The Transplant Institute METHODIST DALLAS

Kidney and Pancreas Pre transplant surgery Guide

Important Phone Numbers

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Dr. Amna Ilahe 972-274-5555 Dr. Silvi Simon

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<u>Surgeons:</u> 214-947-4400

Dr. Richard Dickerman Dr. Alejandro Mejia Dr. Lori Kautzman Dr. Vichin Puri Dr. Carlos Fasola

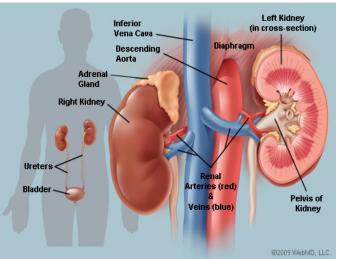
The Kidney

Pre Transplant – Revised 2/2020

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Anatomy

The kidneys are bean-shaped organs that remove waste products and salts from the blood and empty them in the urine. They are in the back of the abdomen, behind the intestines and under the ribs at about the level of the waistline. One kidney lies on either side of the spine. Each weighs about a third to half a pound and has a duct (called a ureter) on its inner surface. The ureter, in adults it is about 10 to 11 inches long, carries urine from the kidney to the bladder, where the urine is temporarily stored. Another duct (called the urethra) carries the urine from the bladder to outside the body.



Functions

The main function of the kidneys is to make urine and maintain the normal makeup of the blood. Kidney functions include:

- Reabsorb water to maintain water balance
- Filter and reabsorb sugars, protein, sodium, and chloride that are useful to the body
- Filter and remove (by means of urine) things that are not useful to the body, such as urea, uric acids, and creatinine
- Make and remove ammonia to help keep the body's acid-base balance
- Produce hormones that stimulate red blood cell production and regulate blood pressure.

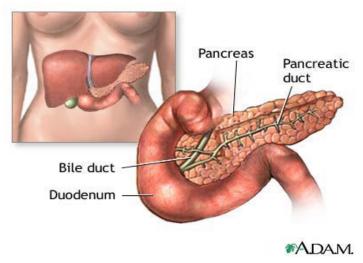
The Pancreas

Anatomy

The pancreas is a small organ, about six inches long, located in the upper abdomen against the spine and connected to the small intestine. Because of this deep position in the body, it can sometimes be difficult to see.

The pancreas is needed to digest food in two ways:

- It makes enzymes that help digest protein, fat, and carbohydrates before they can be absorbed through the intestine.
- It makes cells that produce insulin, which control the use and storage of the body's main energy source, glucose or sugar.



Functions

The pancreas has two functions:

• **Endocrine functions** (secretions that are distributed in the body by way of the bloodstream) and insulin production.

Groups of cells in the pancreas make insulin, a hormone that helps in the production of proteins and certain fats, storage of certain fats, and the body's use of sugar (glucose). Diabetes is the most common disease linked to abnormal production of insulin and low blood sugar.

• **Exocrine functions** (secretions that are released outside the body) and digestion.

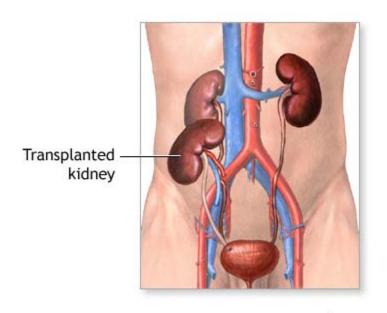
The pancreas makes digestive juices (enzymes), including amylase and lipase. These enzymes are emptied from the pancreas into the small intestine through tubes called the pancreatic ducts.

Transplanted Kidney

While hemodialysis or peritoneal dialysis can eliminate waste and excess chemicals from your blood, unlike the kidneys it cannot produce vital hormones. Through transplantation, you will receive a new kidney that performs all of these important functions, and you won't have to continually interrupt your life for dialysis treatments or depend on machines to keep you going. Whether your kidney is from a living donor or from a deceased organ donor, it will truly be a gift of life.

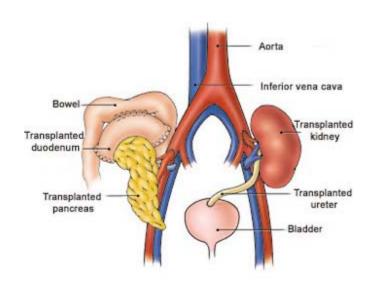
The transplanted kidney will be placed in your lower abdomen. This placement is preferred because your own (or "native") kidneys are not removed unless they are causing you problems and it is easier to biopsy the new kidney in this position.

*ADAM.



Transplanted Pancreas

A successful pancreas transplant will eliminate the need for insulin and will stop the progression of complications from diabetes. Pancreas transplants can be performed alone or in conjunction with a kidney. The pancreas is very fragile so a portion of bowel will be used as a mechanism to handle the pancreas.



Kidney - Pancreas Transplant

Methodist Dallas Medical Center Informed Consent for Kidney and Pancreas Transplant Patients

Evaluation Process

You will be evaluated with consultations, lab tests, and various procedures to determine the appropriateness of transplant. You will meet with many members of the transplant team who may include:

- The **Transplant Coordinator** provides education regarding the transplant evaluation process, listing for transplant, and patient responsibilities before and after transplant. This meeting is intended to provide you with an opportunity to ask questions and to become fully informed about the transplant process.
- A Transplant Nephrologist is a physician who specializes in kidney disease. The
 Transplant Nephrologist assesses medical suitability for transplantation,
 discusses the significance of transplantation (including alternatives and potential
 medical complications), manages transplant-related medical needs before and
 after transplant, participates in care during the transplant hospital admission,
 and follows transplant recipients during clinic appointments at specific time
 periods post-discharge.
- A Transplant Surgeon will meet with you during the evaluation and/or prior to surgery to discuss the appropriateness of a transplant based on the information obtained during your evaluation. The Transplant Surgeon evaluates surgical suitability for transplant, discusses the significance of transplantation with the patient (including the risks, benefits, and surgical complications), discusses the various types of organs available, performs the operation, and provides post-operative care for a defined period of time following surgery.
- An Anesthesiologist may meet with you and review your medical records to determine the need for any additional workup to determine your risk from anesthesia.
- A Social Worker will meet with you to evaluate your ability to cope with the stress of transplantation and your ability to follow a rigorous treatment plan, both before and after transplantation. The social worker will also help to identify your support network. They will discuss psychological risks, the costs associated with your transplant, and the costs associated with the medications you will require after transplant. They will also work with you to help you understand your insurance coverage. It is important that you understand the costs that may not be covered by insurance.
- A **Psychiatrist/Psychologist** may conduct a more in-depth evaluation and assessment. Some patients with a history of drug or alcohol abuse may be required to participate in a rehabilitation program and meet abstinence requirements prior to and after transplant listing.
- A **Registered Dietitian** will perform a nutritional assessment and provide nutrition education.

