

# Living Kidney Donors Network Resource Guide



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## Welcome to the Living Kidney Donors Network (LKDN) Resource Guide

The LKDN hopes you find this information helpful as you cope with your illness. This is a basic reference guide of information we have found in our own journey. Combine your own judgment with the advice of your health care provider to learn more about your options and to discover your best personal approach.

### Disclaimer:

**The Living Kidney Donors Network (LKDN) provides information and communication assistance concerning kidney transplants. Although every reasonable effort is made to present current and accurate information, no guarantee of any kind is made as to the accuracy of the information provided. Any links to external websites are provided as a courtesy and should not be construed as an endorsement by LKDN of their accuracy, content or views. The information provided is not intended, nor should it be considered medical advice. You should always consult your health care provider regarding living kidney donation, transplant or other medical concerns.**

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# Living Kidney Donors Network

## Harvey Mysel, Founder - Living Kidney Donors Network

The Living Kidney Donors Network (LKDN) was established to educate people in need of a kidney transplant about living kidney donation and help them communicate their need to their family members and friends.

After Harvey had proactively managed a kidney condition, (Polycystic Kidney Disease) for over 20 years he learned in 2006 that he was in need of a kidney transplant. Upon hearing this news, Harvey conducted extensive research to explore all options and create a successful action plan. During this process, he learned more about the benefits of living kidney donation compared to one from a deceased donor. He was fortunate that his wife, Amy, was a compatible donor.

Following his successful transplant, it became clear that the programs in place to increase the number of living kidney transplants were not achieving that goal. In 4 out of the previous 5 years, From 2008 to 2009, the number of living kidney transplants increased, however, in each of the previous 4 years, the of living kidney donations decreased, with the total number of transplants decreasing by more than 10%.

Many individuals are simply unaware or uninformed about living donation. The Living Kidney Donors Network Workshops, Webinars and Get–Togehters were developed to provide much needed education and support.

Currently, there are over 83,000 people on the kidney transplant waiting list, which is projected to grow to 100,000 in the next few years. The wait for a deceased donor organ typically exceeds 5 years. In 2009, over 4,600 people died while waiting for a kidney transplant.

Over 80% of the people on the waiting list are also on kidney dialysis. Being on dialysis negatively impacts kidney transplant success rates. One of the LKDN messages is to try and avoid being on dialysis, what is commonly referred to as having a preemptive transplant.

Becoming a living donor is a very personal decision. Donors learn about their recipients need either directly from that person or from someone close to them. However, if the person in need is unaware of the living donation process, the benefits of, or is intimidated by the thought of communicating their situation to others, someone who might be willing to donate never gets that chance.

Many people are unaware of the living donation process or the advances that have been made to make the procedure less invasive and finding a compatible donor easier. Educating someone in need will help empower them to pursue living donation.

- Many people think that finding a compatible donor is like winning the lottery. They are unaware that the anti-rejection drugs make it easier to find a compatible donor...a “perfect match” is no longer needed.

- The surgical procedure for the donor is a major surgical procedure, but “minimally invasive,” often done with a laparoscope, which reduced the amount of time the donor was in the hospital and the discomfort they experienced.
- Most people think that they have to “ask” someone to donate a kidney. When polled, people who donated say that they came forward themselves, when they heard of a friend or family member's need.

Research has shown that when someone is knowledgeable about living donation, they are more willing to talk about their situation.

## **Coaches & Mentoring Programs**

The Living Kidney Donors Network coaches and mentors are transplant recipients, living donors.

### **Coaches**

The Living Kidney Donors Network Coaches play an important role in the Workshops, Webinars and Get-Togethers. They help individuals identify and overcome the fears and concerns they have about letting others know about their condition. The workshops' small group setting, the Coaches help individuals draft talking points and work with them to practice their presentations. They provide constructive feedback on ways that participants can improve their communication skills. They also review good networking practices so everyone will be able to take the information they've learned about living donation, and be effective communicators about their need.

### **Mentors, for Recipients and Donors**

Recipients and donors will likely be going through a new experience. If they are willing to speak to someone who has been through the experience, the Living Kidney Donors Network will match up potential recipients and donors with people who have been there.

