Guide for Kidney Patients

and Their Families

Renewal

5904 13th Avenue
Brooklyn, NY 11219
718 431-9831
info@life-renewal.org

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Introduction

Renewal

Renewal is an organization dedicated to assisting people suffering from various forms of kidney disease and their families. Special attention is given to the orthodox community where there are many issues other than the actual referral of physicians and facilities.

If you are reading this booklet, you are probably considering donating one of your kidneys. At Renewal we aim to assist each and every donor with any help and support they may need. This includes learning about kidney donation, advice on how one can prepare oneself for the donating a kidney, compatibility, and any risks involved.

We have Rabbonim that have graciously agreed to make themselves available to answer questions you may have on any aspect of this most noble gesture. We also maintain a network of donors and recipients who have gone through the process and are most willing to share their experience. A comprehensive list of doctors and facilities is updated to help you receive the best level of care and see to it that the entire procedure is as minimally traumatic as possible. Hopefully, it will be a most uplifting experience and you will return to your normal daily routine in a relatively short time.

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Your Kidneys

Almost every person has two kidneys. They're in the middle of the abdomen in the back, and they're the size of a fist. They drain into two tubes called the ureters, which lead into the bladder.

The kidney is a very important organ, and the most obvious function is that it excretes wastes that we produce from our diet and from our metabolism. What's less obvious is that it's the most important organ that controls the composition of the body fluids. In addition, it does produce a number of hormones that deal with body function.

The kidney is a filtering organ, so blood is delivered to a very unique apparatus in the kidney called the glomerulus, and there, because of pressure dynamics, a component of the blood is filtered across the membrane, and the first process of creating the urine develops. In this segment of the kidney (the glomerulus), the composition of that fluid is very similar to blood. The fluid passes through a series of tubules in a structure called the nephron, and there it's heavily modified. A variety of things that we need are reabsorbed, and a variety of toxins are concentrated until the end of the kidney, and drains into something called a papilla, then into the ureter, and then the bladder, and we have what we term "urine," which is a fluid rich in toxic wastes that is excreted.

There are many segments of the kidney where illness can affect the function. For example, there are inflammatory disorders that affect the glomerulus. There are disorders that affect the tubules and the reabsorptive process. There are specific illnesses that affect the blood vessels that feed the kidney, and then, of course, there are problems with the drainage system and the ureters -- infection, stones, a variety of ailments.

An average human filters about two hundred quarts of blood through the kidneys each day, of which all but two quarts are reabsorbed, which is the urine. The human body has about five or six quarts of fluid to begin with. The kidneys are involved with minute-to-minute regulation of body fluids, so it's very important that a large quantity of fluid be processed, and that's the only way the kidney can control the minute-to-minute regulation. Another way of thinking about it is every time the heart beats, 20% of the blood flow goes directly to the kidney, so it receives more blood flow than any other organ in the body.

That would explain why high blood pressure, then, is so damaging to the kidneys, because there's already a tremendous amount of force of blood going through the kidney system. High blood pressure can be a cause of kidney disease, or a result of kidney disease, because many disorders of the kidney, as part of their features and their presentation, are related to blood pressure elevation. High blood pressure damages blood vessels so that the cardiac output can't get to the kidney and the kidneys lose their ability to act as a regulatory organ and as the kidney fails, the function of the kidney fails and we retain waste products. The hormone function deteriorates, the vitamin D levels go down, the erythropoietin levels go down, and the patients develop a progressive syndrome which we call uremia.

In addition to filtering waste from the body, the kidneys also regulate electrolytes in the body system. Suppose you drink a bottle of orange juice. The body sees a sudden excess of an electrolyte called potassium, so the kidney has sensors which look at the body fluid going through the kidney as plasma, and it detects that the plasma's potassium has gone up, and it immediately increases the excretion of potassium so everything returns to normal. And that's just one electrolyte that the kidney controls. There are at least a hundred elements and electrolytes that are controlled by the kidney.

The kidney also controls the production of red blood cells and controls the number of red cells in the body. It has sensors that look at the oxygen content of the blood flowing through it, and if it detects that

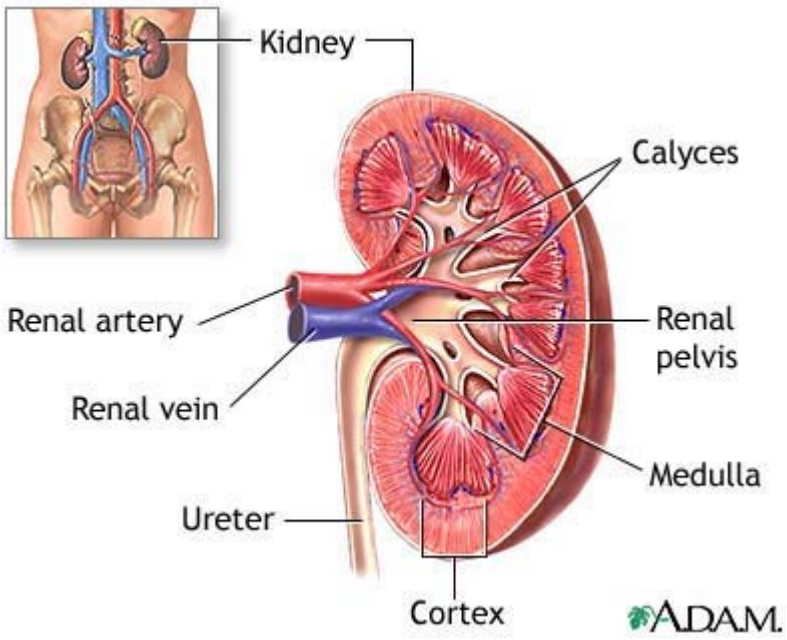
the oxygen concentration is low, it makes a hormone that increases the bone marrow's production capacity to make more red cells. The hormone level is critically important in people with normal kidney function, and people who have failing kidneys don't make this hormone, so one of the features of chronic kidney disease is the anemia that develops. Patients feel horribly fatigued and are unable to make red blood cells. The pharmaceutical industry has cloned the genes to make this hormone, and this medication replaces the natural hormone.

The kidney is also the main organ responsible for regulating the body's internal equilibrium - or the balance of all of our chemicals - and whatever we eat has to be modified by our metabolic process, and the waste products are excreted in the kidney. Without the function of the kidney, we couldn't regulate the levels of electrolytes and hormones and fluid balance.

The kidney makes the active form of vitamin D. Vitamin D exists in a number of different precursor forms ranging from the skin and the liver, and the kidney does the final biochemical modification to make the active form that acts on bones and intestines to absorb calcium and to regulate the control of parathyroid hormone. So in essence, this vitamin D is a regulatory hormone that has a variety of functions in the body. The ones we look at most are bones and calcium, but vitamin D also has some immunoregulatory activity and may be needed as a cancer protective mechanism. There is major research being done in terms of vitamin D metabolites being used as anticancer therapies.

In short, in addition to removing wastes and fluid from your body, your kidneys perform these other important jobs:

- Regulate your body water and other chemicals in your blood such as sodium, potassium, phosphorus and calcium
- Remove drugs and toxins introduced into your body
- Release hormones into your blood to help your body:
    1. regulate blood pressure
    2. make red blood cells
    3. promote strong bones.



