gift from one person to another. Kidneys can come from either deceased or living donors.

#### **Deceased Donor Kidneys**

Deceased donor kidneys (and other organs) are donated after the death of the donor. The suitability of the donor is determined by many factors. These include many of the same criteria used for living donors such as medical history, general health, habits and so forth.

As of November 2019, there were 94,000 persons awaiting a kidney transplant on the wait list in the United States. At the University of Michigan alone, there are nearly 800 patients waiting. Unfortunately, in the year 2018 only 21,167 kidney transplants were performed in the United States. In 2014, 4,761 persons died waiting for a transplant. Because of a severe national organ shortage, alternative solutions to using deceased donor organs have been sought.

#### **Donation After Brain Death (DBD)**

Most deceased organ donors are brain dead. They have suffered complete and irreversible loss of all brain function, and are clinically and legally dead. Mechanical ventilation and medications keeps their heart beating and blood flowing to their organs.

#### **Donation After Cardiac Death (DCD)**

Some people with non-survivable injuries to the brain never become brain dead because they retain some minor brain stem function. If such individuals made the decision to be donors or their families are interested, organ donation may be an option. Donation in such cases involves taking the patient off the ventilator, typically in the operating room. Once the patient's heart stops beating, the doctor declares the patient dead and organs can be removed.

#### **Increased-Risk Donors**

Some donors have been determined to have increased-risk behaviors such as IV drug abuse, long-term stay in a correctional facility, prostitution, etc. (either now or in the past). These donors are determined to be at increased risk of transmission of certain diseases (i.e., HIV, hepatitis C, hepatitis B) to a recipient. All donors, whether they are increased-risk or not, are tested for disease. These tests can detect a donor infection as recently as one week ago. The results of these tests are back before the organs are donated. Increased-risk donors who

test negative and are not now engaging in increased-risk behaviors carry a very low risk of transmission of infection and are therefore used as kidney or pancreas donors. The true risk of transmission is not known but is probably much less than one percent. If a kidney from a increased-risk donor is offered to you, this will be discussed with you at the time of the offer. While we generally recommend accepting such an offer, you will have the option to accept or decline.

### *Kidney Allocation*

#### **Questions and Answers for Transplant Candidates About the Kidney Allocation System**

United Network for Organ Sharing (UNOS) is a non-profit charitable organization that manages the nation's transplant system – known as the Organ Procurement and Transplantation Network (OPTN) – under contract with the federal government. As the OPTN, UNOS helps create and define organ sharing policies that make the best use of donated organs. This process involves continuously evaluating new advances and discoveries so policies can be adapted to best serve patients waiting for transplant.

The kidney allocation system was revised in 2014 as a result of years of review and consensus building among transplant professionals and people who have personal experience with donation and transplantation. Their primary goal was to make the system better without making major changes to the parts of the systems that work well.

The policy as implemented addressed a number of goals to promote organ utilization and equity, notably:

- Improving utility by better matching estimated length of kidney function to estimated time a candidate may need a transplanted kidney
- Enhancing equity by basing transplant waiting time on dialysis, rather than the previous method of beginning waiting time at listing with a transplant hospital
- Increasing transplant opportunities for highly immunosensitized candidates by providing them additional priority, especially those with a CPRA score of 98 or higher
- Increasing transplant opportunities for blood type B candidates (many of whom are ethnic minorities) by facilitating kidney offers to them from donors with blood subtype A2
- Broadening distribution of shorter-longevity kidneys to increase their utilization

More than four years after KAS implementation, the system continues to shape access to transplantation nationwide. UNOS will continue to study the system closely to make sure it is performing as expected. UNOS will address any issues that suggest that the policy is not meeting needs, or if other issues arise.

## **How Are Kidneys Classified?**

Every kidney offered for a transplant has a Kidney Donor Profile Index (KDPI) score. This is a percentage score that ranges from zero to 100 percent. The score is associated with how long the kidney is likely to function when compared to other kidneys. A KDPI score of 20 percent means that the kidney is likely to function longer than 80 percent of other available kidneys. A KDPI score of 60 percent means that the kidney is likely to function longer than 40 percent of other available kidneys.

If you have been listed for some time, you may have heard of a kidney being classified as “standard” or “expanded criteria.” These classifications are no longer used.

## **What Goes Into a KDPI Score?**

- Age
- Height
- Weight
- Ethnicity
- Whether the donor died due to loss of heart function or loss of brain function
- Stroke as cause of death
- History of high blood pressure
- History of diabetes
- Exposure to the hepatitis C virus
- Serum Creatinine (a measure of kidney function)

## **How Will Transplant Candidates be Classified?**

Each kidney candidate will get an individual Estimated Post-Transplant Survival (EPTS) score. This is a percentage score that ranges from zero to 100 percent. The score is associated with how long the candidate will need a functioning kidney transplant when compared to other candidates. A person with an EPTS score of 20 percent is likely to need a kidney longer than 80 percent of other candidates. Someone with an EPTS score of 60 percent will likely need a kidney longer than 40 percent of other people. Your transplant team can calculate your EPTS score for you.