Having direct contact with someone who has been through the experiences can provide an important outlet. Barriers and resistance are removed quickly when speaking to a Mentor.

## Why is There Such a Need for Living Donors?

There have been many attempts to increase the number of organs available for transplant. The Health Resources and Services Administration, (HRSA) State Departments of Motor Vehicles, United Network for Organs Sharing, (UNOS) and many other federal, local and nonprofit organizations have developed programs to bring more attention to the growing need. Millions of dollars are spent on radio and TV commercials asking people to register to be an organ donor. These efforts have failed to increase the number of organs available to meet the demand. Even if **ALL** of the deceased donor organs were able to be used, there would not be enough organs available to meet the demand.

Recently, there have been many proposals to consider programs that would compensate donors. The mention of paying for organs is hotly debated and is not likely to be brought up as a serious option for some time.

As of mid 2011 there are over 90,000 people on the kidney transplant waiting list. The wait for a deceased donor could be 5+ years. Waiting times vary from region to region based upon your blood type and other factors.

The need is greater than the number of available deceased donor kidneys. As the waiting list continues to grow, wait times to receive a deceased donor kidney will naturally increase.

Kidney damage most often results from a chronic illness over a period of years causing kidney failure. The most common conditions causing end stage kidney failure and the need for a transplant are:

- Diabetes is a leading cause of chronic kidney failure in the United States. Chronic kidney failure is related to both type 1 and type 2 diabetes. The obesity epidemic, which often leads to diabetes, is becoming the major contributor to chronic kidney disease. (CKD)
- Elevated blood pressure can damage the kidney and ultimately result in the kidney's ability to filter waste from your blood.
- An enlarged prostate, kidney stones or tumors, or can result when urine backs up into your kidneys from your bladder, increasing pressure in your kidneys, reducing their function and causing kidney failure.
- There are many kidney diseases that inhibit the kidney's function. These include clusters of cysts in the kidneys (polycystic kidney disease), kidney infection and inflammation of the glomeruli, a condition that causes your kidneys to leak protein into your urine and damages nephrons.
- Kidney artery stenosis is a narrowing or blockage of the kidney (renal) artery before it enters your kidney, which impairs blood flow and leads to kidney damage.
- Toxins can develop from ongoing exposure to fuels and solvents, such as carbon tetrachloride, and lead — in lead-based paint, lead pipes, soldering materials, jewelry and even alcohol distilled in old car radiators — can lead to chronic kidney failure.

Chronic kidney failure is a gradual loss of your kidneys' filtering ability. When kidney function is seriously impaired, dangerous levels of fluid and waste can quickly accumulate in your body.

In the early stages of chronic kidney failure, you may have few signs or symptoms. Many people with chronic kidney failure don't realize they have a problem until their kidney function has decreased to less than 25 percent of normal.

# **An Overview of Living Kidney Transplantation**

Living donation occurs when a person decides to donate one of their kidneys to someone in need of a transplant. This is referred to as a directed donation, the donor has decided to donate to a specific person. Some people decide to donate to anyone who needs a kidney transplant, this is commonly referred to as an Altruistic or non directed donation. They do not specify who should receive their Gift.

Donating a kidney is the most frequent type of living organ donation and a living kidney transplant has the highest success rate of all transplant procedures. Other organs which can be donated via living donation are liver, lung, small bowel and pancreas.

Being born with one kidney is not as unusual as you might imagine. About 1 in every 750 people is born with one kidney, and their life expectancy is the same as someone who has 2 kidneys.

## **Who Can Donate a Kidney?**

A living kidney donation usually comes from a family member i.e. a parent, child, brother or sister or other relative. A donor can also be a spouse, friend or co-worker. Or it can be a stranger. A genetic link between donor and recipient, although beneficial, is not always required. This is largely due to improved anti-rejection medications. These type of “non related” transplants are becoming more common. Ten years ago almost 80% of the living kidney donations were from related donors, now, it is less than 60%.