Facts about Kidney Disease

More than ten million Americans have kidney problems. Some of these problems include: infections, kidney stones, kidney cancer and Polycystic Kidney Disease. Many people also have chronic kidney disease (CKD). When one has CKD, the kidneys do not work as well as they should. CKD can lead to kidney failure. Kidney failure can only be treated with dialysis or a kidney transplant. Here are some facts about kidney disease:

1. About 1 in 12 people in America has a kidney or urinary tract disease.
2. Over 20 million adults over age 20 have chronic kidney disease.
3. Diabetes is the number one cause of kidney failure. High blood pressure is number two.
4. Over 80,000 people die from kidney failure each year. Kidney disease is America's ninth leading cause of death.
5. There are 450,000 people being kept alive through dialysis or kidney transplants.
6. Over 65,000 patients are on the waiting list for a kidney transplant. Sadly, only 15,000 will get a new kidney this year.

Source: American Kidney Fund
http://www.kidneyfund.org/kf_disease.asp

Chronic Kidney Disease

An estimated 6.5 percent of adults 20 years of age and older have physiological evidence of chronic kidney disease (20 million adults).

Chronic or End-Stage Kidney Disease - ESKD (also known as End-Stage Renal Disease - ESRD) is a complete or near complete failure of the kidneys to function to excrete wastes, concentrate urine, and regulate electrolytes.

It is estimated that more than 1.2 million people worldwide suffer from end-stage renal disease (ESRD), a number that is growing at a rate of approximately six-to-seven percent annually. Additionally, the National Kidney Foundation (NKF) predicts that the number of kidney failure patients in the U.S. will double in the next ten years. This growth is influenced in part by diseases associated with the aging population such as diabetes and high blood pressure, two leading causes of ESRD.

End-stage kidney disease occurs when the kidneys are no longer able to function at a level that is necessary for day to day life. It usually occurs as chronic renal failure progresses to the point where kidney function is less than 15% of baseline. At this point, the kidney function is so low that without dialysis or kidney transplantation, complications are multiple and severe, and death will occur from accumulation of fluids and waste products in the body.

In the United States, more than 400,000 people are on long-term dialysis and more than 200,000 have a functioning transplanted kidney. ESKD almost always follows chronic kidney failure, which may exist for 10 to 20 years or more before progression to ESKD.

Chronic Kidney Disease Treatment

Treatment options for patients whose kidneys no longer function enough for them to live without renal therapy intervention are dialysis and kidney transplantation. Dialysis and transplantation are treatments used to replace lost kidney function. A successful transplant can help the patient return to a state of good health. A transplant is a treatment, however, not a cure.

There are two kinds of dialysis-Hemodialysis and Peritoneal Dialysis. Dialysis does some of the things a normal kidney does, such as: removes extra water from the body and removes the waste products that have built up in the blood. Hemodialysis is usually done in a dialysis center, where nurses and technicians do the dialysis treatment. There are some patients however who use this therapy at home. Peritoneal Dialysis is always done as a home therapy. This treatment is for patients who want to be more independent. Peritoneal dialysis is done at home and/or at work. The patient sees his/her doctor and nurse monthly.

Hemodialysis

This form of dialysis removes waste products from the blood by passing it out of the body, through a filtering system (dialyser) and returning it, cleaned, to the body.

The waste products pass through the membrane into a dialysis solution (dialysate), then out of the machine. The "clean" blood is carried on through and returned safely to the body.

This happens over and over again throughout the dialysis session. Each time the "clean" blood is returned to the body, it picks up more waste products from the cells it circulates through, and brings these newly-collected toxins back to the dialyser to be removed.

Fresh dialysate is passed through continuously, to make the rate of the cleaning process as fast as possible.

As well as cleaning the blood, the dialysis machine also removes excess water. This part of the process is called ultrafiltration which can be done separately without dialysis.

It takes about 4 hours (perhaps more) to complete a good session of hemodialysis, which needs to be done 3 times a week.

Nocturnal Hemodialysis

Hemodialysis is an intermittent process. Wastes accumulate between dialysis sessions and are removed by the dialysis procedure. Standard dialysis as practiced by most U.S. centers today consists of 3 treatments weekly, Mon-Wed-Fri or Tue-Thu-Sat, lasting typically 3-4 hours each. The 3-4 hour dialysis treatment is designed to remove 48-72 hour of wastes and fluids which have accumulated since the last

treatment. Removing this much waste and fluid accumulation in a short period of time can lead to blood pressure instability and a "washed out" feeling after the dialysis treatment.

Nocturnal hemodialysis is designed to shorten the time between dialysis sessions, usually 6 nights per week, and lengthen the time of dialysis, usually 8 hours, so that there is less accumulated waste and fluid to remove over a longer period of time. This leads to a gentler treatment which is better tolerated by most patients. Nocturnal hemodialysis is performed by the patient at home after sufficient training and certification.

With nocturnal hemodialysis, blood pressure is often normal with no medication, anemia is better needing less treatment with Epogen, diets and fluids are not restricted, sleep patterns return to normal and the patient's general sense of well being is increased.

Nocturnal hemodialysis has been found to improve the quality of sleep and daytime cognitive functioning. On quality-of-life questionnaires patients have reported significant improvement in most areas. Patients have noted increased energy levels, better appetites and improved skin color and condition. Diet is not restricted, and most patients are able to return to work.

Not all patients are good candidates for nocturnal hemodialysis as it takes motivation to care for oneself and attention to detail and procedure to perform a safe and effective dialysis treatment for oneself.

Peritoneal Dialysis (PD)

The inside of your abdomen is called the peritoneal cavity and it is lined with a thin membrane called the peritoneum. This membrane surrounds the intestines and other internal organs. In peritoneal dialysis, this cavity is filled with dialysis fluid which enters the body through a permanently implanted catheter.

Excess water and wastes pass from the blood through the peritoneum into the dialysis fluid. This fluid is then drained from the body and discarded. In most cases this treatment can be performed without assistance, at home or at work.

A tube called a catheter, made of soft, non-irritating plastic, is inserted in your abdomen below and to one side of your navel, and stays there as long as you are using this type of dialysis. The catheter may be inserted at the bedside using local anesthetic, or in the operating room, depending on what is best for the patient. The dialysis fluid flows into, and is drained out of, the peritoneal cavity through this special tube.

The insertion of the catheter may cause discomfort for a brief period, but peritoneal dialysis is not painful. However, care must be taken to avoid infection.

Peritoneal dialysis can provide good, efficient dialysis but needs to be monitored carefully. It needs to be performed daily with breaks only because of unusual circumstances.

Kidney Transplant

A kidney transplant is a surgical procedure to implant a healthy kidney into a patient with kidney failure.

Kidney transplants have now become almost commonplace, with a success rate that increases every year. There are people still alive who have had their new kidneys for more than 40 years. *(Catherine Paykin, Transplant Program Director for the National Kidney Foundation)*

In 2005 alone, there were more than 16,000 kidney transplants in the United States, according to the federal Organ Procurement and Transportation Network; about 6,000 more than all kidney transplants conducted between 1954 and 1973.

A transplant patient's chances of surviving with a successful graft are higher than ever. People undergoing a kidney transplant these days have a better than nine-in-10 chance of surviving, and a better than eight-in-10 chance their body will not reject the new organ, experts say.

There are a number of breakthroughs that have allowed the success rate to grow, chief among them the development of immunosuppressive drugs. These drugs trick the body into thinking the foreign organ is its own organ and not attacking it. Before the development of these drugs, transplants could only take place between identical twins or close family members. The refinement of those drugs now allows transplantation between completely unrelated people.

Another breakthrough involved the development of tissue typing. This let doctors better assess whether an organ from an unrelated donor stood a chance of surviving in a patient's body. Tissue typing is similar to blood typing, but much more complex. In blood typing, you have A, B and O, in tissue typing, there are now more than 300 types. Tissue typing and immune system suppression with drugs was first used in a human kidney transplant in 1962, paving the way for transplantation of other organs.