## **What Goes Into a EPTS Score?**

The EPTS is calculated based on facts about the candidate that affect how long you are likely to need a kidney. These factors include:

- Age
- Length of time spent on dialysis
- Having received a previous transplant (of any organ)
- Current diagnosis of diabetes

## **How Will the KDPI and EPTS Scores Be Used in Allocating Kidneys?**

The 20 percent of kidneys that are expected to last the longest – those with a KDPI score of 20 percent or less – will first be offered to patients likely to need a transplant the longest – those with an EPTS score of 20 percent or less. If a kidney with a KDPI of 20 percent or less is not accepted for any of these patients, it will then be offered to any other person who would match, regardless of their EPTS score.

Kidneys with high KDPI scores are expected to function for a shorter amount of time than others. They may be best used to help candidates who are less able to stay on dialysis for a long time. The 15 percent of donated kidneys likely to function the shortest time (those with a KDPI greater than 85 percent) will be offered first to a wider area of the country than other kidneys. The goal is to encourage use of these kidneys by finding suitable patients as quickly as possible.

Your transplant team can discuss with you the best options for matching based on your EPTS score and the types of kidneys that would best meet your need.

## **What Will Change for Hard-to-match Patients?**

Some patients are hard to match with most kidney offers. There are a couple of options to possibly help decrease a patient's wait time.

In some cases, people have developed immune system responses that make it very difficult to find a kidney their body won't reject. This may happen because of having a previous transplant or blood transfusions, or even from pregnancy. People who are "highly sensitized" often wait five or more years before receiving even one kidney offer.

The allocation system gives highly immune sensitized candidates more priority for kidneys they aren't likely to reject. People who have a slightly higher sensitivity get slightly more priority. People who are very highly sensitized (98 percent or above) get much more priority. Kidneys that are offered first to highly sensitized candidates, but don't get accepted for them, are then offered to other patients.

Your transplant team can discuss with you whether you are sensitized and, if so, the additional priority you would receive for matching kidneys.

Another option to help reduce wait time is for people with blood type B. People on the deceased donor waitlist that are blood type B often wait longer for a kidney than people with other blood types. This is in part because it is harder to find a donor with type B blood.

For these recipients, they may be able to receive a donor kidney from a donor that is blood type A. Donors with blood type A generally can't donate to a person with blood type B. However, some blood type A donors have a "subtype" that allows them to match a type B candidate. The system gives first priority for these donor kidneys for type B patients. Since blood type A donors are more common than blood type B donors, more offers should be available for type B.

Your transplant team will discuss this option with you if you are blood type B.

### **How is Waiting Time Calculated?**

If you are listed for a transplant before you begin dialysis with a medical definition of kidney failure (having a creatinine below 20 ml/minute), your waiting time will start the day you are listed.

If you began dialysis before you were listed for a transplant, your waiting time is calculated from your dialysis start date. This is the most objective and consistent way to measure when your need for a transplant began.

A transplant program may evaluate you and list you for a transplant even before you start dialysis. If you are listed early, you can be matched for a deceased donor kidney based on medical matching criteria in the kidney allocation policy. You would not receive additional priority for waiting time until you either start dialysis or have kidney failure.

### **What if I'm Not Listed for a Transplant But Want to Be?**

Talk to your doctor about your current health and your treatment options. If you want to be considered for a kidney transplant, it would be best to get evaluated and listed by a transplant hospital when, or just before, you start dialysis or reach end-stage kidney failure. This will allow you to be considered as early as possible for a kidney offer.

### **For More Information**

Start with your doctor or the medical team at your transplant center. They know the most about your specific medical conditions and treatment. Don't be afraid to ask questions. It will help you to have a detailed understanding of all your treatment options.

UNOS' Patient Services phone line [(888)-894-6361] can provide information about the OPTN and UNOS allocation policy and other resources available to you. Additional information is available online on the following websites:

- [www.transplantliving.org](http://www.transplantliving.org)
- [optn.transplant.hrsa.gov](http://optn.transplant.hrsa.gov)
- [www.unos.org](http://www.unos.org)
- [srtr.org](http://srtr.org)

The UNOS mission is to advance organ availability and transplantation by uniting and supporting its communities for the benefit of patients through education, technology and policy development.