A good living donor candidate is someone who is healthy, well-informed and makes a voluntary decision to donate one of their kidneys. Living donors must be over 18 and usually less than 70 years of age. They must be in good general health with no evidence of significant high blood pressure, diabetes, cancer, kidney disease, heart disease or hepatitis.

Several tests will be necessary to determine if their kidney is compatible with the intended recipient.

## **The Different Living Kidney Transplants are:**

### **Related**

Related living donors are healthy blood relatives of transplant candidates. They can be:

- brothers and sisters
- parents
- children over 18 years of age
- other blood relatives (aunts, uncles, cousins, half brothers and sisters, nieces and nephews)

### **Non-Related**

Unrelated living donors are healthy individuals emotionally close to, but not related by blood to transplant candidates. They can be:

- spouses
- in-law relatives

- close friends
- co-workers, neighbors or other acquaintances

### **Non-Directed (Altruistic)**

Non-directed donors are living donors who are not related to or known by the recipient, and make their donation purely out of selfless motives. This type of donation is also referred to as anonymous, altruistic, altruistic stranger, and stranger-to-stranger living donation.

Individuals who are interested in becoming non-directed donors should contact transplant centers in their area to discuss the possibility of becoming a donor.

### **Blood Type Incompatible**

This type of donation allows candidates to receive a kidney from a living donor who has an incompatible blood type. To prevent immediate rejection of the kidney, recipients undergo treatments before and after the transplant to remove harmful antibodies from the blood.

## Benefits of Living Donation

Kidney transplants has saved and improved the lives of people with kidney failure. Kidney donation from deceased donors has not been able to keep up with the need for kidney transplants. Over 4,500 people die every year waiting for a kidney transplant.

Living kidney donation has revolutionized kidney transplantation and is now preferred when compared to a deceased donor transplant. The real benefits of living donation are now recognized:

Living donation has many advantages:

- Living donation eliminates the recipient's need to wait for a transplant on the national waiting list.
- Short and long term survival rates are significantly better and provide a better outcome than transplants from deceased donors. (On average approximately 18 years for a kidney from a living donor, compared to 13 years for a kidney from a deceased donor).
- You know the donor, his/her lifestyle choices and history
- The kidneys almost always start functioning immediately, deceased donor kidneys can take from a few days up to a few weeks to start functioning. (Sleepy Kidney)
- Shortens the waiting time for others on the waiting list
- Health deteriorates the longer someone is on dialysis and each additional year someone is on dialysis their post transplant results are significantly poorer.
- A kidney transplant doubles the life expectancy compared to dialysis treatment.
- Kidney dialysis costs Medicare over \$3 Billion a year....about 6% of Medicare's **total** budget.
- May be able to avoid being on dialysis. Most patients find dialysis interferes with their daily life schedule, often making them unable to work full or part time.
- You have time to plan for the transplant
- Waiting for a deceased donor can be very stressful.
- The surgery can be scheduled at a mutually-agreed upon time rather than performed as an emergency operation.
- Perhaps the most important aspect of living donation is the psychological benefit. The recipient can experience positive feelings knowing that the gift came from a loved one or a caring stranger. The donor experiences the satisfaction of knowing that he or she has contributed to the improved health of the recipient.

There is little debate over the benefits of transplantation compared to being on kidney dialysis. Life expectancy figures comparing the two are surprising. A man between the ages of 40 – 45 could expect to live about 8 years on dialysis, if he were to receive a transplant, he could expect to live more than 20 years. Women who start dialysis between the ages of 55 – 59 could expect to live approx 5 years. However, they could live more than 16 years with a transplant, and someone's life would improve dramatically when they are not dependent on dialysis treatments.

## **Donor Information: Information you could hand out to someone showing an interest in donating.**

Making the decision to become a living kidney donor may be one of the biggest decisions a person can make during their lifetime. The decision must be a well-informed one that is “right” for the potential donor, and recipient.

Learn as much as you can about living donation. You can only make an informed decision by getting as much information as possible and discussing your interest with your family as well as your healthcare professionals.