The 1960s provided breakthrough after breakthrough in the field -- the first liver transplant, the first pancreas transplant and the first heart transplant. But it wasn't until the 1980s that a pair of events -- one medical, the other governmental -- combined to make transplant science even more commonplace.

The first was the discovery and widespread use of the immunosuppressive drug cyclosporin, which was so effective in preventing rejection that it opened up a new era in transplant surgery. It made transplant surgery so successful that in 1984 Congress stepped in to create the Organ Procurement and Transportation Network to help patients in need of a transplant find donor organs. That ushered in a new wave of management and treatment of transplants.

In the 1980s, the federal government also made transplant surgery more available to all patients by allowing Medicare to pay up to 80 percent of the cost of immunosuppressive drugs. The drugs are so expensive that poorer people could not afford transplants. But the doctors argued that even though the drugs are so expensive, they are cheaper than going on dialysis.

The major problem now facing transplant doctors isn't a matter of death and rejection, but rather supply and demand. There is a critical shortage of available organs in the United States (http://www.unos.org). Currently there are more than 92,000 people waiting for an organ that could save their lives. This has caused doctors to go back to the use of living organ donors, something that the field had grown away from in the 1970s and 1980s with the successful use of organs from brain-dead donors.

Patients with chronic kidney disease can receive life-saving dialysis therapy until a donor becomes available. The donated kidney may be from:

- Living related donor -- genetically related to the recipient, like a parent, sibling, or offspring
- Living unrelated donor -- like a friend or spouse

- Deceased donor -- a recently deceased individual who has no known chronic kidney disease

The healthy kidney is transported in a cool saline solution that preserves the organ up to 48 hours. This gives time to perform blood and tissue donor-recipient matching tests, which are done before the operation.

The most common form of organ donation today is from people who have expressed a wish to donate their organs after their death. As a result of a severe shortage of non-living donors (most people needing a kidney transplant will be on a waiting list for one to three years), living donors are also used for about one-third of kidney donations.

According to the National Kidney Foundation, live kidney donation typically offers the recipient:

- a shorter wait for a new kidney
- a better match and less chance of rejection, and the possibility of taking fewer anti-rejection medications (if the donor is a close blood relative)
- the ability to plan the surgery on an elective basis, rather than as an emergency procedure whenever a kidney becomes available
- kidneys from living donors don't need to be transported from one site to another, so the kidney is in better condition when it is transplanted and it usually starts working right away (kidneys from non-living donors may not function normally for several days or even weeks)

According to UNOS more than 6,500 of the kidney transplants done in 2005 were from living donors (http://www.optn.org/latestData/step2.asp). Because people can live a normal life with only one kidney, healthy adults may choose to donate one of their two kidneys to a family member or friend.

Doctors at the University of Maryland Medical Center say that contrary to conventional thinking, a kidney transplant can significantly improve the heart function of people on dialysis with a serious form of heart failure. In a study published in the April 5, 2005 issue of the Journal of the American College of Cardiology, the researchers found that a majority of patients who had systolic heart failure, in which the heart's left ventricle was weak and not pumping blood efficiently, had a dramatic recovery after their kidney transplant.

Overall, after a kidney transplant, the heart's pumping ability improved in more than 86 percent of the patients. For 70 percent of the patients, pumping ability returned to normal or close to normal following the transplant. Even more dramatic, the majority of the patients with the worst heart failure (about 20 percent of those studied) regained significant cardiac function following the transplant.

Becoming a Donor

At most transplantation centers, acceptable living donors are usually between 18 and 60 years of age and have blood and tissue types compatible with the recipient. In some cases donors are older - with a mother donating a kidney to her child at age 62, and Fairview Health Services in Minnesota reporting that a donor was 75 years old. All living donors must be healthy and have excellent kidney function.
Most often the living donor is a close relative of the recipient, such as a parent, sibling, aunt, uncle, or grandparent. Sometimes, though, living unrelated donors with close emotional ties to the recipient could also be matching donors.

The safety of the donor is of the utmost importance. The donor should be assured that he or she will be evaluated by a kidney specialist to confirm suitability and safety for donation and surgery. Donating a kidney will not cause illness or disease.

Once a donor has recovered from the surgery, he or she is able to return to a normal lifestyle. As a matter of fact, the life expectancy of living donors is the same as if they had not donated. The remaining single kidney is able to meet the body's needs very well. It actually enlarges to do the work formerly shared by both kidneys. If the donor is a woman who wishes to have children in the future, studies have shown that kidney donation does not affect completion of a safe pregnancy.

The operation may be done as laparoscopic surgery, which involves a smaller incision, requires a shorter hospital stay, and allows for a faster recovery. Typically, the hospital stay for a living kidney donor is two to four days.

There are always possible risks with any surgery; however, these are reduced by the extensive evaluation done on all donors.

All medical expenses that are related to the evaluation of a potential donor, the transplant nephrectomy operation and hospitalization, and the immediate follow-up care of the potential donor, are paid completely by the potential recipient's insurance coverage. As a potential donor, you should not see any bills related to your medical evaluation or hospitalization for this possible transplant procedure.

"Donors subsequently felt an immense sense of personal satisfaction from donating." (Paul Gill, of the School of Nursing and Midwifery Studies – Cardiff University)

Risks to Donor

To quote medical literature and statistics is beyond the scope of this booklet. We will however, bring here from two sources which discuss the risks to the donor.
Following is a question asked of Jeff Punch, an Associate Professor and Chief of the Division of Transplantation, University of Michigan and his response:

Question:
I am contemplating on whether to donate my kidneys to my 16 year old niece. Her father was just ruled out and I am the next suitable match. What are the short and long term risks for myself? How long, on the average, can my niece last especially after being diagnosed with sclerosis of the kidney? She has post strep glumononephritis. I have a three year old…is it hereditary…my older sister has lupus and my youngest sister died of leukemia…is it worth it to donate given our family background and diagnosis? Thanks for reading.

Your swift response is most appreciated.

Answer:
The results with kidney transplantation from a living donor are excellent, and the risk to the donor is small. However, no one should feel coerced or compelled to donate a kidney. The short and long term risks are well documented. You will need to plan on 4 to 6 weeks off work, some pain and discomfort due to the incision, and you must spend time being carefully evaluated prior to being accepted as a potential donor. The mortality for the operation for the donor is estimated to be 0.03%, or one in 3,000 chance of

dying from the surgery. This risk is far less than the general mortality of an appendectomy, a hernia repair, or a gall bladder operation.
The mortality of a person on dialysis that is 0-19 years old is about 4% per year in the US. The average wait for a kidney in this state (Michigan) is about 3 years. However, dialysis is a very large imposition on one's life. Most people on dialysis spend at least 12 hours a week involved in some aspect of dialysis regardless of the type of dialysis they use. Even though survival may be good, the opportunity to lead a "normal teenage" life will be more difficult while on dialysis. For example, normal pubertal growth and maturation may not occur in a renal failure patient. On the other hand, a successful kidney transplant from a living donor may last for decades. In the case of a successful transplant, the recipient generally has few restrictions on their life. Most transplant patients say they feel much healthier, energetic, and well than when they were on dialysis.
Post strep glomerulonephritis is related to an infection, and is therefore not known to be hereditary to my knowledge. Part of the evaluation process of every potential living kidney donor is a careful investigation to exclude any potential donors that may have unsuspected underlying medical diseases that would make them at a higher risk to donate, and to exclude any familial kidney diseases.
The decision to donate a kidney is a very personal one. You must discuss it frankly with your immediate family members and with the physicians that would be performing the surgery, and decide for yourself if it is "worth it". For many, the chance to give such a priceless present to another human being is a once in a life time opportunity to feel really good about one's self.