### *Living Kidney Donation*

There are several advantages for a transplant candidate receiving a living kidney transplant as opposed to receiving a kidney from a deceased donor. The major advantage is that the recipient does not have to wait as long for a transplant. In some cases the transplant can occur before the patient begins dialysis. Another advantage of living donor kidney transplantation is that it can give patients the chance to receive a transplant before the onset of debilitating complications of their kidney disease, or before they become too ill to have a transplant. A living donor can come from either a direct donation or through our paired program. Donors do not need to be compatible to donate. Please see the living donor kidney transplant section for complete information on the process and options for living donation.

## **Pancreas**

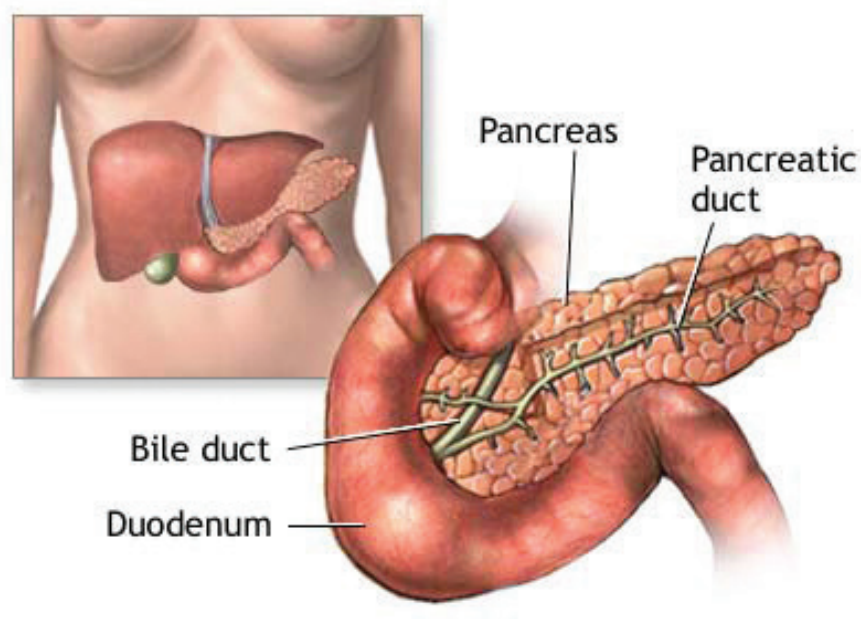
### *Normal Pancreas Function*

Your pancreas is a gland near the stomach that supplies the intestines with digestive fluid and secretes insulin. Insulin is a hormone regulating the amount of glucose in the blood. A lack of insulin causes diabetes.



## *Pancreas Transplantation*

Pancreas transplantation may be performed on patients with Type 1 diabetes mellitus so that the complications of Type 1 diabetes mellitus can be avoided, halted or delayed. It can prevent life-threatening hypoglycemia (low blood sugar). Since severe Type 1 diabetes is often associated with chronic kidney failure, many patients who need a pancreas transplant also need a kidney transplant. The major difference between kidney and pancreas transplants is that while kidney transplants can be expected to significantly prolong the lives of recipients, the same is not true for pancreas transplant recipients. Therefore, for pancreas recipients, there must be a reasonable expectation that your quality of life will be improved.



Pancreas transplant can be performed in one of three different operations depending upon your needs. Since severe Type 1 diabetes is often associated with chronic kidney failure; many patients who need a pancreas transplant also need a kidney transplant.

The operations for pancreas transplant include:

- **Simultaneous Pancreas Kidney Transplant (SPK)**

A simultaneous pancreas kidney transplant is an operation that transplants a kidney and a pancreas during one operation. This option is selected when you have Type 1 diabetes mellitus and are at or near end stage renal failure.

- **Pancreas After Kidney (PAK)**

A pancreas transplant after kidney transplant is done if you need a pancreas and have already had a successful kidney transplant. You must be stable and at least three months after your kidney transplant. This is typically done if you have Type 1 diabetes mellitus and already have a kidney transplant.

- **Pancreas Transplant Alone (PTA)**

A pancreas transplant alone is done when you have Type 1 diabetes mellitus with life-threatening high or low blood sugar that is unresponsive to maximum medical management and insulin therapy. Patients who receive PTA do not have kidney disease.

Your transplanted pancreas will be placed in your pelvis through an incision that starts above your belly button and extends down to in front of the bladder. Your native pancreas is not removed and therefore remains in your body. After the transplanted pancreas is connected to your blood supply, it usually begins to make insulin and the blood sugar levels become normal. The pancreas is then attached to your intestine so that fluid made by the pancreas that aids digestion can drain into it. The pancreas transplant operation usually lasts two to four hours but if it is combined with a kidney transplant it can take three to six hours.

### *Some Patients Cannot be Listed for a Pancreas Transplant*

Pancreas transplantation is not usually done in patients with Type 2 diabetes mellitus. Although these patients may have trouble making enough insulin, they also have a decreased sensitivity to the use of insulin. Insulin resistance is a problem that a pancreas transplant cannot correct. These patients would continue to require insulin even if they received a pancreas transplant.