**Your decision to become a living donor is a voluntary. Your health care team will remind you that you can change your mind at any time.**

Living kidney donor transplantation is possible because we are born with two kidneys. When surgeons remove a donor’s kidney, the remaining kidney grows to provide adequate kidney function.

Living kidney donor transplantation is the medically preferred alternative for someone who needs a kidney transplant... If a patient can receive a kidney from a relative or friend, he or she need not wait for a deceased donor organ to become available and kidneys from a living donor function better and survive longer than kidneys from a deceased donor.

### **Donor Risks**

The surgical risk to a living kidney donor is real but small. The removal of a kidney is a major surgical procedure and has the usual risks associated with any surgery. As with all major surgical procedures, you will experience pain. You may also have nausea or vomiting, and bloating. Other complications which can occur include infection, bleeding, pneumonia, blood clots or allergic reactions to medications. All of these complications are infrequent but are associated with any major operation.

Data from long term studies (see Supporting Documents,) on kidney donors are showing that kidney donors have a lifespan and hypertension rates comparable to the general population. Everyone’s health condition is different, and you should discuss these risks in more detail with your doctors.

After the transplant, donors should be more conscientious about following up with their health care providers on a regular basis. Prior to the transplant you should also evaluate your life, health, and disability insurance policies and make sure they have the necessary coverage in place before the donation.

The reference above to the health insurance is not related to the transplant. The recipients insurance should cover the cost of the transplant but you should confirm this with the hospital and insurance company. The donor’s health insurance information should not be requested by the hospital.

## **The Evaluation Process**

The evaluation process for a living kidney donation is different at each hospital, and can be done in 2 or 3 weeks if necessary, but it can take 2 to 4 months to complete. Many tests are done to determine if the donor is healthy enough to donate a kidney. These tests may be time consuming, and require travel and possibly time off from work. A suitable donor is someone that is healthy enough to donate. A suitable donor is deemed compatible if tests show that their kidney will not be rejected by the recipient.

The living donor candidate meets with different members of the healthcare team during the evaluation process. These may include nephrologists, transplant surgeons, clinical nurse specialists, nurse practitioners, social workers, transplant coordinators, cardiologists, psychologists and psychiatrists.

## **Psychosocial Assessment**

The donor candidate will also go through a psychosocial assessment:

- To give the potential donor an opportunity to express their feelings, motivations, or concerns
- To assess the donor's motivation
- To evaluate if there is any family pressure or financial incentive to donate
- To make sure the donor has all the necessary information to make a decision about donation
- To provide emotional support to the donor during and after the donation process
- To assist the donor in discussing their decision with their family and/or the potential transplant recipient

**Your decision to become a living donor is a voluntary. Your health care team will remind you that you can change your mind at any time.**

## **Assessment of General Health**

The potential donor undergoes a complete medical history review (including hereditary diseases) and a physical exam including several tests such blood, urine and X-rays. For example, an X-ray of the lungs may be done to determine if there are any abnormalities. Other tests such as electrocardiogram (ECG) may be done to assess heart function.

Other tests may include:

- Blood work
- A glucose test to rule out diabetes
- A glomerular filtration (GFR) test, which determines the level of your kidney function
- An electrocardiogram (EKG), which charts your heart's electrical activity to make sure there won't be any complications during surgery
- A 3-dimensional CAT scan to examine your kidneys to determine if there are any defects that may put you at risk for donor surgery
- Chest X-ray
- Blood pressure – sometime may involve wearing a blood pressure cuff over the course of a full day

- Other tests may be required by the hospital

Women will have the following additional tests:

- Pap test is a routine test in which a sample is taken from the uterine wall to check for abnormalities, such as pre-cancerous cells.
- Mammogram

## **Compatibility Tests**

Your blood type will be one of the early factors in determining who can receive your kidney.

First, a simple blood test is performed to determine your blood type and that of the recipient. Here's how your blood type should be compatible with the recipient's blood type:

If you have blood type A, your recipient should have blood type A or AB.

If you have blood type B, your recipient should have blood type B or AB.

If you have blood type AB, your recipient must have blood type AB.

If you have blood type O, you are a universal donor and can donate to someone of any blood type: A, B, AB or O.