Following is an article written by Dr. William M. Bennett, a nephrologist at Legacy Good Samaritan Hospital in Portland, Oregon:

What Are The Risks For A Living Donor In Kidney Transplant And How Are They Screened?

Interestingly, after losing a kidney to surgery, the remaining one usually gets bigger and takes over some of the function, especially in younger donors. Many people are born with only one kidney, so it's not unusual to be walking around with one kidney.

Most transplant centers are doing more and more living transplants. The donor's health becomes a concern because they are a patient too, and we wouldn't want to do anything that would jeopardize their health.

But living donors live as long as or longer than people who don't donate, probably because they are screened so thoroughly and not allowed to donate unless they are in perfect health.

Spousal transplants have become much more common. The motivation to do it is wonderful and I think it can be quite positive for both the donor and the recipient.

There is also a resurgence in interest in making life better for the donor. We have new techniques to make the donor operation much shorter, with a shorter hospital stay, with laparoscopic surgery - making it much easier on the donor. This is quite exciting.

Why Be a Donor

Each year, the number of end stage renal disease (ESRD) patients waiting for a transplant increases. According to the OPTN (The Organ Procurement and Transplantation Network) as of October 28, '05 there are 63,856 patients on the waiting list for a kidney transplant. (Source: http://www.optn.org). Each month, approximately 2,000 more names are added to the list.

The number one issue facing transplant today is the critical organ shortage. The kidney transplant wait list has increased at a much greater rate than the number of transplants performed. The persistent shortage of organs has challenged transplant patients and professionals to find alternative methods to increase organ donation. This unfortunate situation means that one might wait three years (or more) to receive a cadaveric kidney. Unfortunately, everyday over 10 people die while waiting for a vital organ transplant such as a heart, liver, kidney, pancreas, lung or bone marrow!

Because of the lack of available donors in this country, 3,886 kidney patients died in 2004 while waiting for life-saving transplants.

Live donor transplantation has become increasingly common, due in large part to the success of the procedure and the shortage of cadaveric organs. Living donation allows the immediate transplantation of kidneys into recipients so operations can be scheduled electively once a suitable living donor has been identified. This avoids the long waiting times encountered with cadaveric donation. At one time, only family members were considered for live donation. Now spouses and other non-related donors are considered. The longest functioning kidney transplants between people that are not identical twins were performed in the year 1963 and were still functioning as of 1998. In the year 2000, 5,300 of the more than 13,000 kidney transplants performed in the United States involved living donors. One year after surgery, 97.6 percent of kidneys transplanted from living donors were still functioning well.

More than 71,000 people across the country have undergone major surgery to give away an organ, according to the United Network for Organ Sharing (UNOS). Many came through the experience without serious problems. They have saved the lives of their mothers, sons, friends and even strangers.

Decisions about *any* major surgery need to be made thoughtfully in partnership with medical experts you know and trust. If you decide to pursue becoming a living kidney donor, start by talking with your family and your health care provider. Even if you are not a good match for your friend, or if your friend decides to explore other options, you can still donate your kidney to one of the many people suffering from severe kidney failure. Most people can donate. Those who can't, include anyone who has been treated for cancer, heart disease, high blood pressure, diabetes, kidney stones, HIV or other communicable diseases.

Once you receive a clean bill of health, it's time to contact a transplant center. Each transplant center has its own criteria for eligibility, which includes a visit to a psychiatrist or social worker to ensure, among other things, that the gesture is made freely and without coercion.

At Renewal we are available for you and you may feel free to discuss any concerns or issues you may have. Furthermore, should you need any referrals or guidance to a physician or medical facility, we will be more than glad to help you with that.

You are highly likely to recover quickly. You're in excellent condition or you wouldn't be allowed to donate. You've already been tested for the possibility of something going wrong with your remaining kidney in the future and have been medically cleared. Because this is voluntary or elective surgery, it can probably be scheduled in advance and take place at a time that works for you as well as the recipient.

Be advised that at all times you may decide that donating is not for you and there will be absolutely no coercion or any means of trying to convince you otherwise.

Make a list of all the questions you want answered. Some questions you may want to ask are – would I be able to stay active and exercise? Would I be able to continue drinking eight glasses of water a day? How

long is the recovery time? Be sure to write all the questions down as you think of them, otherwise you may not remember them.

Making the Choice to Donate

The following is based on an article written by a donor:

So you're thinking of donating? If you know of anyone who is suffering from kidney failure, then one thought will definitely be there. That is the thought of losing someone you know, with the knowledge that you can do something to save that individual. This person may be a friend, a family member, or a total stranger (as has happened quite often). In either case, the decision is not only a personal one but a family one as well. It is strongly suggested that you discuss the options with family and friends, as well as do your own research via doctor, transplant coordinators, or people who actually donated. Before going into deep thought about the situation, the first thing you should do is get your blood tested. Because no matter how much you may want to donate, unless you are the right blood type you can't.

Donor Testing

So you got your blood checked once. Your blood will be checked many more times for your blood type, blood sugar and many other things. But first, you will be introduced to your Transplant Coordinator. A transplant coordinator is like your mentor through the whole donation process. Your transplant coordinator will be there during before and after surgery. He/she will walk you through the whole process, talk with you about the process to make sure you have the mindset to donate and set a surgery date for you. After they double check your blood compatibility they will want to make sure you are not prone to diabetes. They will probably do a glucose analysis. Basically you drink a sweet syrupy drink and check you blood every half hour for about five hours. Next, believe it or not, they need to make sure that you actually have two kidneys. Sometimes people are born with one, (sometimes even three) and they aren't even aware of it. In order to do this they will give you a CT scan, MRI or something similar. A substance is injected into you as they run the x ray machine up and down your body and this actually takes a picture of your whole insides. This is also important because depending on your insides you may be able to do a laparoscopic donation rather than the traditional donation. Traditional surgery is a larger cut, with more time for recovery. Laparoscopic surgery entails smaller incisions and less recovery time. The whole testing process usually takes anywhere form 3 weeks to 3 months depending on the urgency of the donation.

The Surgery

The day before surgery, remember not too eat too much and you might be required to give yourself a fleet enema. You will most likely have the surgery early in the morning. Getting prepped actually takes about two hours. You and the recipient will be in the same room. The donor typically goes in about 2 1/2 hours prior to the recipient. The two are in adjacent operating rooms.

Recovery

When you're out you are not really aware of what the actual surgery was like, but the next day you do. It is common to have pain the first 48 hours after surgery. They doctors actually make you get up out of bed the night of or day after surgery, since they want the donor to get on the road to recovery (the recipient's surgery actually involves a lot less cutting). A catheter is inserted and is usually taken out after 24 - 48 hours. All in all, the average stay in the hospital is 2-5 days for laparoscopic and 5-9 days for traditional surgery. In the hospital friends and family are always welcome. Donating a kidney does not hold you back

from doing anything. The only thing is that if you are going to play physical sports, or engage in other activities, you need to be conscientious of the fact that you only have one kidney and don't let anyone hit you hard there.

Source: http://www.angelfire.com/md2/Kidney/

Compatibility and Ability to Donate

Living donor kidney transplantations are arranged after full evaluations of both the donor and recipient. Comprehensive evaluations of both individuals are completed prior to transplantation. These extensive evaluations ensure safety for both the donor and recipient. Blood and human leukocyte antigen (HLA) typing is done to make sure that the potential donor is a good match for the recipient. This matching process minimizes the risk that the organ will later be rejected by the recipient.