### *Pancreas for Transplantation - Where Do They Come From?*

All organs available for transplantation are a result of a gift from one person to another. All pancreas transplants come from deceased donors.

- **Deceased Donor Pancreas**

Each pancreas is donated after the death of the donor. The suitability of the donor is determined by many factors. These include many of the same criteria used for living donors such as medical history, general health, habits and so forth.

The facts about pancreas transplant as of November 2019 include:

<b>Persons Awaiting Transplant</b>	<b>Pancreas</b>	<b>Kidney/Pancreas</b>
Persons in U.S. awaiting a transplant	827	1,651
Persons at MM awaiting a transplant	6	16
Number of transplants in U.S. in 2018	192	835

## **The Immune System**

The job of the immune system is to fight infections and to keep us from getting cancer. The immune system does this by recognizing antigens, which are small particles found on the surface of all cells of the body, viruses and bacteria. The cells of your body have the same antigens that your immune system has. Your immune system leaves them alone. A cancer, a virus or bacteria, or transplanted tissue may not have the same antigens as your immune system. The immune system will attack these “foreign” antigens and make antibodies against them.

### *Understanding the Immune System*

#### **What is an Antigen?**

An antigen can be a “self” or “foreign” protein. When the immune system recognizes an antigen as “foreign” it will develop antibodies specific to the antigen.

#### **What are Antibodies?**

Antibodies are proteins formed by the immune system of the “self” in response to the “foreign” antigen. They function to neutralize the antigen. When they interact, a reaction occurs that can cause destruction of tissue. When the antigen is present in a kidney transplant, the reaction between antibodies and antigen can cause rejection.

#### **How Antibodies Develop**

People can develop antibodies to foreign antigens after being exposed through a pregnancy, transfusion, infection or transplant. If any of these happen to you, it is important that you send a blood sample to the tissue typing lab within seven to 14 days of the event. To request a kit (a tube and packaging material), call the tissue typing lab at **(734) 647-2774** and ask for a post-transfusion sample kit. Take this to your local lab and have your blood drawn. Then, mail the specimen back to MM and let your coordinator know.

## *Understanding the Matching Process*

### **What is Matching?**

When we speak of a donor and a recipient as being a “match,” it really means that their blood groups are compatible and that they have a negative crossmatch. Your coordinator can answer any questions that you may have.

### **Blood Types**

A suitable donor has a compatible blood type with the recipient. Human blood types are O, A, B and AB. The Rh factor, positive or negative, is not part of kidney or pancreas matching. Once it is known that your blood type is compatible with your donor, we obtain blood samples from both of you to determine your tissue types and crossmatch.

### **What is Tissue Typing?**

Your white blood cells, also called leukocytes, have a special group of antigens on them called Human Leukocyte Antigens or HLA. Tissue typing is how we find out which ones you have. This is necessary information to have before a person can receive a kidney transplant.

Each person inherits two sets of HLA, one from each parent. Each set is called a haplotype. A haplotype contains three antigens. Brothers and sisters also have one haplotype from each parent. This is why parents and siblings have a better chance of a close match, than do unrelated donors. If two siblings have all six antigens exactly the same, then we call this a two-haplotype match. When the donor is not related to the recipient, the tissue typing terms change. Antigen matching is then expressed by the number of antigens out of six that are the same for the donor and the recipient. While there is some advantage in having a well matched donor, any healthy compatible donor is a “good donor” and the odds of a good result are high.

### **What is Crossmatching?**

Crossmatching is done after blood and tissue typing are completed and a donor is identified. This test checks to see if the recipient has developed antibody against the donor. A small amount of the recipient’s blood is mixed with the potential donor’s white cells. If antibodies in the recipient’s blood attach to the donor white cell antigens, the white cells are injured. This is called a positive crossmatch. This means that if a transplant took place between this recipient and donor, the recipient’s immune system would attack the transplanted tissue. The crossmatch must be negative for the transplant to be done.

## What is Antibody Screening?

Antibody screening is also called PRA (panel reactive antibody). This test can tell us if there are antibodies that a recipient has that would cause a reaction against certain donors. Recipients can be exposed to different antigens through blood transfusions, other transplants or pregnancy. The body then protects itself from these “foreign” exposures mentioned above and makes antibodies. The body does not want to see that specific foreign antibody again or it will attack it. For example, if we transplanted a kidney with that specific foreign antibody, the body would attack that kidney. Antibody screening is performed monthly while the recipient is listed. This is done to monitor for any changes in the PRA level. The PRA score is given as a percentage and can be from 0% to 99%. The higher the PRA level, the harder it is to find a compatible kidney for the recipient.