 Some patients may be referred to another service for consultation. For example, many patients need to be seen by a pulmonologist (lung doctor) or a cardiologist (heart doctor) to assess for other medical conditions.

Many different tests are done to determine if you are a suitable transplant recipient. Some of the following tests may be included in your evaluation process. Remember, other tests may need to be done based on the results of these tests.

- Blood tests help to determine the extent and/or cause of your kidney and/or pancreas disease. Other tests will determine your blood type for organ matching and screen for your immunity to or the presence of specific viruses, including HIV. Additional blood tests may be used to determine how well other organs are functioning.
- A chest x-ray helps your physician identify any problems with your lungs.
- An EKG, echocardiogram and/or stress test will show how well your heart is beating and the function of your heart valves. This will help your physicians decide if your heart function is strong enough for transplant surgery.
- An ultrasound of your kidneys and abdomen helps assess the size, shape, and circulation of your kidneys and/or pancreas.
- Pulmonary function tests may be required, especially if you have a history of smoking or a history of lung disease. This is a breathing test to analyze your lung capacity.

Surgical Procedure

The potential benefits of transplantation cannot result from surgery alone and are dependent upon your following the rigorous treatment plan prescribed by your physicians. You must be aware of the potential risks and complications outlined in this document that can result in serious injury, and death. Your physicians cannot predict exactly how your body will respond to a transplant. It is never fully known how the condition that caused your underlying kidney and/or pancreas disease will affect your transplant. The operation is complex and the risks are high. The overall success rate, roughly defined as the patient surviving with the transplanted organ for at least one year, is about 96-97%%. In other words, the chance of dying following a kidney and/or pancreas transplant is about 3-4% in the first year. The success rate varies according to how sick the patient is prior to the transplant surgery, with sicker patients having a lower chance of a successful outcome.

Donated organs are allocated according to the policy of United Network for Organ Sharing (UNOS). The Kidney Allocation System was revised in December 2014 and uses a point system to calculate longevity of the kidney and the compatibility of the donor organ with the recipient. This system will be discussed with you by the transplant coordinator. Being placed on the transplant waiting list does not guarantee the availability of a kidney and/or pancreas or receiving a transplant.

The Transplant Operation

When a donor organ becomes available, you will be called and you must come to the hospital right away. If the organ has a Kidney Donor Profile Index (KDPI) greater than 85% our surgeon will review this with you and assist you in making your decision. It is at this point that the surgeon has a clear picture of the risks associated with this particular organ versus the risk of waiting for the next available donor and can base the specific recommendations on this information. You always have the option to decline an organ.

During the transplant surgery you will be put under general anesthesia, which means you will be given medications to put you to sleep, block pain, and paralyze parts of your body. You will also be placed on a machine to help you breathe. The anesthesiologist will talk with you in more detail about the risks of anesthesia. The transplant surgeon will make an incision in your abdomen. Through this incision a donated kidney and/or pancreas will be placed into your abdomen.

Drains may be put into your body to allow fluids to be removed and to help you heal. Special mechanical boots or sleeves around your legs will be used to keep blood flowing through your legs to try to prevent dangerous blood clots. You will be in the operating room approximately 4-6 hours.

Post-Surgical Care and Recovery need post transplant living information

After the surgery you will be taken to the intensive care unit where you will be closely monitored. You will be on a machine to help you breathe and you will have many tubes and drains in place. Intermittent pressure boots or sleeves around your legs will be used to prevent blood clots.

Immediately following the surgery, you will experience pain. This will be carefully monitored and controlled. Most transplant recipients have a significant reduction in the pain two to three weeks after surgery.

When your medical condition has stabilized you will be transferred to the transplant floor. Your length of stay in the hospital will depend on the rate of your recovery. You will remain in the hospital as long as your physicians feel hospitalization is necessary. Most patients stay in the hospital for approximately one week, but hospitalization time can vary depending on the severity of your illness prior to transplant or complications after surgery.

After you leave the hospital you will still be recovering. HERE For the first 4-6 weeks you will have some restrictions on your daily activities. If you experience any post-operative complications your recovery time may be longer. During the recovery period the transplant team will follow your progress. You will need to be monitored on a long-term basis and you must make yourself available for examinations, laboratory tests and scans of your abdomen to see how well your transplanted organ is working. Biopsies may be done as needed to diagnose possible complications including rejection or recurrent disease.

The transplant team will see you regularly for three to six months post transplant. Every effort is made to transition your routine medical care to your primary care physician.

You will be followed in the transplant clinic for life. For most patients this involves frequent lab work and a yearly clinic visit. Patients who develop complications may need to be seen more often by the transplant team.

Alternative Treatments

Alternative treatments or therapies may be available for your medical condition, including initiating or remaining on dialysis and continuing current treatment regimens for your diabetes. Additional alternatives will be discussed with you by the Transplant Nephrologist.

Potential Medical/Psychosocial Risks

There are inherent risks in all surgeries, especially surgeries conducted under general anesthesia. Many complications are minor and get better on their own. In some cases, the complications are serious enough to require another surgery or medical procedure.

Bleeding during or after surgery may require blood transfusions or blood products that can contain bacteria and viruses that can cause infection. Although rare, these infections include, but are not limited to, the Human Immunodeficiency Virus (HIV), Hepatitis B Virus (HBV), and Hepatitis C Virus (HCV).

There may be a delay in the function of your transplanted organ. Such a delay may increase the length of your hospital stay and increase the risk of other complications. There is a possibility that the transplanted organ will not function. When this occurs a second transplant is needed.

There are other risks associated with transplants. Infections from bacteria, viruses, or fungi, acute rejection, and side-effects from drugs that suppress the immune system are all possible complications. Side-effects from immune-suppressing drugs include kidney problems, gastrointestinal complaints, blood count abnormalities, nerve damage, high blood pressure, weight gain, diabetes, and others. There may be a need for repeated biopsies, surgeries, and other procedures, or a prolonged intensive care unit or hospital stay after a transplant.

