Transplants at University Hospital

In 1964, a team of surgeons at the University of Michigan Health System (UMHS) performed the first kidney transplant operation in Michigan. Our transplant surgeons do more than 250 kidney transplants a year. This makes the UMHS 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, UMHS 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 the 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 hypertension, glomerulonephritis, hereditary diseases such as polycystic kidney disease or Alport’s syndrome, metabolic diseases such as diabetes mellitus or inborn errors of metabolism such as oxalosis or cystinosis, obstructive uropathy, medication toxicities, multisystem diseases such as vasculitis, amyloidosis or systemic lupus erythematosus, congenital malformations including vesical ureteral reflux, hypoplasia or dysplasia, and 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. 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 August 2008 there were 76,502 persons awaiting a kidney transplant on the wait list in the United States. At the University of Michigan alone, there were 1,078 patients waiting. Unfortunately, in the year 2007 only 10,587 kidney transplants from deceased donors were performed in the United States and 4,443 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 entails taking the patient off the ventilator, typically in the operating room. Once the patient’s heart stops beating, the physician declares the patient dead and organs can be removed.

**Expanded Criteria Donors (ECD)**

Expanded Criteria Donor (ECD) kidneys are one way of increasing the available kidneys. A kidney from an expanded criteria donor may be a good option for some waiting for a transplant. They may be from donors who are older than 60 years of age or between 50 and 59 years of age with a history of high blood pressure, decreased kidney function, or a stroke at the time of their death. You may ask to be listed for an ECD kidney. This may be to your advantage if you have just been listed and are older than 60, or if you have diabetes and are over forty. If it appears you are a good candidate for an ECD kidney, the team will talk with you about this option in greater detail.

**High-Risk Donors**

Some donors have been determined to have high-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 higher risk of transmission of certain diseases (i.e., HIV, Hepatitis C, Hepatitis B) to a recipient. All donors, whether they are high-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. High-risk donors who test negative and are not now engaging in high-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 1%.

**Allocating Deceased Donor Kidneys**

Kidneys that become available from deceased donors are offered to specific patients based on a tightly controlled system. The local Organ Procurement Organization (OPO) in the geographical area of the donor oversees the donation and coordinates offering the kidney to the person identified on the wait list. OPOs are regulated by the federal government and strictly follow federal guidelines.
Kidneys are allocated to patients based on a point system. Points are given for waiting time, the closeness of the match, age less than 18, and panel reactive antibody (PRA). Once a deceased donor kidney is offered to the transplant center for a specific patient, the transplant coordinator has a one-hour time period to contact the patient and to accept or reject the offer for that patient. If the offered kidney is accepted, the patient proceeds to arrive at the hospital safely by the appointed time. If the offer is rejected, the OPO offers the kidney to the transplant center for the next identified person on the wait list.

**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 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.

**Living Kidney Donors with a History of Hypertension**

Potential living kidney donors who are over the age of 50 with a history of hypertension may be eligible to donate a kidney. There is a protocol in place and the living donor coordinator will review the requirements to see if the potential donor qualifies.

**Related and Unrelated**

Living donors may be related or unrelated to the recipient. Individuals who wish to be considered as a living kidney donor must contact the Transplant Donor Coordinator to indicate their interest. The Transplant Donor Coordinator will review the process with the interested party prior to setting up an evaluation appointment.

Living donors are prohibited by law from being paid or receiving any other financial incentives to donate. Living donors must be 18 years of age or older.

Parents, children, siblings, other relatives as well as in-laws and close friends can be considered for living kidney donation. The potential donor and recipient must have compatible blood types and they must have a negative crossmatch. Please refer to “The Immune System” on page 9 of this section for more information on the immune system, antigens, antibodies, matching, tissue typing and crossmatching.
Some health circumstances prevent an individual from donating a kidney. For instance, individuals with a current history of diabetes or cancer may not be eligible to donate. The Transplant Team may review the data on potential donors with a relevant history prior to scheduling an evaluation appointment.

**Desensitization**

Many patients who are waiting for a kidney transplant may not be able to receive one because they are considered “sensitized.” Other patients cannot receive a kidney transplant because their blood is incompatible with the donor. Sensitization and blood incompatibility are caused by antibodies against human cells or blood types. Antibodies are proteins made by white blood cells generally used to help the body fight infection.

Antibodies are also made any time your immune system finds a protein it considers “foreign.” A person can develop antibodies from previous transplants, blood transfusions or pregnancy. Antibodies against blood types are developed after birth, which is a normal body response. This normal immune response requires careful matching of compatible blood types between the transplant donor and the transplant recipient.

If a kidney transplant is performed in a patient with antibodies against human cell or blood types, the antibodies will bind to the transplant causing severe rejection and destruction of the kidney.

A process called “desensitization” now provides an opportunity for sensitized and blood type incompatible patients to receive a kidney transplant. Desensitization removes unwanted antibodies from the blood stream using medications and a process similar to dialysis (dialysis removes chemicals from the blood, while this process removes harmful antibodies). The process prepares the patient for a successful transplant and occurs as a monthly infusion process for the first six months, followed by two additional infusions at nine months and one year after treatment begins.

Insurance approval is required before desensitization can begin. Please contact your Financial Coordinator if you are a candidate for, and are interested in pursuing, desensitization.