## Pre-Transplant Evaluation

### *Referral Process for a Transplant Evaluation*

Patients may be referred by any doctor or patients may also refer themselves.

### *Pre-Transplant Evaluation Appointment*

A kidney and/or pancreas transplant evaluation is actually a series of visits with several doctors and other members of the transplant team, **all occurring on the same day**. This appointment will take four to eight hours. During the initial evaluation appointment you will see a transplant coordinator, a physician assistant or nurse practitioner, a nephrologist (kidney doctor), a surgeon, a social worker and a dietitian. Each member of the team has a specific role in the evaluation process. Please refer to the Transplant Team section of this guide for further information.

On the day of evaluation you will attend a patient education class for patients and families of potential kidney and/or pancreas recipients and potential living kidney donors. There is a wealth of information shared during the evaluation appointment and the patient education class. We require you to bring a support person to be with you throughout the evaluation day to take notes and ask questions.

Your evaluation appointment will include a history and physical exam in addition to other testing. After all the test results are compiled, the transplant team will meet to discuss whether transplantation is an appropriate treatment option for you. It is important to remember that you are **NOT** listed for a transplant at the end of your evaluation appointment.

### *Selection Criteria*

Written criteria specific to each organ are used in evaluating all individuals who present for transplantation. The criteria include a) the indications for transplantation, b) the relative contraindications for transplant, and c) the absolute contraindications (if there are any). Please refer to “Selection Criteria” at the end of this section.

### *Tests and Procedures During Evaluation*

#### **Initial Testing**

The following is a list of preliminary testing that can be expected in order to determine if you are an appropriate candidate for kidney and/or pancreas transplant. Many times all of the testing below can be accomplished on the day of evaluation.



- A complete history and physical exam to evaluate your general health is performed. It is very important that you be completely honest with us about your health history.
- Blood studies will include blood chemistries, blood counts, blood type, immune system function and tests for certain infectious diseases.
- A chest X-ray is taken to determine the health of your lungs and respiratory tract.
- An EKG of your heart is done. Further diagnostic testing of your heart may be necessary, such as a stress test or cardiac catheterization.

Additional testing may be necessary depending on your individual medical history.

#### *Additional Testing*

Often the results of one test lead the team to request additional testing. When this occurs, the results from the additional testing are necessary before the team can make a determination about your candidacy for transplant. The transplant team wants to ensure you are as healthy as you can be for your transplant and that you will benefit from a transplant.

When additional tests are ordered, they can often be done by your primary care physician or local lab. Occasionally, we require a specific test be completed at a MM facility. You will receive written instructions for the tests that are needed.

If you are asked for additional testing, do not be discouraged. Most people who get listed and transplanted are asked to have additional testing after their initial evaluation.

For additional information, see “Summary of Tests for Kidney and Pancreas Transplant Patients” on page 45 of the Resources section.

### *Testing Complete – Results Reported*

It is important to note that all requested testing must be completed and the results must be obtained by the transplant team in order for your case to proceed to be reviewed at the evaluation meeting. Failure to complete the testing or get the results submitted can lead to delays in the process.

### *Health and Social Considerations for Listing*

#### **Smoking Policy**

Tobacco use constricts the blood vessels, compromises blood flow to the extremities and is a risk factor in coronary artery disease. Transplant recipients who smoke and/or use smokeless tobacco products have worse survival of their transplant. They also have higher risks of infection and of developing cancer. Going through tobacco withdrawal at the time of surgery is an unnecessary stress. The Michigan Medicine campus environment is smoke-free, therefore, no smoking is permitted on the grounds.

Transplant candidates are recommended to stop smoking and/or using smokeless tobacco products before transplant and to maintain abstinence from tobacco products after transplant. Smoking cessation assistance can be received through your primary care physician or through your transplant social worker. Available smoking cessation programs include:

- **MM Tobacco Consultation Service**  
**(734) 998-6222**  
**[quitsmoking@med.umich.edu](mailto:quitsmoking@med.umich.edu)**
- **Michigan Tobacco Quitline**  
**(800) QUIT-NOW, (800) 784-8669**
- **SmokeFree.gov**  
A text messaging program for smoking cessation

## Alcohol and Drug Policy

Alcohol and illicit street drugs can cause serious health problems for the transplant recipient. Addiction to alcohol or drugs may cause a person to place more importance on getting their alcohol or drug than on caring for their transplant. Use of alcohol and drugs can make you forget to take your medications, neglect lab work and doctor's appointments and can impact your ability to follow up on all aspects of your pre- and post-transplant care. Use of alcohol or drugs as a way to deal with stress and worry is a possible sign of addiction.

Patients identified by the transplant team as having significant substance abuse issues will be expected to work with the transplant social worker to establish an appropriate treatment plan.

Insurance companies may withhold coverage for your transplant if there is evidence of untreated (past or present) alcohol or substance abuse.