There is a slight increase in the risk of certain kinds of cancer (including skin cancer and post-transplant lymphoproliferative diseases or lymphoma) because of the immunity-suppressing medications.

Emotional and psychosocial issues before and after transplant vary. Anxiety, stress, and depression have been noted. Should you experience these, please notify your Transplant Surgeon, Transplant Nephrologist, Transplant Coordinator, or Transplant Social Worker.

Miscellaneous risks:

Despite the use of compression boots, blood clots may occasionally develop in the legs and can break free and occasionally move through the heart to the lungs. In the lungs, they can cause serious interference with breathing, which can lead to death. Blood clots

are treated with blood-thinning drugs that may need to be taken for an extended period of time.

The risk of infection is higher for transplant recipients than other surgical patients because the treatments needed to prevent organ rejection make the body less capable of fighting infection. The abdominal incision for the transplant and any incision needed for the kidney bypass machine (neck, underarm, and groin) are potential sites for infection. Infections in the sites where tubes are placed in your body (tubes to help you breathe, tubes in your veins to provide fluids, nutrition and to monitor important body functions) can cause pneumonia, blood infections and local infections.

Damage to nerves may occur. This can happen from direct contact within the abdomen or from pressure or positioning of the arms, lets or back during the surgery. Nerve damage can cause numbness, weakness, paralysis and/or pain. In most cases these symptoms are temporary, but in rare cases they can last for extended periods or even become permanent.

Other possible complications include: injury to structures in the abdomen, pressure sores on the skin due to positioning, burns caused by the use of electrical equipment during surgery, damage to arteries and veins, pneumonia, heart attack, stroke, and permanent scarring at the site of the abdominal incision.

National and Transplant Center-Specific Outcomes

The most current data available from the Scientific Registry of Transplant Recipients (SRTR) describing patient and graft survival one year after transplant is represented in the attached document and do not significantly differ compared to national data.

Notification of Medicare Outcome Requirements not Being Met by Center

Specific outcome requirements need to be met by transplant centers and we are required to notify you if we do not meet those requirements. Currently, Methodist Dallas Medical Center meets all requirements for transplant centers.

Organ Donor Risk Factors

Certain conditions in the donor may affect the success of your transplant such as the donor's history and the condition of the organ when it is received in the operating room for your surgery. Additionally, there is a potential risk that you may contract HIV and other infectious diseases if they cannot be detected in the donor.

Right to Refuse Transplant

You have the choice not to undergo transplantation. If you choose not to have a transplant, treatment for your kidney and/or pancreas disease will continue. If you do not undergo the transplant surgery, your condition is likely to worsen. If you have kidney disease, dialysis will need to be initiated or continued with a decrease in your life expectancy.

Transplantation by a Transplant Center Not Approved by Medicare

If you have your transplant at a facility that is not approved by Medicare for transplantation, your ability to have your immunosuppressive drugs paid for under Medicare Part B could be affected.

After you have a transplant, health insurance companies may consider you to have a pre-existing condition and refuse payment for medical care, treatments or procedures. After the surgery, your health insurance and life insurance premiums may increase and remain higher. In the future, insurance companies could refuse to insure you.

Waiting Time Transfer and Multiple Listing

If listed for transplant, you have the option of being listed for transplant at multiple transplant centers and the ability to transfer your waiting time to a different transplant center without loss of the accrued waiting time.

Concerns or Grievances

The United Network for Organ Sharing provides a toll-free patient services line to help transplant candidates, recipients, living donors, and family members understand organ allocation practices and transplantation data. You may also call this number to discuss a problem you may be experiencing with your transplant center or the transplantation system in general. The toll-free patient services line number is 1-888-894-6361.

Consent revision 6/17/16

Methodist Dallas Medical Center Kidney and Pancreas Transplant Program

The Transplant Process

Information by Phase	Responsible Party
Referral Phase & Evaluation Phase	
Estimated timeline:	Methodist Dallas Medical
120 days after financial approval obtained	Center
Priority areas of focus:	
Insurance verification	
 Medical management of kidney disease 	
Evaluation testing	
Outside referral/application received	
Verification of insurance benefits for transplant evaluation and approval, or	
denial process started.	
Discussion of financial responsibility (cost of surgery, cost of medications, cost	
of follow-up care). Options for fund raising.	
Historical data reviewed with patient and entered into computer.	
Evaluation and completion of any additional required tests. Physician consults	
scheduled. Results entered into computer.	
Presentation to committee and documentation of selection committee results	
(within 2 weeks of completion of tests).	
"Approval," "Hold," or "Denial" process started	
If needed, additional tests or procedures are ordered and completed for	
patient to meet listing requirements.	
Listing Phase	
Estimated timeline:	Methodist Dallas Medical
38 months is the average waiting time for transplant (based on 2006 data)	Center
Priority areas of focus:	
 Placement of patient on transplant waiting list after insurance 	
approval	
 Medical management of kidney disease 	
 Annual testing updates 	
Risk for disease recurrence	
 Risk for developing complications of immunosuppression. 	
Listing and organ acceptance criteria determined.	
Medical necessity letter sent to insurance company and "approval to list"	
received.	
Listing letters and educational materials sent to patient within 10 days of	
listing.	
Annual updates as required.	
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UNET forms prepared and uploaded.	
UNET forms prepared and uploaded.	

Methodist Dallas Medical Center Kidney and Pancreas Transplant Program The Transplant Process

Information by Phase	Responsible Party
Transplant Event	
Estimated timeline	Methodist Dallas
4-5 days	Medical Center
Priority areas of focus:	
 Surgery and post-operative course of treatment. 	
 Patient/family education. 	
Arrival at hospital after notification by transplant coordinator	
Labs, EKG, CXR	
 History and physical 	
 Consents for treatment, blood, surgery 	
 Surgical Process (IV lines, drains, incisions) 	
 ICU (ventilator, monitors) 	
Notification of transplant event to referring physician	
Patient education to prepare for discharge, including self-care	
after transplant surgery, routine follow-up requirements, and	
discharge needs such as social worker, dietitian, pharmacist, and	
transplant coordinator.	
 Medications 	
• Diet	
Infection	
Rejection	
 Self-care at home 	
 Sexual activity 	
 Communication with donor family 	
 Lab tests 	
When to call	
 Follow-up labs and appointments 	
 Annual follow-up requirements 	

Methodist Dallas Medical Center Kidney and Pancreas Transplant Program The Transplant Process