Blood Type (A, B, AB or O) Scientists have known for many years that blood group matching is important in transfusion and it is equally important in kidney transplantation. The basic donation pathways in kidney transplantation are very similar to those used in blood transfusions.

There are four major blood types in humans. These types are simply noted as blood type A, B, AB and O. Another factor, the Rh factor, adds a plus or a minus following the above blood type letter, so that all of us have a blood type such as A+ or B- and so on. This plus or minus factor, however, relates only to a particular cell type in the blood and this factor is not part of the kidney. Thus, the positive or negative feature in blood typing has nothing to do with the matching of a kidney between a donor and a recipient. It remains, however, important in matching when a blood transfusion is considered. Because the positive and negative features of a blood type are not important in kidney matching, we will not further mention that aspect of matching.

In most circumstances, the person with blood type O is the universal blood donor. This means that a person with blood type O may donate to a person with any other blood type. A person with blood type A may donate to a person with blood type A or AB and a person with blood type B may donate to a person with B or AB. A person with blood type AB may only donate to an individual who has that same blood type.

Looking at this from the recipient's point of view, a recipient with blood type O can receive a kidney only from a donor with blood type O. A recipient with blood type A may receive a kidney from a recipient with blood type O or A and a recipient with blood type B can receive a kidney from a donor with blood type O or B. Obviously, a recipient with blood type AB can receive a kidney from a person of any blood type.

The following chart illustrates which blood types are compatible with each other:

Recipient blood group	Donor blood group
O	O
A	A or O
B	B or O
AB	A, B, AB, or O

In general, hospitals will not do a transplant if the blood types do not match. But, there are facilities such as Presbyterian Hospital in NYC, Johns Hopkins, University of Minnesota, and others that do non-blood type match transplants, as well as non-matching antigens. And there is usually no problem getting follow-up back home afterwards from the nephrologist.

By filtering kidney patients' blood of antibodies that normally would reject a donor kidney, transplant surgeons have been successful in transplanting the organs between any two people regardless of blood type or prior exposure to their tissue type.

The natural antibodies (blood proteins) most people have would destroy an organ from someone of a different blood type, so transplant patients historically had to have a compatible blood type donor. But by filtering the blood of antibodies and giving patients a medication that prevents the antibodies from coming back, doctors are crossing these barriers.

Harmful antibodies are removed with a process called plasmapheresis, a procedure similar to dialysis that removes the plasma portion of the blood where antibodies are located. The number of plasmapheresis treatments required by the recipient before surgery varies depending on the amount of harmful antibodies in their blood.

After each plasmapheresis the recipient receives an intravenous infusion of immune globulin to replace antibodies needed to fight infections and help prevent harmful antibodies from returning. Once the antibodies against the donor's blood type decrease to very low levels, the transplantation can take place.

Worldwide experience shows that 82 percent of blood type incompatible kidney transplants are working one year after transplant and 78 percent are functioning five years after transplant.

HLA

Human Leukocyte Antigens (HLA), also known as histocompatibility antigens, are molecules found on all nucleated cells in the body. Histocompatibility antigens help the immune system to recognize whether or not a cell is foreign to the body. Human leukocyte antigens are used to determine the compatibility of kidneys for transplantation from one individual to another. The major groups of HLA antigens are HLA-A, HLA-B, and HLA-DR. Generally speaking, the smaller the number of HLA mismatches the better the compatibility between donor organ and recipient. These antigens are inherited

in a set of three from each parent (the set of HLA-A, B, and DR antigens received from a parent is called a haplotype).

In any given family there are several types of matches that can be found. A brother or sister of a patient has a one in four (25%) chance of being a full match. Parents are usually a half match for their children, and vice-versa. In a kidney transplant, a "perfect" match means that all six key HLA antigens match between donor and recipient. Fewer antigen matches mean a greater chance that the recipient's immune system may reject the transplanted organ. On average, a living donor kidney from even a completely non-blood related person will function better than most cadaveric kidneys.

The genetics involved can be complex, but the goal is to measure the number of "matching" antigens between the potential donor and the transplant recipient. The closer the "match", the more likely the success of the transplant. The numerous possible variations and combinations of antigens make this a very specialized and sometimes difficult testing process. For example, considering just the known serologically defined HLA-A, B and DR antigens, there are more than 3 billion possible combinations which can be theoretically assembled.

Crossmatch

As part of the donor-recipient testing, once the antigen "match" has been established, the laboratory does a pre-transplant "crossmatch." The crossmatch is a test which determines if the recipient has an antibody to the donor's HLA antigens and visa versa (donor to recipient). This is different from the HLA typing and matching process. The crossmatch helps to predict the likelihood of an immune reaction between donor-recipient pairs as a positive crossmatch can lead to transplant rejection.

Crossmatching is a very sensitive and final test performed on a kidney donor and a particular recipient. Laboratory techniques for crossmatching have been refined and now enable scientists and physicians to define how a kidney transplant recipient may respond to particular cells or proteins of the kidney donor. These refinements in testing have led to very accurate tests that were not available even a few short years ago.

The basic crossmatch test involves a mixing of cells and serum to determine whether or not the recipient of a kidney will respond to the transplanted organ by attempting to reject it. In recent years, scientists have applied more intricate tests and obtained more accurate results of crossmatching. This has allowed for a possible detection of a recipient who would reject an organ and therefore essentially prevent the transplant by indicating that rejection would occur. Thus, better kidney transplant outcomes may be due, at least in part, to our placing donor organs into recipients because we can much better determine and predict how the recipient may respond to that organ. Crossmatch testing, therefore, has come a long way and assisted all involved in transplantation in improving long-term results.

Crossmatch testing, which involves several different phases and, perhaps, as many as 10 to 15 different or separate tests, comes down to a fairly simple final result. Either the crossmatch is positive or negative. A positive crossmatch means that the recipient has responded to the donor and that the transplant should not be carried out. A negative crossmatch means that the recipient has not responded to the donor and therefore transplantation should be safe. While this language may appear a bit backwards, we should all think of a crossmatch as the test indicating a no go or go for a transplant operation. A positive crossmatch essentially says the following to a recipient: you will respond to the donor organ by rejecting it and the operation should not be performed. A negative crossmatch says to the recipient: you will not respond to the donor organ and the operation should be performed. If we look at the crossmatch in this way, the positive and negative results make sense to all concerned.

Donor Medical Evaluation

Once the decision is made as to who will be the potential donor, the medical evaluation of that donor can begin. If the donor lives a great distance away from the transplantation center, arrangements can be made to have most of the tests for this evaluation can take place close to the donor's home.

The potential donor's outpatient medical evaluation usually consists of the following:

- history and physical
- further blood tests
- urine studies – includes 24 hour collection of urine for creatinine clearance and total protein excretion
- chest x-ray, possible ultra sound of kidneys
- EKG; stress test if this is abnormal
- nephrology consult (kidney specialist who acts as the donor's doctor, not the recipient's doctor)
- psychosocial evaluation
- renal arteriogram (Special X-ray procedure to show the anatomy of the kidneys. It checks for blockages of renal arteries and renal function. The renal arteriogram is normally the last test before the decision to proceed to transplant).

These studies are performed to ensure that the donor is perfectly healthy with normally functioning kidneys. If there are any significant concerns, the potential donor will not be operated on.