## Mental Health

Managing chronic illness can be stressful and challenging and some patients experience occasional or ongoing depression or anxiety. In addition, kidney transplant recipients are prescribed medication that may cause mood changes for a short time after transplant. If you are a patient who is dealing with depression, anxiety or any other mental health issue, the transplant team will discuss a plan for managing your symptoms. This may include a referral to a mental health professional for therapy or medication management. If you are already followed by a local therapist or psychiatrist, the transplant social worker will talk with you about requesting a letter summarizing your care and treatment plan at your evaluation appointment.

## Social Support Plan

**Patients must be able to identify a reliable support system.** To ensure a successful transplant outcome, it is important to discuss the need for ongoing social support with your family and friends. Your transplant social worker must speak with your support people to confirm that they are able to help you with the following tasks::

- **24/7 on-call driver:** You will need to identify a friend or family member who can bring you to Ann Arbor when you receive the call for transplant. This call can come anytime, day or night.
- **Main support person while in the hospital:** The inpatient transplant team will want to provide education and instruction to you and your main support person before you are discharged. The team will educate you and your support person regarding medication instructions, follow-up clinic appointments and weekly labs. Having another person hear this information helps you to remember the team's instructions after you have returned home.



- **In-home support:** For two weeks after your discharge, you will need 24-hour support by a family or friend. During this time, you will need help with cooking, shopping, laundry or cleaning. You may have family members who live with you and can provide this support during your recovery. If you live alone, you will need to ask others to stay with you and help you with these tasks. Having a conversation with your support person can help you know what tasks he/she is able to provide during your surgical recovery. Religious communities or other community groups can also be good sources of support for these needs.
- **Driver to weekly clinic appointments:** You will have weekly clinic appointments with your transplant nephrologists for six weeks after you are discharged from the hospital. You will not be able to drive for two to four weeks after your surgery and when you are no longer taking narcotic pain medications. You must identify a friend or family member to help you with transportation to Ann Arbor for these clinic appointments.

### Social Support Plan

- On-Call Driver – 24/7
- Support person during hospital stay
- In-home support after surgery
- Driver to weekly clinic appointments

**If your original caregivers are no longer available, please notify your transplant social worker, as other caregivers will need to be identified. Transplant Social Work can be reached at (800) 333-9013.**

### Active Participation in Your Healthcare

In order to have a successful transplant outcome, it is vital that both the patient and his/her caregiver develop a positive relationship with the transplant team. The transplant experience can include both ups and downs and the team requires regular, consistent and accurate communication about all aspects of your care. This communication may be related to medications, symptoms, outside hospitalizations or tests and discussions about the plan for managing the health of your transplant. Some of this communication may be with the doctors or with nurses or other support staff. The entire transplant staff is committed to providing quality service and patient care. Please return all calls from the University of Michigan promptly.

### *Evaluation Meeting*

Every patient case is discussed at the Kidney and Pancreas Transplant Evaluation Meeting at which time medical, surgical and psychosocial history are reviewed. The evaluation committee members review each patient's case and test results to determine whether there are any issues which need to be further addressed before the patient can be placed on the transplant list.

There are three potential decisions that may be made regarding a patient during the Kidney and Pancreas Transplant Evaluation Meeting:

- The patient meets the criteria and is approved to be listed
- The patient does not meet the criteria and cannot be listed
- More information or testing is needed to make the determination and the decision is deferred until the information can be obtained.

You will receive a letter within two weeks of the committee's decision informing you of the decision and any additional steps you need to take.

## Getting Listed

If it is determined that you are an appropriate candidate for placement on the transplant list, you have completed all the appropriate tests and have received authorization from your insurance company, you are then listed for kidney and/or pancreas transplant. At that time, you and your referring doctors will receive a letter about the transplant committee's decision.

### *To Remain Active on the Waiting List*

To remain active on the waiting list, you must keep up with the listing requirements which include:

- **You will have yearly follow-up visits with the transplant team.** These are much shorter than your evaluation appointment. At these visits, we will update your health information, ensure that transplant that is still a good option for you, and review any testing that will be needed in the coming year. Certain types of patients may have these visits every six months.
- **Send in your monthly blood sample without fail.** This sample is used to repeat antibody screening before a transplant and is required to maintain your active status on the transplant list. If you do not receive a blood draw kit, call the transplant office so that one can be sent to you. Without a current blood sample you **CANNOT** be considered for any deceased donor kidney.
- **If you are diabetic, you must need cardiac testing.** A dobutamine stress echocardiogram or similar stress test will be the first requirement. Your cardiologist may deem additional studies are necessary.
- **If you are female and over the age of 18, we strongly recommend yearly gynecologic clearance done by your local doctor.** If you are female and over 40, we strongly recommend yearly mammograms. For some patients who have a history or family history of gynecologic or breast cancer, it will be required that either a pap smear or mammogram be done before listing can occur. We ask that you forward the results of your pelvic exam/PAP smear and mammogram to our office.