The Transplant Process	·
Information by Phase	Responsible Party
Discharge – 90 Days after transplant	
Priority areas of focus:	Methodist Dallas
 Detection and treatment of postoperative problems 	Medical Center
 Patient and family education 	
 Hypertension prevention or management 	
 Diabetes prevention or management. 	
Home health	
Safety evaluation	
PT/OT	
Medication teaching	
 Wound assessment 	
Diabetic teaching	
Clinic Visit & Lab Schedule	Methodist Dallas
• 0-21 days	Medical Center/
• 22-28 days	Dallas Transplant
• 29-48 days	Institute
• 49-90 days	
Complete assessment with each office visit identifying any	
problem areas or areas for further focus, including:	
 Physical complaints 	
 Psychological complaints 	
Social issues	
Financial issues	
 Understanding of self-care and compliance 	
Nutritional issues	
 Identification of need to see other team members for 	
consult	
 Reinforcement of previous education 	
Patient education of post-transplant self-care and routine follow	
up requirements.	
Completion of disability and medical leave forms.	
Letter to referring physician and PCP regarding post-transplant	
events and current plan of care.	

Methodist Dallas Medical Center Kidney and Pancreas Transplant Program The Transplant Process

Information by Phase	Responsible Party
91 Days – 1 Year Post-Transplant	
Priority areas of focus: Detection and treatment of postoperative problems Patient and family education Hypertension Diabetes Lipid management.	Methodist Dallas Medical Center/Dallas Transplant Institute /Referring Nephrologist
Clinic Visit & Lab Schedule	
91-180 days181-360 days.	
Patient education of post-transplant self-care and routine follow-up requirements.	
Complete assessment with each office visit identifying any problem areas	
or areas for further focus, including:	
Physical complaints	
Psychological complaints	
Social issues	
Financial issues	
 Understanding of self-care and compliance 	
Nutritional issues	
 Identification of need to see other team members for consult 	
Reinforcement of previous education	
Completion of disability and medical leave forms.	
Completion of UNOS data forms at 6 months and 1 year.	Methodist Dallas Medical Center
Letter to referring physician annually regarding post-transplant events	Methodist Dallas Medical
and current plan of care.	Center/
	Dallas Transplant
	Institute

Methodist Dallas Medical Kidney and Pancreas Transplant Program The Transplant Process

Information by Phase	Responsible Party
Annually Post-Transplant	
Priority areas of focus:	Methodist Dallas Medical
 Diabetes 	Center/Dallas Transplant
 Hypertension 	Institute /Referring Nephrologist
Lipid management	Nephrologist
Cancer screening	
Clinic Visit & Lab Schedule	
 Every 2 to 3 months and annually 	
Patient education of post-transplant self-care and routine follow-up	
requirements	
Complete assessment with each office visit identifying any problem areas	
or areas of further focus, including:	
Physical complaints	
 Psychological complaints 	
Social issues	
Financial issues	
 Understanding of self-care and compliance 	
Nutritional issues	
 Identification of need to see other team members for consult 	
Reinforcement of previous education.	
Completion of UNOS data forms annually.	Methodist Dallas Medical
	Center
Letter to referring physician annually regarding post-transplant events	Methodist Dallas Medical
and current plan of care.	Center/
	Dallas Transplant
	Institute

Care plan revision 9/1/17

The Transplant Team

The skilled health care professionals who make up your transplant team share a common goal: the success of your kidney and/or pancreas transplant. Each of members of this team will take a personal interest in answering your questions and taking care of your medical needs. They will also help you keep your spirits up throughout your journey.

We encourage you to meet each of these team members and keep the lines of communication open. They will count on you to express your concerns and fears, and you must tell them immediately if there are any changes in the way you feel physically. In this respect, you are the most important member of the transplant team.

Each transplant program is unique. The following is a list of transplant team members and their responsibilities.



Transplant surgeon

This physician will perform the transplantation procedure. He or she will examine you each day and check your incision to make sure it is healing properly.

Transplant physician/nephrologist

You will see your transplant physician/nephrologist during your hospital stay. Each day, he or she will examine you, check your test results, and adjust your medication as needed.

Again, be sure to let your doctor know of any change in the way you feel, no matter how insignificant it may seem to you. And remember, your doctor expects you to ask questions, so be sure to speak up.

Transplant coordinator

This team member, a registered nurse, will be responsible for:

- Coordinating and scheduling all of your pre-transplant-surgery testing and will be responsible for maintaining updated testing while you are on the waiting list for an organ.
- Locating your donor kidney and/or pancreas, testing for donor compatibility, contacting you once a kidney and/or pancreas has been found, and coordinating your transplant surgery
- Teaching you how to take care of yourself before and after transplantation, including how to take your medication and when to return to the transplant center for follow-up visits.



Floor or staff nurse

This nurse may help to coordinate the activities of your other caregivers, as well as tend to your needs during your hospital stay and prepare you for your discharge. Your nurse will keep the lines of communication open between you and the other members of your transplant team.

Social worker

Your social worker can advise you about Medicare, Medicaid, and other insurance coverage and can link you to services and people in the community who can help with your recovery after you leave the hospital. If you need transportation, help at home, or a hand when you go back to school or work, your social worker can help you to arrange it. He or she can also help with psychosocial and family matters.

Dietitian

Following your doctor's orders, a registered clinical dietitian can create a special diet plan that will help you stay healthy and avoid excessive weight gain after your surgery. Follow the diet plan prepared for you, and take advantage of the pointers that your dietitian offers. Proper nutrition can speed your recovery and help you stay healthy.

Pharmacist

The transplant pharmacist will review your medication list prior to transplant and will consult with physicians regarding medications while you are hospitalized. Prior to your discharge, the pharmacist will meet with you to educate you and your family about your new medications.