The success of desensitization depends on the amount of antibodies. Patients with very high levels of antibodies are likely to fail this treatment and, as a better option, may benefit from the Kidney Paired Donation Program (KPD). The Kidney Paired Donation Program (KPD) offers the matching of incompatible living donor/recipient pairs to others with a complementary incompatibility until a compatible or better suited donor is identified.
**Paired Donation**

Occasionally a healthy and suitable individual comes forward to donate for their loved one only to find they are not a match (either by blood type or positive crossmatch) for their loved one – yet they want to donate. Paired kidney donation is aimed at providing transplant opportunities for these potential donors and recipients. This program identifies “pairs” where the donor from one pair donates their kidney to the recipient of the second pair and vice versa.

Paired donation is only available to recipients who are actively listed for a kidney transplant and have exhausted all other living donor options.

If you have questions about the paired donation program, please ask your Transplant Coordinator.
**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

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.

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 August 2008 include:

<table>
<thead>
<tr>
<th>Persons Awaiting Transplant</th>
<th>Pancreas</th>
<th>Kidney/Pancreas</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persons in U.S. awaiting a transplant</td>
<td>1,590</td>
<td>2,268</td>
</tr>
<tr>
<td>Persons at UMHS awaiting a transplant</td>
<td>15</td>
<td>30</td>
</tr>
<tr>
<td>Number of transplants in U.S. in 2007</td>
<td>469</td>
<td>862</td>
</tr>
<tr>
<td>Number of persons died waiting in 2007</td>
<td>19</td>
<td>208</td>
</tr>
</tbody>
</table>

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 -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 UMHS 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.

<table>
<thead>
<tr>
<th>Blood Type</th>
<th>Can Receive Blood From</th>
</tr>
</thead>
<tbody>
<tr>
<td>O</td>
<td>A or O</td>
</tr>
<tr>
<td>A</td>
<td>B or O</td>
</tr>
<tr>
<td>B</td>
<td>A, B, AB or O</td>
</tr>
<tr>
<td>AB</td>
<td></td>
</tr>
</tbody>
</table>

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 the body 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 physician 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 physicians and other members of the Transplant Team, all occurring on the same day. This appointment will take at least five to six hours. During the initial evaluation appointment you will see a transplant coordinator, a physician assistant or nurse practitioner, a nephrologist (kidney specialist), a surgeon, a social worker and a registered nurse. 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 urge 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 contra-indications for transplant, and c) the absolute contra-indications (if there are any). Please refer to “Selection Criteria” on page 8 in the “Resources” section of this patient education guide.

**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.

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 UMHS 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 11 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 University of Michigan Health System 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 prior to 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:
Before Transplant

- Kick the Habit – UMHS Tobacco Consultation Service
  (734) 936-5988
  www.quitsmoking@med.umich.edu

- Michigan Department of Community Health
  (800) 537-5666

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 will require you to have a plan for these specific tasks that you will need help with:
• **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 one to 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 they are able to provide during your surgical recovery. Church communities or other community groups can be good sources of support for these needs also.

• **Driver to weekly clinic appointments:** You will have weekly clinic appointments with your transplant nephrologists for about six weeks after you are discharged from the hospital. You will not be able to drive until three weeks after your surgery and when you are no longer taking narcotic pain medications, so please ask a friend or family member to help you with transportation to Ann Arbor for these clinic appointments.

If you have difficulty identifying friends or family to help you with any of these areas of support, notify your Transplant Social Worker, so you can work on a plan together.

**Active Participation in Your Health Care**

In order to have a successful transplant outcome, it is vital that both the patient and their caregiver develop a positive relationship with the Transplant Team. The transplant experience can include both ups and downs and the team wants to develop 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 physicians or with nurses or other support staff. The entire transplant staff is committed to providing quality service and patient care.
**Evaluation Meeting**

Every patient case is discussed at the Kidney and Pancreas Transplant Evaluation Meeting at which time their 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:

- **Send in your monthly blood sample without fail.** This sample is used to repeat antibody screening prior to 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, yearly cardiac clearance is required.** 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 physician. 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. 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, prior to transplantation is very important. We recommend you learn all you can about your disease, testing, medications and the transplantation process prior to 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.** Dialysis patients are on a renal diet and should follow these guidelines as outlined by their dialysis dietitian. Other patients may be on a low sodium diet for their heart condition. Diabetic patients are required to adhere to their diabetic diet.

- **Patients who are overweight should lose weight.** This will reduce the risk of complications before, during and after transplantation. If the Transplant Team recommends weight loss, talk to your registered dietitian or primary care physician for a weight loss plan that is best for you. Some patients may be required to lose weight before being transplanted.

- **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 physician or nurse for help locating a resource to assist 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 15 in the “Post-Transplant Care” 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 assist 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. A support group is a way to receive support from others who are going through a similar experience. Your social worker can connect you with a support group in your local area.

- **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 a 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. 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.

Where and Who to Call When You're Sick – Prior to 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 support structure changes and those you planned to assist 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 they need to be able to find you when the kidney or pancreas becomes available 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.

- **If you use a pager or a cell phone, answer it 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. With the number of pagers being used, it is also possible you have received a misdialed page. If you have any question about who paged you, call the hospital page operator at (734) 936-6267, and ask for the kidney transplant coordinator on call. One of them will return your page, no matter what time of the day or night it might be.

- **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:

- Patient Education Guide (this manual). This will be used throughout your inpatient stay to continue your education on medications and care following transplant.
- Cane, walker or any other aids you use to remain ambulatory
- Glasses or visual aids, such as a magnifier
- Hearing aids
- Learning aids, such as a tape recorder
- Any medications (in their original containers) that you take
- Money for parking
- Money for meals for your companion during your operation
- Phone numbers and names of individuals you will want your companion to contact following your transplant

When You Arrive at the Hospital

When you arrive at the hospital, go directly to the unit of University Hospital identified by the transplant coordinator.