### *Being Placed on Hold*

If the above requirements are not met, you may be placed “on hold.” Patients on hold cannot be offered donated organs, but continue to accrue waiting time. You must meet the requirements before you will be eligible to receive organ offers. **It is in your best interest to keep your testing current when listed. It is your responsibility to make sure testing is completed and the results are sent to our office. You should contact your transplant coordinator to review your results.**

Other medical issues can cause a patient to be placed on hold, such as infections, stroke, heart attack, other significant illness or significant operations, and blood transfusion. You will be placed on hold for three months after a blood transfusion. Patients may be placed on hold for non-medical reasons too, including change or loss of insurance, social support issues, compliance issues, substance abuse issues, untreated psychiatric issues and/or the patient’s going out of town. Transplant social workers are available to help patients remove barriers to transplantation and will work with you, your family and your dialysis center toward this goal. Please keep the transplant team informed of any changes in your health, insurance or personal situation.

### *Maintaining Health While Waiting for Your Transplant*

#### **Maintain a Healthy Lifestyle**

Staying as healthy as possible, physically and emotionally, before transplantation is very important. We recommend you learn all you can about your disease, testing, medications and the transplantation process before your operation.

**Staying physically healthy** includes the following;

- **Stay as active as possible.** A daily program of moderate exercise, as well as participating in your normal activities can help maintain general strength and energy levels, and help to maintain stable lab values. Daily walking is a great activity for maintaining good cardiovascular health and for maintaining a healthy weight. If you are on dialysis, you may use foot pedals (offered at some dialysis centers) to “bicycle” during your dialysis session. If you are unsure of your physical limitations, you should discuss exercise with your doctor. You may choose to work with a physical therapist to find an exercise program that meets your needs and builds strength.
- **Follow your recommended diet.** While you wait for a kidney transplant, it is important that you follow the special diet recommended by your doctors and registered dietitian. These changes are often used to treat heart disease, diabetes and kidney disease. When kidneys are not working well, waste products can build up from the foods and drinks you consume. People with kidney disease are often told to adjust protein, sodium, potassium,

phosphorus, calcium and fluids in their diet. If you have diabetes, controlling your blood sugar can prevent further damage to your kidneys. Eating three balanced meals at regular times can improve blood sugar control. Following these recommendations will help you stay as healthy as possible. It is important to remember that the healthier you are going into surgery the better the chances are for a positive outcome.

- **Patients who are overweight should lose weight.** Planned weight loss can improve health by controlling blood pressure, decreasing risk for heart disease, improving blood sugar control and decreasing risk of transplant complications. Some patients may be required to lose weight before being transplanted. If the transplant team recommends weight loss, please refer to the Weight Loss section of this book. It is important to check with your doctor or dietitian before trying quick fixes such as diet pills or herbal products. Some of these supplements can do more harm than good. The Transplant Center has a registered dietitian available to help you by calling **(800) 333-9013** or by reaching the dietitian at her direct number at **(734) 936-8290**.
- **Patients who smoke should quit.** It has been shown that smoking decreases the survival of the transplant, in addition to causing other health issues. If you have difficulty quitting, you should ask your doctor or nurse for help locating a resource to help you in quitting.
- **Patients (female) should avoid pregnancy while waiting for a transplant.** Some patients are interested in the possibility of becoming pregnant and having a baby after a transplant; this is often possible. For more information on this topic refer to page 14 in the Post-Transplant Care section and on page 14 in the Medicines section.
- **Talk with your transplant coordinator** if you have any questions about maintaining a healthy lifestyle.

### *Staying Emotionally Healthy is Very Important*

Transplant social workers are trained to help patients and their loved ones to cope with the challenges of chronic illness and the specific challenges of kidney transplant and ongoing care. Here are some suggestions from our social work team about emotional health:

- **Share your feelings.** The wait for a kidney transplant can take years and it is common to have feelings of frustration, anxiety and sadness during your time on the waiting list. If you begin to feel overwhelmed by these or other emotions, we encourage you to talk to your transplant social worker, your dialysis social worker, or a friend or family member. If these emotions are making it difficult for you to function on a daily basis, individual counseling might be helpful for you.