Pre-transplant-surgery Testing

Throughout this period, you'll find yourself taking many tests, and you may wonder when it will all end. Keep in mind that you are taking a giant step forward in the transplantation process. These tests will help your transplant team discover potential problems before they occur and determine if transplantation is truly the best option for you. When all of your test results are in, your doctors will have a clear picture of your overall health status. This increases the likelihood of success. Your transplant team may ask you to undergo any of the following procedures:

- Chest X-ray will tell your doctors if your lungs and lower respiratory tract are healthy.
- **Electrocardiogram (EKG or ECG)** will reveal how well your heart is working and may reveal heart damage that was previously unsuspected.
- **Echocardiogram** uses ultra-high-frequency sound saves to also reveal how your heart is working and if there is any previously undetected heart damage.
- Stress Test is an exercise session to measure the strength of your heart.
- Abdominal Ultrasound will evaluate the status of your native kidneys
- Colonoscopy will help your doctors be certain you are free of intestinal abnormalities.
- Blood tests, including a blood count, blood and tissue type, blood chemistries, immune system function, and certain infectious diseases will screen for abnormalities and type your blood for cross-matching.
- Pulmonary function test reveals how well your lungs are working, and it is conducted by breathing into a tube attached to a measuring device.
- Other tests may be performed as part of your overall workup, including a gynecological exam, pregnancy test, and mammogram (for women) or prostate-specific antigen blood test (for men).

During these tests, your doctors, nurses, and technicians will make you as comfortable as possible.

Organ Donation Selection and Matching

Blood Typing and Antibodies

If you are receiving an organ from the list, blood types and antibody levels will affect how long you will wait for an organ. Your blood type and antibody level will be checked during the work-up process.

Panel Reactive Antibodies

Panel reactive antibodies (PRA) is the measurement of a patient's level of sensitization to donor antigens. In other words, it is a predictor as to whether your body will accept a particular donor organ without having a bad reaction. The PRA is measured by percentage, from 0% to 99%.

The higher the PRA, the more sensitized a patient is to the general donor pool and the more difficult it can be to find a suitable donor. A patient may become sensitized as a result of pregnancy, a blood transfusion, or a previous transplant.

About 30% of patients waiting for an organ transplant are considered sensitized. Sensitized patients have developed harmful antibodies in their blood against foreign tissue. Sensitized patients may wait three to four times longer than unsensitized patients for a compatible deceased donor kidney and/or pancreas.

For example, if a recipient has a PRA of 60%, then this patient will have a bad reaction to 60% of the donor organs kidneys offered. Conversely, this also means that the recipient will have a good reaction to 40% of the donor organs

The final decision on whether or not you get the organ(s) that are being offered is by doing a cross-match test. With this test, our HLA lab will put a sample of your blood with the blood of the donor to see if your blood reacts negatively to the donor's blood. If a bad reaction occurs, you will not get that kidney and/or pancreas. This test usually takes about five hours and cannot be started until we receive blood from the donor.

If a patient's PRA is below 10%, then a cross-match test might not be required. A very important part of omitting the cross-match test involves our HLA professionals ensuring that your PRA is below 10% and making sure your PRA has been consistently low for the past three months. This will eliminate the five hours of waiting for the completion of the cross-match test, speeding the transplantation process — which are good for the new organ(s).

Your dialysis center should check your PRA periodically once you are on the list.

Important terms to know

- **Antigen** is a substance, usually a protein, that the body recognizes as foreign and that can evoke an immune response.
- Antibody is an immunoglobulin produced in the body in response to bacteria, viruses, or other antigenic substances. They are part of the body's immune response.
- **Sensitization** is a reaction in which specific antibodies develop in response to an antigen. Allergic reactions result from excess sensitization to a foreign protein.

Selection Committee

After all of your pre-transplant-surgery testing has been completed, your case will be presented to the selection committee. The selection committee is made up of physicians, social workers, nurses, and other disciplines involved in transplantation. Once you are approved by the selection committee and are listed, your waiting time begins.

Living Donors

Living kidney donors are usually from the immediate family — mother, father, sisters, brothers, or children. They may also be cousins, aunts, or uncles. Frequently, a person will receive a kidney from a living but unrelated individual, such as a spouse, in-law, or even a friend.

There are several advantages to receiving a kidney from a living donor:

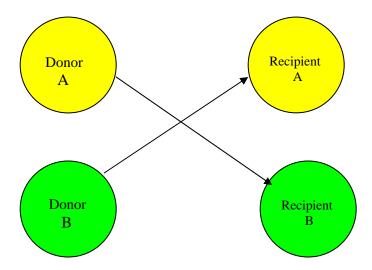
- Related living donors are more likely to be good matches, though it is not guaranteed.
- Transplant surgery can be scheduled with greater preparation
- The donation and transplant procedures take place at the same facility, eliminating delay in transporting the organ so it is in the best condition for transplant.
- A kidney from a living donor generally functions immediately after transplantation, while a deceased donor kidney may take longer to regain normal function.

For a healthy individual, donating a kidney is safe and recovery is rapid. Having only one kidney will not affect the donor's health in any way. For your new kidney to work properly, you and the donor's kidney must be blood-type compatible. To determine this compatibility, the following parameters may be used:

Blood Type	Can receive a kidney from blood type:	
0	0	O, A, B, AB
Α	A, O	A, AB
В	В, О	B, AB
AB	AB, A, B, O	AB

Paired Donation

This is sometimes referred to as "donor swaps" and can occur if a living donor and recipient are not compatible. In this case pair can enter the system, and periodic match runs will be performed to attempt to locate a pair(s) in a similar circumstance. This process enables two or more transplants to occur.



In the illustration above, Donor A and Recipient A were incompatible and Donor B and Recipient B were incompatible. However, Donor A was able to donate to Recipient B and Donor B was able to donate to Recipient A; therefore, a paired donation was able to take place.

Deceased Donors and Kidney Allocation

A majority of all kidney recipients receive organs from deceased donors. Because of a shortage in donor organs, the waiting period for a suitable deceased donor kidney may be two years or longer. In December 2014, the Kidney Allocation System (KAS) was revised. The primary goal was to make the system better without making major changes to the parts of the system more effective. People who are expected to need a kidney for the longest time will be matched more often with kidneys that have the longest expected function.

How will kidneys be classified?

Every kidney offered for a transplant will have a Kidney Donor Profile Index (KDPI) score. This is a percentage score that ranges from zero to 100 percent. The score is an estimate of how long the kidney is likely to function when compared to other kidneys.

What goes into a KDPI score?

The KDPI is calculated based on factors that affect how long a the kidney is long the kidney is likely to function. These factors include:

- 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 an estimate with how long the candidate will need a functioning kidney transplant when compared with other candidates.

What goes into an 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 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.

Some patients are hard to match with most kidney offers because they have uncommon blood types or likely to have an immune system rejection for most kidneys. The new system will seek to boost their chances of getting a matching offer.