Transplant Procedure (Donor)

Traditional

For the traditional donor nephrectomy (sometimes called "open" donor nephrectomy), the kidney is removed through a 4 to 8 inch incision in the flank area, right underneath the rib cage. In rare cases a section of the last rib may need to be removed. Loss of this rib does not cause any disability or additional discomfort. The average length of stay in the hospital is four to five days and return to work after discharge can be four to six weeks, especially if the job involves heavy lifting.

Advantages

1. The major advantage with this technique is the surgeon's ability to see and remove the kidney with minimal risk of trauma to the organ.

2. Most kidneys donated using this technique begin to function as soon as they are transplanted. This allows the recipient to begin taking immunosuppressive medication immediately, which decreases the chances of a rejection episode.

Disadvantages

1. The disadvantages associated with this approach are similar to any other surgical procedure that is done under general anesthesia. Many of these complications are preventable. Both pre-

admission and transplant staff will spend time educating donors as to their role and responsibility after surgery to help prevent complications. The most commonly reported complications are pneumonia, blood clots, constipation and infection.

2. The hospital stay is longer than most, and it will take time to return to a normal lifestyle.

Advanced - Laparoscopic

Some donors may qualify for an alternate procedure, the laparoscopic donor nephrectomy. This surgical approach takes approximately three to four hours.

Many hospitals now offer this new minimally invasive approach to living donor nephrectomy. In this approach, four or more small (approximately one inch) incisions are made in the abdominal wall. Video equipment and instruments are inserted through these punctures to visualize, dissect, clip, and staple. Once the kidney is freed from its attachments, it is extracted from the abdomen through a five- to seven-inch incision that extends slightly above and slightly below the belly button, and cooled. It is then prepared for immediate implantation into the recipient, following the donor surgery. This minimally invasive procedure results in less pain, a reduction in hospitalization from five days to two or three days and a return to normal activity in about a week for the donor. A donor whose work involves heavy lifting is still required to recover for six weeks before returning to full duty. However, many times employers will allow the donors to return to "light duty" until their six-week recovery is completed.

"The availability of laparoscopic kidney removal for living donors has led to a greater willingness by potential donors to step forward and undergo the procedure in order to help a loved one."
-Dr. Ronald Pelletier, Assistant Professor, Surgery – Ohio State University

Advantages

1. A shorter hospital stay
2. Decreased need for pain medication
3. Earlier return to activities of daily living
4. Earlier return to work

Disadvantages

1. The complication rate has been reported to be slightly higher than that of the traditional open donor nephrectomy. Some have reported a higher incidence of surgical damage to the blood vessels and ureter.
2. The requirement for blood transfusions has been slightly higher for those undergoing the laparoscopic procedure.
3. It has also been reported that the recipient's risk of delayed kidney function is higher due to decreased blood flow to the kidney when gas is placed in the abdomen of the donor. In addition there is some trauma to the kidney when it is removed from the small incisions. This may lead to a slow return of kidney function when the kidney is transplanted into the recipient. If this does

occur, the recipient is not able to start normal doses of immunosuppressive medication as quickly, which may account for higher incidence of rejection of the kidney after surgery.

Mini-Nephrectomy

One consequence of the wide acceptance of laparoscopic donor nephrectomy has been the development of mini-approaches to open donor nephrectomy. Donor mini-nephrectomy involves removing the donor kidney through a small abdominal incision. In contrast to traditional kidney surgery (using a 6-8 inch incision, overlying the rib cage), the mini-nephrectomy is performed through a 3-4 inch incision on the abdomen. The recovery time is quicker with mini-nephrectomy compared with the traditional approach.

There were no complications with mini-nephrectomy. No differences were noted in the recipient's kidney function with any approach. The donor's length of stay in the hospital ranged from 2-5 days in all groups. The average length of stay was reduced for Groups II and III compared with the traditional approach. No differences were observed for length of stay, the need for pain medication or return to work for the mini-nephrectomy compared with laparoscopic nephrectomy.

Mini-nephrectomy and laparoscopic donor nephrectomy are comparable procedures. Mini-nephrectomy is a retroperitoneal (situated behind the peritoneum) operation, which offers some advantages over the abdominal surgery required by laparoscopy. Recovery time for the donors and return to full activity is the same for both operations. Short-term benefits for the donor and long-term results for the kidney recipient are identical. The location of the incision (abdomen versus pubic region) is one of the few significant differences.

After the Operation

How does living donation affect the donor?

Studies have shown that one kidney is enough to keep the body healthy by removing wastes and excess fluid from the blood. Living donation does not change life expectancy, and after recovery from the surgery, living donors can continue to lead normal lives. The usual recovery time after the surgery is short, and donors can generally resume their normal home and work activities within 2 to 6 weeks (usually depending on procedure done).

People who give a kidney usually continue to live a normal, healthy life after the donation. However, there appears to be an increased risk of high blood pressure and extra protein in the urine beginning several decades after giving a kidney. Moreover, the decision to donate one kidney obviously results in an otherwise not needed operation, which leaves the donor with one instead of two kidneys. Consequently, the very unlikely but possible loss of the remaining kidney later in life (e.g., in an accident or because of a tumor) could leave the donor her- or himself in need of dialysis and transplantation.

It is also important to realize that, although living kidney transplants are highly successful, problems may occur. Sometimes, the kidney is lost to rejection, or the original disease that caused kidney failure may come back in the transplant, causing it to fail.

Doctors maintain that the donor would be able to maintain his/her lifestyle. They also say that in the case of a woman donor, she could still have children, but would be considered a higher risk pregnancy than if she had two kidneys. Pregnant women are prone to kidney infections.

Leann Slaby is the daughter of a diabetic that needed a kidney transplant. In 1997 she donated one of her kidneys. In an article written for the National Kidney Foundation, she writes "I've proven that a kidney donor can even do extraordinary things, like survive on a tropical island in the South Pacific for 30 days without the luxuries of home! Early in 2004, I was chosen to be a contestant on CBS's *Survivor: Vanuatu*, which finished airing in December 2004. In my audition tape, I mentioned that I donated my kidney to my father and that part of the reason for my application was to show people that you can live an ordinary or even extraordinary life after becoming a living donor. I thought that by going on the show, and getting people talking about organ donation could only be a good thing."

Additional Resources

The Transplant Patient Partnering Program
http://www.tppp.net/kidney.html
http://www.tppp.net/resources/links.html

TransWeb
The Northern Brewery
1327 Jones Drive, Suite 201
Ann Arbor, Michigan 48105
734-998-7314
http://www.transweb.org

National Kidney Foundation
731 James Street, Suite 200
Syracuse, NY 13203-2040
315-476-0311
Toll Free: 877-8KIDNEY
http://www.kidney.org

United Network for Organ Sharing (UNOS)
700 North 4th Street
Richmond, Virginia 23219
804-782-4800
http://www.unos.org

Transplant Living
888-894-6361
http://www.transplantliving.org

Coalition on Donation
700 North 4th Street
Richmond, VA 23219
804-782-4920
http://www.shareyourlife.org

Glossary

A

Acute Rejection
The host recognizes the graft as foreign and mounts an immunological attack on the graft tissues. Most acute rejections occur in the first year.

Allocation
The process of determining how organs are distributed. Allocation includes the system of policies and guidelines, which ensure that organs are distributed in an equitable, ethical and medically sound manner.

Allograft
An organ or tissue that is transplanted from one person to another of the same species: i.e. human-to-human. Example: a transplanted kidney.

Anti-Rejection Drugs (immunosuppressive drugs)
Drugs that are taken to help the body accept the transplanted organ.