- **Talk to a transplant peer mentor.** The Transplant Center has peer mentors who are patients that have received kidney and/or pancreas transplants. They are happy to share their experience with you hear about transplant from a patient’s perspective. They are available to speak with you in person, on the phone or via email. To get connected with a peer mentor, please talk to your coordinator or social worker.
- **Stay involved.** Keeping life as normal as possible helps maintain stability during the waiting period. You should try to stay involved in work and leisure activities as your health will allow. If your health limits your ability to continue to work or participate in some activities, be creative and find new outlets or interests to focus on.
- **Learn to relax.** You should identify those activities that you find relaxing and make a commitment to yourself to do at least one relaxing activity each day. Some activities that help reduce stress are taking a walk, listening to or playing music, reading, relaxation classes, talking with friends or family, writing, drawing, painting, as well as many other activities. Avoid unhealthy outlets of stress such as abusing drugs or alcohol, overeating, or isolation from friends and family.
- **Engage in activities that promote your spiritual well-being.** For patients who turn to faith or spirituality as a source of strength, you may find that connecting with your spiritual community for prayer and comfort may ease your mind, body and spirit.

Contact your transplant social worker if you need support regarding coping with your wait time or any other concerns you have about your emotional health. Transplant Social Work can be reached at **(800) 333-9013**.

### *Where and Who to Call When You’re Sick – Before Transplant*

Many problems may occur while waiting for a transplant. It is extremely important to remain in contact with your transplant coordinator.

- **Pre-Transplant Kidney and Pancreas Coordinators**  
**Call (800) 333-9013**  
 Hours: Monday-Friday, 8 a.m.-4:30 p.m. Closed holidays.



Call if:

- You are hospitalized outside the University of Michigan Hospital
- Your medical condition changes
- Your telephone numbers change
- Your medical insurance changes
- You need to travel out of town
- You or your family have questions or concerns
- Your care and support plan and those you planned to help you are no longer available

### *The Call Comes When An Organ Becomes Available for You*

The call advising of an available organ being offered for you can come at any time. The first notification comes to the transplant coordinator, who works in collaboration with the surgeon.

The transplant coordinator on call has one hour to accept or decline the organ offer. In this time when the kidney or pancreas becomes available, they need to be able to find you and to review current information with the surgeon. To ensure the organ can be considered for you, take the following precautions:

- **Keep transplant team informed about how to reach you.** We need to be able to reach you 24 hours a day. Make sure that the transplant coordinators have phone numbers for family, friends, places of employment, or anyone who might know your whereabouts if you are not home. If you have privacy manager on your telephone, we recommend that you remove it. The University of Michigan does not identify itself on these machines. If you don't pick up our call or answer quickly, you may miss your chance for a kidney. If you have an answering machine on your phone, be sure to turn the machine off at night.
- **Answer your phone even if you do not recognize the telephone number calling.** You may not recognize the number, but it may well be one of the coordinators trying to reach you. Do not start for the hospital without actually speaking to a coordinator.
- **If you plan to leave home for business or vacation, call the Transplant Office** to give your destination. Should a kidney become available, we will do our best to locate you and offer you the chance to return for the transplant.
- **It is important to realize that even after you arrive at the hospital, the transplant team may determine that the donor organ is not suitable.** While this can be very disappointing, remember that sometimes this cannot be determined until the last minute, and the transplant team is committed to giving you the best possible outcome.

### *Transportation to the Hospital*

The transplant coordinator on call coordinates the necessary arrangements for the transplant operation. You will have adequate time to travel to the hospital. Your travel time has been considered in making the arrangements for the operation. Drive safely. Wear a seat belt.

### *What to Bring When You Come to the Hospital*

It is a good idea to be prepared for your hospitalization by having a bag packed with the things you need to bring to the hospital when you are admitted. In addition to your personal clothing and toiletry items, we suggest you bring the following:

- Bring educational materials. They will be used throughout your inpatient stay to continue your education on medications and care following transplant.
- Personal items, clothing for discharge
- Glasses
- Hearing aids
- Current medications
- Money for parking, meals for your companion
- Phone numbers of family and friends who will be caring for you during your recovery
- Canes or other walking devices



### *When You Arrive at the Hospital*

- Park in the parking structure P2 and proceed to the Main Hospital entrance at Taubman Center 1st floor lobby.

- **From the Main Hospital Entrance, go directly to the unit of University Hospital identified by the transplant coordinator.**

If you are asked to go to an inpatient unit (for example, 5C), please go directly to the unit as directed by your coordinator and check in at the nurses' station. Staff at the hospital entrance can guide you to this location.

If you are asked to go directly to Pre-Op, please proceed to the Red Pillar (University Hospital 1st floor). You will check in via the Surgery Reception front desk or, if you're arriving after hours and the desk is closed, call the OR front desk via the phone number listed on signage next to the Red Pillar.

- **Do not check in at Admissions or Emergency Room.**

Going to the Admissions area or Emergency Room will cause an unnecessary delay.

- **Patients arriving after 10 p.m.**

The number of hospital entrances after 10 p.m. is limited. You will need to enter via the Main Hospital entrance at Taubman Center. There will be staff available 24 hours a day to guide you.