Summary:

- The new system will give immune sensitized candidates more priority for kidneys they aren't likely to reject.
- People who have a slightly higher sensitivity will get slightly more priority than they would have under the previous system.
- People who are very highly sensitized (98 percent or above) will get much more priority.
- Kidneys that are offered first to highly sensitized candidates, but don't get accepted for them, will then be offered to other patients.
- If you began dialysis before you were listed for a transplant, your waiting time will now be calculated from your dialysis date. This is the most objective and consistent way to measure when your need for a transplant began.

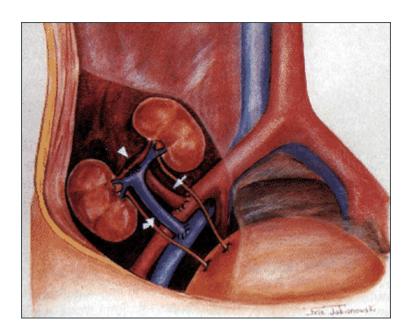
A transplant program may evaluate and list you for a transplant even before you start dialysis. If you are listed early, you can be matched for deceased donor kidneys based on medical matching criteria in the kidney allocation policy. You would not receive additional priority for waiting time until you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

Donation after cardiac death

Donation after cardiac death (DCD) is an option for families of patients who have had severe brain injuries but do not meet the criteria for brain death. After the decision has been made that this patient has no chance of surviving and the family has decided to withdraw treatment, the family is offered the option of DCD. Once the patient's heart stops beating, the physician declares death. Following an additional five minutes of waiting to ensure the heart does not start beating again, organ recovery begins and the organs are recovered. Typically these organs are placed on kidney pumps to evaluate and preserve their function until the transplant occurs. Improved medications and surgical techniques dramatically improve the outcomes of transplants from DCD donors.

Pediatric en bloc donors

These are kidneys from children, and they are too small to be transplanted individually. Pediatric kidneys are removed as a single unit and transplanted together in an adult to provide adequate organ function. They will continue to grow in size months after transplant.



Increased-risk donors

Increased-risk donors could be infected with HIV, viral hepatitis, or other viral or bacterial disease. The Public Health Service (PHS) has determined that increased-risk donors are those who meet any of the criteria listed below. There are no statistics currently available regarding the precise risk of an increased-risk donor actually having any of these diseases, and there are no tests available that can detect all diseases that a donor may have. Although rare — and with no known cases at our transplant center — there have been some reported cases of a blood test not detecting the presence of diseases in the donor.

In most instances, an infection is usually detectable in a donor's blood within three months of exposure. On rare occasions, it may still be undetectable up to one year after exposure. If a donor is tested during this time, he or she may test negative but be infected with a disease and be capable of transmitting that infection to a transplant recipient.

The PHS considers organ donors increased-risk if they meet any of the following criteria:

- People who have had sex with a person known or suspected to have HIV, HBV, or HCV infections in the preceding 12 months
- Men who have had sex with men (MSM) in the preceding 12 months
- Women who have had sex with a man with a history of MSM behavior in the preceding 12 months
- People who have had sex in exchange for money or drugs in the preceding 12 months
- People who have had sex with a person who had sex in exchange for money or drugs in the preceding 12 months
- People who have had sex with a person that has injected drugs by intravenous, intramuscular, or subcutaneous route for nonmedical reasons in the preceding 12 months
- A child who is <18 months of age and born to a mother known to be infected with, or at increased risk for HIV, HBV, or HCV infections
- A child who has been breastfed within the preceding 12 months and the mother is known to be infected with, or at increased risk for HIV infection
- People who have injected drugs by intravenous, intramuscular, or subcutaneous route for nonmedical reasons in the preceding 12 months
- People who have been in lockup, jail, prison, or a juvenile correctional facility for more than 72 hours in the preceding 12 months
- People who have been newly diagnosed with or have been treated for syphilis, gonorrhea, chlamydia, or genital ulcers in the preceding 12 months
- People whose medical/behavioral history cannot be obtained or risk factors cannot be determined, the donor should be considered at increased risk for HIV, HBV, and HCV infection because the donor's risk for infection is unknown
- People who cannot be tested for HIV, HBV, and HCV infection because of inadequate blood samples due to hemodilution (i.e. blood transfusions) that could result in false-negative tests

Donors who meet the following criterion should be identified as being at increased risk for recent HCV infection only:

• People who have been on hemodialysis in the preceding 12 months

The Waiting List

Once your name has been placed on the waiting list for a new kidney and/or pancreas, it may take several months or longer to locate the right one for you.

The waiting list is a nationwide computerized network called UNOS (United Network for Organ Sharing), to which all transplant centers in the U.S. belong. UNOS, which is supervised by the federal government, helps to ensure that patients throughout the country receive health organs as soon as they become available. Priority is given to patients who have waited the longest.

All patients awaiting organ transplantation are registered and listed nationally with UNOS. Local and regional lists may be accessed from the national list. A local list may include patients from several hospitals within a geographic area that is covered by one organ-procurement organization; the larger regional list may include all patients in several counties or even several states.

When patients awaiting transplant are entered into the UNOS computer, their HLA characteristics are also registered. Everyone has at least six important antigens; a "perfect match" occurs when the donor's six antigens match those of the recipient. When organs become available for transplantation, they are registered with the UNOS national computer to determine whether there is a perfectly matched recipient.

If a perfect match isn't available, organs are allocated based on a point system. To be as fair as possible, this point system is based on degree of mismatch — the lower the chances of a mismatch, the more points a patient awaiting transplant receives and the faster he or she is likely to receive a kidney and/or pancreas. The lower the point total, the longer the wait is likely to be.

Once a kidney and/or pancreas become available to you, you do not need to concern yourself with the characteristics of your donor. Your transplant team is experienced in all aspects of your transplant care and has your best interest in mind at all times.

Planning for Your Transplant Surgery

The Hardest Step of All

Until now, you have been moving full speed ahead in preparation for your surgery. But now all you can do is wait. The days and weeks may seem to drag by while the transplant team waits for UNOS to locate the appropriate organs for you. Try not to lose your momentum. Take positive steps to deal with the stresses of waiting and stay focused on reaching your destination. Remember — a healthier and more independent life is waiting for you.

Make a List and Pack Ahead of Time

Pack an overnight bag in advance. Make a list of items you will need in the hospital after your surgery, as well as the people you need to have contacted when you get the call that a kidney and/or pancreas is available. Give the list ahead of time to a family member or friend whom you can trust to pack any last-minute items and make the calls while you're on your way to the transplant center.