Antibody
A protein molecule produced by the immune system in response to a foreign body, such as a virus or a transplanted organ. Since antibodies fight the transplanted organ and try to reject it, recipients are required to take anti-rejection (immunosuppressive) drugs.

Antigen
A foreign substance, such as proteins in a transplanted organ, that triggers an immune response. This response may be the production of antibodies, which try to destroy antigens and reject the transplanted organ.

B

Biopsy
A tissue sample from the body, removed and examined under a microscope to diagnose for disease, determine organ rejection, or assess donated organs or tissues.

Blood Vessels
The veins, arteries and capillaries through which blood flows in the body. Certain blood vessels can be donated and transplanted.

Brain Death
Irreversible cessation of cerebral and brain stem functions; characterized by absence of electrical activity in the brain, blood flow to the brain, and brain function as determined by clinical assessment of responses.

C

Cadaveric
Deceased.

Cadaveric Transplant
The transplant of an organ from a deceased donor. The preferred term is Deceased Donor Transplant.

Candidate
A person registered on the organ transplant waiting list. When an organ is offered on behalf of the candidate, he or she is then referred to as a Potential Transplant Recipient (PTR).

Cardiac
Having to do with, or referring to, the heart.

Chronic
Developing slowly and lasting for a long time, possibly the rest of a person's life. For example: chronic kidney failure.

Chronic Rejection
Slow, continuous immunological attack of the host immune system on the transplanted organ usually resulting in progressive loss of organ function.

Corticosteroid
A synthetic hormone, which stops the body's normal reaction to infection and foreign tissue, such as a transplanted organ. Prednisone is a corticosteroid.
Criteria (Medical Criteria)
A set of clinical or biologic standards or conditions that must be met.

Cyclosporine
A drug used to prevent rejection of the transplanted organ by suppressing the body's defense system. Considered an immunosuppressant.

D

Deceased Donor Transplant
The transplant of an organ from a deceased donor.

Deceased Donor
An individual whose tissues or organs are donated after suffering brain death or cardiac death.

Delayed Function
A condition in which the transplanted organ does not work well right after the transplant. Many kidneys have a delay before they begin to function well. Kidneys can sometimes take as long as three weeks to "wake up." Sometimes a kidney recipient needs dialysis until the kidney starts to work.

Department of Health and Human Services (HHS)
This department of the federal government is responsible for health-related programs and issues.

Dialysis
A mechanical process designed to partially perform kidney functions, including correcting the balance of fluids and chemicals in the body and removing wastes. See *Hemodialysis* and *Peritoneal Dialysis*.

Diastolic Blood Pressure
The bottom number in the blood pressure measurement (80 in a blood pressure of 120/80), indicating the pressure in the arteries when the heart is at rest.

Donor
Someone from whom an organ or tissue is removed for transplantation.

Donor Registries
Available 24 hours a day, seven days a week, online registries provide authorized professionals access to a confidential database of registered organ donors, allowing easy and quick confirmation of an individual's consent to organ donation. All registries are voluntary and some are affiliated with the local motor vehicle bureau, while others are independently operated.

E

ECG
Electrocardiogram.
End Stage Organ Disease
A disease that leads to the permanent failure of an organ and for which the patient requires dialysis or a transplant.

End Stage Renal Disease (ESRD) Program
Part of the Medicare program that provides medical coverage to people with end stage kidney disease or renal failure to help pay for dialysis or transplantation.

End Stage Renal Disease/Chronic Kidney Failure (ESRD)
Irreversible kidney failure.

Expanded Criteria Donor Kidney
A kidney donated for transplantation from any brain dead donor over the age of 60 years; or from a donor over the age of 50 years with two of the following: a history of hypertension, a terminal serum creatinine greater than or equal to 1.5 mg/dl, or death resulting from a cerebral vascular accident (stroke).

G

Genetic Matching
See tissue typing.

Glomerular Filtration Rate (GFR)
A measure used to determine kidney function, the GFR indicates the kidney's ability to filter and remove waste products.

Graft
A transplanted organ or tissue.

Graft Survival
The period of time an organ functions successfully after being transplanted. Graft survival is usually measured in one, three and five years time periods.

H

Health Maintenance Organization (HMO)
An insurance plan encompassing a network of health care providers including doctors, hospitals, pharmacies, and other medical facilities and professionals where an individual and his/her employer pay a fixed monthly fee for services, regardless of the level of care.

Hemodialysis
A treatment for kidney failure where the patient's blood is passed through a filtering membrane to remove excess fluid and wastes.

Histocompatibility
The examination of human leukocyte antigens (HLA) in a patient, often referred to as "tissue typing" or "genetic matching." Tissue typing is routinely performed for all donors and recipients in kidney and pancreas transplantation to help match the donor with the most suitable recipients to help decrease the likelihood of rejecting the transplanted organ.

Human Immunodeficiency Virus (HIV)
The virus destroys cells in the immune system, which makes it difficult for the body to fight off infections; toxins, or poisons; and diseases. HIV causes AIDS, a late stage of the virus characterized by serious infections, malignancies and neurological dysfunctions.

Hypertension
High blood pressure. Occurs when the force of the blood pushing against the walls of the blood vessels is higher than normal because the blood vessels have either become less elastic or have gotten smaller. Hypertension causes the heart to pump harder to move blood through the body. It can cause kidney failure and heart disease if not treated.

I

Immune Response
The body's natural defense against foreign objects or organisms, such as bacteria, viruses or transplanted organs or tissue.

Immune System
The organs, tissues, cells and cell products in your body that work to find and neutralize foreign substances including bacteria, viruses and transplanted organs.

Immunosuppression
Prevention or inhibition of the immune system to respond to foreign substances in the body. Medications often used to prevent a recipient's immune system from rejecting a transplanted organ or tissue include prednisone, methylprednisolone, azathioprine, mycophenolate mofetil, cyclosporine, tacrolimus, and sirolimus, among others.

Immunosuppressive
Relating to the weakening or reducing of your immune system's responses to foreign material; immunosuppressive drugs reduce your immune system's ability to reject a transplanted organ.

Infection
A condition that occurs when a foreign substance, such as bacteria, enters your body, causing your immune system to fight the intruder. All transplant recipients can get infections more easily because their immune systems are suppressed. It is more difficult for them to recover from infection (such as urinary tract infections, colds and the flu).

Inflammation
The swelling, heat and redness your body produces when it has an injury or infection.

Informed Consent
A person's voluntary agreement, based upon adequate knowledge and understanding of relevant information, to participate in research or to undergo a diagnostic, therapeutic, or preventive procedure.

Investigational
A drug or procedure that is not yet Federal Drug Administration (FDA) approved for marketing.

K

Kidneys
A pair of organs that remove wastes from your body through the production of urine. All of the blood in your body passes through the kidneys about 20 times every hour. Kidneys can be donated from living and cadaveric donors and transplanted into patients with kidney failure.

L

Leukocyte
A white blood cell.

Liver
The largest organ in the body, made up of a spongy mass of wedge-shaped lobes. The liver secretes bile, which aids in digestion, helps process proteins, carbohydrates, and fats, and stores substances like vitamins. It also removes wastes from the blood. A living donor can give part of their liver, after which the liver will regenerate itself in both the donor and recipient.

M

Match
The compatibility between the donor and the recipient. The more appropriate the match, the greater the chance of a successful transplant.

Multiple Listing
Being on the waiting list at more than one transplant center.

N

National Organ Transplant Act (NOTA)
Legislation that allows donor designation to be indicated on a driver's license or an official signed donor document, which gives hospitals legal authority to proceed with organ procurement, even against the wishes of the family. No additional consent form is required.