Be Ready to Move Fast

When you get that phone call, everything will seem like a blur. Suddenly, after what seems like months of standing still, you will have to move quickly. You must get to the transplant center without delay. When you get organs from a deceased donor, there is a time limit, so do as much as you can in advance to prepare for the last leg of this journey.

If Methodist Dallas Medical Center is Nearby

Choose a designated driver, if possible someone who will be nearby when you get the call. Know where this person is at all times so you can reach him or her by phone. Map out your route to the transplant center and check on lodging within driving distance of the transplant center. If your loved ones know where they will be staying when they arrive, they can relax and focus all of their attention on you and your surgery.

If Methodist Dallas is Far From Home

Plan to stay in the area for six weeks after transplant. Methodist Dallas has contracts with certain hotels, and the cost is \$35 a night during this six-week period for the patient and their spouse. Two additional guests may stay with you for an additional \$10 per night per person. The hotel costs are subject to change as our contracts are renegotiated. Be prepared to pay the entire bill when you check out.



Dealing with Stress

Waiting for your transplant can trigger feelings of stress and anxiety. The following strategies can help you manage your stress:

- Take care of yourself. Eat right, take prescribed medications, and follow a daily exercise program.
- Stay involved. To the best of your ability, keep up with your studies, work, and leisure activities. Just because you're waiting doesn't mean you have to put everything else on hold
- Share your feelings. If you feel depressed or uneasy, talk it out. Your transplant team can answer your questions, ease your fears, and help you cope. Your social worker and local clergy are more than good listeners. They can put you in touch with a support groups in your area.
- Find a creative outlet. If you have a hobby, enjoy it to the fullest. It will distract you and help you relax. Consider pursuing a new interest, something that will absorb your energy and leave you feeling fulfilled. Ask your doctor for guidelines on the kinds of activities that are right for you.
- Spend time with family and friends. Good company will take your mind off waiting as well as enrich your life. Laughter really is the best medicine.
- Learn relaxation techniques. Reading and listening to music or relaxation tapes can
 work wonders. If you are visually impaired, your local library can provide audiotapes
 of a variety of books.



Methodist Dallas Medical Center Kidney and Liver Transplant Education and Support Meeting

For patients, family and friends

Second Monday of Every Month

6:30 pm - 8:00 pm

Liver Institute
Methodist Dallas Medical Center
1411 N. Beckley Avenue
Pavilion III, 2nd Floor
Dallas, Texas 75203
214-947-4629



*Parking available in Parking Garage B, next to Pavilion III
Press button to get a ticket to enter garage
Please enter building through main door
Call **214-933-9667** if door is locked

When You Arrive at Methodist Dallas

When you arrive at Methodist Dallas, you will be directed to the Outpatient or Emergency Department for admission. There you will have a thorough physical examination, including blood work, chest X -ray, and EKG. You will have dialysis if you need it, and a final cross-match test will ensure that you and your new kidney and/or pancreas are compatible. Your transplant surgery will not take place if one of the following issues occurs:

- You have an infection or have developed any other medical problem that would interfere with surgery or recovery.
- Something is wrong with the donor or organ during the donor surgery.
- Your final cross-match test shows that there is a good chance your new kidney and/or pancreas will be rejected by your body.

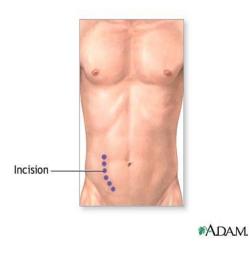
If surgery is postponed, your transplant team can help you through the disappointment. Remember, this is only a temporary setback. The search for a new organs kidney will go on, and none of the work you have done so far will be lost.

When Your Team Gives the Go-Ahead for Your Transplant Surgery

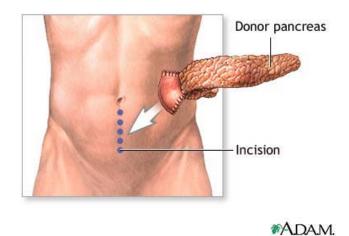
You may receive a sedative to help you relax and feel sleepy before you go to the operating room. When you awake from surgery, you will have a new kidney and/or pancreas and a new lease on life.

The Procedure

You will be under general anesthesia throughout your surgery. Once you are asleep, your transplant surgeon will make an incision 8 to 10 inches long, just above your groin. The surgical team will then attach the artery and vein of your new kidney to one of your arteries and veins, and they will attach the new kidney's ureter (the tube that carries urine to the bladder) to your bladder. If you still have one or both of your own kidneys, they will not be removed. The procedure usually takes about three hours to compl



Kidney transplant Incision



Pancreas and kidney/pancreas transplant incision

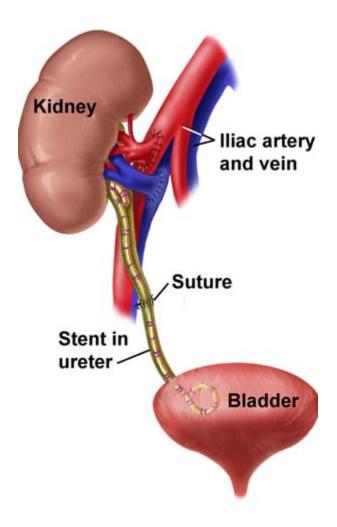
In the Intensive Care Unit

You will wake up in the intensive care unit (ICU) and stay there at least overnight. You will then be moved to the transplant floor to complete your hospital stay. This is what you can expect:

- You will feel pain and discomfort, but the medication you receive will help to relieve
 it.
- You may or may not feel nauseated from the anesthesia. If you do, it will wear off gradually. Tell your nurse so he or she can help you.
- You will be asked to cough periodically to keep your lungs clear. If it hurts to cough, ask someone to support your abdomen and back with his or her hands or a pillow.
- You will have a tube in your throat during surgery to help you breathe, but it will be removed before you wake up from surgery. Your throat may feel sore or scratchy for a few days after surgery.
- You may have a catheter inserted near your collarbone or in your neck that will help your transplant team keep an eye on your fluid levels and for medication administration. This catheter will come out several days after surgery.
- You will also have a catheter in your bladder to help you pass urine. It may feel uncomfortable and you may feel that you have to urinate constantly. It will be removed a few days after surgery.
- If you don't produce urine right away after surgery, you may need dialysis for a short time. Do not regard this as a setback or complication; the transplanted kidney can be temporarily "in shock" for a few days but then become fully functional.

Stents

During surgery, you may have a stent placed in your ureter (the duct that goes from the transplanted kidney to the bladder). This stent is a plastic tube that will keep the ureter open. Your urologist will decide when to remove it, which is usually four to six weeks after surgery.



The length of your hospital stay will depend on your progress. Barring complications, you could be released in about four to five days. Remember that procedures vary slightly from hospital to hospital. If you feel uneasy about anything that is happening to you, talk to someone on your transplant team. They care, and they're committed to making you feel as comfortable as possible until you go home.

Immunosuppressant Medications

Below is a list of immunosuppressants that are available. Typically patients take three of these immunosuppressants such as Prograf, Myfortic and Prednisone. Please keep in mind this will not be the only medications you will be taking after you receive your kidney.

<u>Prograf</u> (tacrolimus): Joins up with cells of your immune system that would ordinarily attack your transplant and turns them off.

Side Effects: Headache, insomnia, high blood pressure, mood swings, tremors, nausea and vomiting, diabetes or high blood sugar, increased risk of cancer.

<u>Myfortic</u> (mycophenolate): Decreases the number of white blood cells to prevent rejection.

Side Effects: Nausea and vomiting, diarrhea, decreased white blood cell count, and increased risk of cancer.

<u>Deltasone</u> (prednisone): Alters the action of the white blood cells to help your body prevent rejection.

Side Effects: Fluid retention, puffy cheeks, night sweats, mood elevation or depression, acne, increased appetite, increased blood sugar, cataracts, and increased risk of cancer especially skin cancer.

Other Immunosuppressants available:

<u>Cell Cept</u> (mycophenolate mofetil): Decreases the number of white blood cells to prevent rejection.

Side Effects: Nausea and vomiting, diarrhea, decreased white blood cell count, and increased risk of cancer.

Neoral (cyclosporine): Attacks specific cells in your blood stream to prevent rejection.

Side Effects: Tremors, elevated blood pressure, headaches, flushing of the skin, increased risk of cancer, kidney toxicity, swelling or bleeding of the gums, and increased growth of hair on face and chest.

Rapamune (sirolimus): Keeps your immune system from making a certain type of white blood cell that causes transplant rejection.

Side Effects: High cholesterol, high triglycerides, high blood pressure, low platelet count, low potassium, acne, anemia, joint pain, rash, diarrhea.

Post Transplant Follow Up Appointments

It will be necessary to attend frequent follow up appointments after your transplant to assure that your transplanted organ(s) are functioning properly. One of your medications will be adjusted based on blood levels so frequent blood tests will be required as well. The transplant team will inform you of lab or doctor appointments. You will need a driver to take you these appointments when you first leave the hospital until you are cleared to drive yourself. The time varies by patient.

In the beginning, it may seem like many visits to the lab and/or doctor but that will decrease over time when the team feels your transplant status is stable.

A Continuing Journey

Once your transplant surgery is behind you and you have made a strong recovery, you can look forward to years of good health and independence. Even though you have reached your goal, this is by no means the end of your journey.

You will be given another guide describing your care after your transplant surgery. This guide outlines the steps you should take from now on to stay well, and it provides information on programs and organizations that can help you stay healthy and happy.



MyChart Patient Portal

MyChart offers patients personalized and secure online access to portions of their medical records. It enables you to securely use the internet to help manage and receive information about your health. With MyChart, you can use the internet to:

- Request medical appointments
- View your health summary
- View test results
- Request prescription renewals
- Communicate electronically and securely with your physician office's care team.

Your provider is able to determine which types of test results are able to be accessed through MyChart. Further, tests of a sensitive nature are not released to MyChart.

Your test results are released to your MyChart account after a physician has reviewed them. This is generally within three to seven days.

MyChart is a free service offered to our patients.

All you have to do is register!

- 1. Go to MyChart.MethodistHealthSystem.org.
- 2. Click on "Sign Up Now" under "New User?"
- 3. If you have an activation code, enter it here alone with your Social Security number and date of birth. (If don't have an activation code or have lost yours, you can click on "Request Online" under "No Activation Code?" Then complete the form.)
- 4. Enter what you'd like to use for your username and password, as well as a security question and answer.
- 5. Decide if you'd like to opt in for email or text notifications.
- 6. Accept the terms and conditions.

The Organ Procurement and Transplant Network Toll-free Patient Services Line: Your Resource for Organ Transplant Information

If you have a question regarding your own medical care, you always should call your transplant hospital first. However, for general organ transplant-related information, you should call the Organ Procurement and Transplantation Network (OPTN) toll-free patient services line at 1-888-894-6361. Anyone, including potential transplant candidates, candidates, recipients, family members, friends, living donors, and donor family members, can call this number to:

- Talk about organ donation, living donation, the transplant process, the donation process, and transplant policies.
- Get a free patient information kit with helpful booklets, waiting list and transplant information, and a list of all transplant hospitals.
- Ask questions about the OPTN web site (http://optn.transplant.hrsa.gov/), the United Network for Organ Sharing (UNOS) web site (http://unos.org/), or the UNOS web site for living donors and transplant recipients. (http://www.transplantliving.org/).
- Learn how OPTN can help you.
- Talk about any concerns that you may have with a transplant hospital.

The nation's transplant system, the OPTN, is managed under a federal contract by the United Network for Organ Sharing (UNOS), which is a non-profit charitable organization. The OPTN helps create and define organ sharing policies that make the best use of donated organs. This process continuously evaluating new advances and discoveries so policies can be adapted to best serve patients waiting for transplants. To do so, the OPTN works closely with transplant professionals, transplant patients, transplant candidates, donor families, living donors, and the public. All transplant programs and organ procurement organizations throughout the country are OPTN members and are obligated to follow the policies the OPTN creates for allocating organs.

The OPTN are responsible for:

- Providing educational material for patients, the public, and professionals.
- Raising awareness of the need for donated organs and tissue.
- Coordinating organ procurement, matching, and placement.
- Collecting information about every organ transplant and donation that occurs in the United States.

Remember, you should contact your transplant hospital directly if you have questions or concerns about your own medical care including medical records, work-up progress, and test results.

OPTN/UNOS is not your transplant hospital, and staff at OPTN/UNOS will not be able to transfer you to your transplant hospital, so keep your transplant hospital's phone number handy. However, while you research your transplant needs and learn as much as you can about transplantation and donation, we welcome your call to our toll-free patient services line at 1-888-894-6361.