Noncompliance
1) Failure of patients to follow the instructions of the medical team.
2) Failure of OPTN members to adhere to the policies and bylaws of the OPTN.

O

Organ
A part of the body made up of tissues and cells that enable it to perform a particular function. Transplantable organs are the heart, liver, lungs, kidneys, pancreas and intestines.

Organ Donation
To give an organ or a part of an organ to be transplanted into another person. Organ donation can occur with a deceased donor, who can give kidneys, pancreas, liver, lungs, heart, intestinal organs, and with a live donor, who can give a kidney, or a portion of the liver, lung, or intestine.

Organ Preservation
Methods used to preserve organs while they are out of the body, between procurement from a donor and transplantation into a recipient.

Organ Procurement
The removal or retrieval of organs from a donor for transplantation.

Organ Procurement and Transplantation Network (OPTN)
In 1987, Congress passed the National Organ Transplant Act that mandated the establishment of the OPTN and Scientific Registry of Transplant Recipients. The purpose of the OPTN is to improve the effectiveness of the nation's organ procurement, donation and transplantation system by increasing the availability of and access to donor organs for patients with end-stage organ failure. The Act stipulated that the Network be a non-profit, private sector entity comprised of all U.S. transplant centers, organ procurement organizations and histocompatibility laboratories. These members along with professional and voluntary healthcare organizations and the representatives of the general public are governed by a Board of Directors which reports to the Division of Transplantation, HRSA and ultimately HHS. UNOS holds the OPTN contract.

Organ Procurement Organization (OPO)
An organization designated by the Centers for Medicare and Medicaid Services (CMS) and responsible for the procurement of organs for transplantation and the promotion of organ donation. OPOs serve as the vital link between the donor and recipient and are responsible for the identification of donors, and the retrieval, preservation and transportation of organs for transplantation. They are also involved in data follow-up regarding deceased organ donors. As a resource to the community OPOs engage in public education on the critical need for organ donation.

P

Panel Reactive Antibody (PRA)
The percent PRA value is a measure of a patient's level of sensitization to HLA antigens. It is the percentage of cells from a panel of blood donors against which a potential recipient's serum reacts. The PRA reflects the percentage of the general population that a potential recipient makes antibodies (is sensitized) against. For example, a patient with a PRA of 80 percent will be incompatible with 80 percent of potential donors. Kidney patients with a high PRA are given priority on the waiting list. The higher the PRA, the more sensitized a patient is to the general donor pool, and thus the more difficult it is

to find a suitable donor. A patient may become sensitized as a result of pregnancy, a blood transfusion, or a previous transplant.

Peritoneal dialysis
A treatment technique for kidney failure that uses the patient's own body tissues inside of the abdominal cavity to act as a filter. The intestines lie in the abdominal cavity, the space between the abdominal wall and the spine. A plastic tube called a "dialysis catheter" is placed through the abdominal wall into the abdominal cavity. A special fluid is then flushed into the abdominal cavity and washes around the intestines. The lining (peritoneum) of the abdominal cavity and of intra- abdominal organs act as a filter between this fluid and the blood stream. By using different types of solutions, waste products and excess water can be removed from the body through this process.

Plasmapheresis
A process in which plasma is removed from blood and the remaining components, mostly red blood cells, are returned to the donor. The process is used in transplantation to remove pre-formed antibodies.

Procurement
The surgical procedure of taking an organ from a donor. Also referred to as procurement and recovery.

Pulmonary
Having to do with, or referring to, the lungs.

R

Recipient
A person who receives a transplant.

Recovery (Organ)
The surgical procedure of removing an organ from a donor.

Rejection
A phenomenon that occurs when a recipient's immune system attacks a transplanted organ, tissue, or cell. Immunosuppressive drugs help prevent rejection.

Renal
Having to do with, or referring to, the kidneys.

Required Request
Hospitals must tell the families of suitable donors that their loved one's organs and tissues can be used for transplant. This law is expected to increase the number of donated organs and tissues for transplantation by giving more people the opportunity to donate.

Retransplantation
Due to rejection or failure of a transplanted organ, some patients receive another transplant after having returned to the waiting list.

Retrieval
The surgical procedure of taking an organ from a donor. Also referred to as procurement and recovery.

Risk Pools
State-created, nonprofit associations that do not require tax dollars for operational purposes. The risk pools are a temporary stopping place for individuals who are denied health insurance for medical reasons. Risk pools often help individuals who, because of their physical condition, are unable to purchase health insurance at any price.

S

Scientific Registry of Transplant Recipients (SRTR)
As called for by the National Organ Transplant Act (NOTA), the purpose of the SRTR is to provide ongoing evaluation of clinical data about donors, transplant candidates, and recipients, as well as patient and graft survival rates. The SRTR contains historical data from October 1, 1987 to present. The registry also tracks all transplant patients from the time of transplant through hospital discharge, and then annually, until graft failure or death. With oversight and funding from the Division of Transplantation, the SRTR is currently administered by University Renal Research and Education Association (URREA), in collaboration with the University of Michigan.

Steroids
Naturally occurring substances found in your body which include hormones that help control important bodily functions. Synthetic or man-made steroids can be used to suppress your immune system.

Survival Rates
Survival rates indicate what percentage of patients are alive or grafts (organs) are still functioning after a certain amount of time. Survival rates are used in developing OPTN policy. Because survival rates improve with technological and scientific advances, developing policies that reflect and respond to these advances are expected to also improve survival rates.

Systolic Blood Pressure
The top number in your blood pressure (the 120 in a blood pressure of 120/80) measures the maximum pressure exerted when the heart contracts.

T

Tissue
An organization of a great many similar cells that perform a special function. Examples of tissues that can be transplanted are blood, bones, bone marrow, corneas, heart valves, ligaments, saphenous veins, and tendons.

Tissue Typing
A blood test that helps evaluate how closely the tissues of the donor match those of the recipient.

U

Uniform Determination of Death Act (UDDA)
The National Organ Transplant Act (1984 Public Law 98-507), approved October 19, 1984 and amended in 1988 and 1990, outlawed the sale of human organs and provided for the establishment of the Task Force on Organ Transplantation; authorized the Secretary of HHS to make grants for the planning, establishment, and initial operation of qualified OPOs; and established the formation of the Organ Procurement and Transplantation Network (OPTN) and Scientific Registry of Transplant Recipients (SRTR).

United Network for Organ Sharing (UNOS)
The private, nonprofit membership organization that coordinates the nation's transplant system through HRSA's OPTN contract. As OPTN contractor, UNOS is responsible for meeting all contract requirements. As contractor since the first OPTN contract award in 1986, UNOS has established and strives to continually improve tools, systems and quality processes that support OPTN contract objectives and requirements. These include:
Managing the national organ transplant waiting list;
Collecting, managing and reporting of sensitive clinical data in a secure, fail-safe environment,
Facilitating an open, inclusive forum for development and continuous refinement of evidence-based policies and standards,
Member and policy performance assessment to ensure equitable, safe treatment of candidates and recipients,
Increasing donation and making the most of every organ that is donated through patient, public and professional education.

V

Vascular
Referring to blood vessels and circulation.

Ventilator
A machine that "breathes" for a patient when the patient is not able to breathe properly.

Virus
A group of tiny organisms capable of growing and copying themselves while living within cells of the body.

X

Xenograft
An organ or tissue procured from a different species for transplantation into a human.

Xenotransplantation
Transplantation of an animal organ into a human. Although xenotransplantation is highly experimental, many scientists view it as an eventual solution to the shortage of human organs.