Transplants are being done between recipients and donors who have incompatible blood types. The type of preconditioning done to cleanse the recipient's blood of antibodies depends on the patient's blood type and other factors. It usually involves some combination of the following therapies before transplantation:

- Plasmapheresis — to physically remove antibodies.
- Immunoglobulin — also called gamma globulin, which appears to decrease antibody activity destructive to the graft. The mechanism is poorly understood since gamma globulin are themselves antibodies that disarm foreign antigens by binding to them.
- Splenectomy — the spleen concentrates B lymphocytes around its blood vessels to fight infection so removing it in a person with very high levels of antibodies wards off graft rejection.

If your blood type is different from your donors', you should discuss ABO Incompatibility transplants or pair kidney exchange options with your transplant center.

If the basic health screening and laboratory tests are normal, more blood is drawn for testing to determine compatibility between donor and recipient. These special tests are called tissue typing and cross-matching, and they help to determine if the recipient may reject the kidney.

## **Tissue Typing**

Tissue Typing is a blood test that evaluates the compatibility or closeness between your tissues and the recipient's. A human lymphocyte antigen (HLA) blood test is used to determine tissue type and help ensure that you're a good genetic match for the recipient. In an HLA blood test, the tissue typing lab can identify and compare information about you and your recipient's

antigens (the "markers" in cells that stimulate antibody production) so they can match your kidney to the recipient.

While siblings (brothers and sisters) have the best chance of being a perfect match (6 of 6 antigens), advancements in anti-rejection medications have greatly reduced the occurrence of rejection in kidneys from unrelated donors and less of an emphasis is placed on Tissue Typing. A zero match does not necessarily preclude a person from being a donor. Researchers are also making strides in the development of treatments, which will significantly increase the donor success rate when tissue doesn't closely match.

### **Cross Matching**

In cross matching, your blood and the recipient's blood are placed together in a test tube and examined to see if there is cell damage. If all your cells survive, there is a negative cross match, which is considered a good result. If your cells begin to die, a positive cross match results and you are disqualified as a donor to that recipient.

# Aligning Yourself with a Transplant Hospital and Getting on the Transplant Waiting List

Once your doctor or nephrologist tells you that your kidney functions have declined to the point where you qualify, (or will qualify soon,) to be on the kidney transplant waiting list. What should you do?

1. You should learn as much as possible about the hospitals in your area and choose the one that best meets your needs and will be covered by your insurance company. Some insurance carriers require you to receive your transplant at specific hospitals in order for the procedure to be covered. You should make a list the qualities in the hospital and the staff that are important to you. Review the UNOS web site and the statistics they have on the transplant hospitals that you are evaluating.
2. Make an appointment to visit the hospital. During your visit, the hospital's transplant team will evaluate you (your medical history, current condition of health, and other factors) to determine if you would be a good candidate and qualify for a transplant. If living donation is of interest, express that to the staff. Although there are national standards, each hospital has their own criteria for accepting a patient for a living kidney transplant.
3. During the evaluation, you should learn as much as possible about that hospital and its transplant team.
4. If you are told that the hospital will not place you on the waiting list, or that you do not qualify for a living kidney transplant, review the reasons why and see if you could make lifestyle changes so you can qualify.

## Partial list of questions to ask, for you and to ask when visiting a transplant hospital: (Questions should be for you and your donor)

1. Will you be seeing the same doctors for your visits, pre and post transplant
2. How many surgeons perform kidney transplants and will you know which surgeon will be doing the surgery
3. How long will you be in the hospital
4. Review in detail the surgical procedures
5. Can you take a tour of the hospital rooms where you will be staying
6. Are there any visitor restrictions
7. What are their follow up requirements and how often will you be required to go to the hospital following your transplant and how much time will these follow up visits typically require?
8. How many of your types of procedures have the surgeons performed. (Don't be afraid to ask your surgeon how long they've been doing these procedures and their success rates)
9. What is their policy on evaluating potential donors? I.e. will they evaluate more than one donor at a time?
10. Will they council potential donors if they need to make some lifestyle changes to qualify to donate. (I.e. lose weight, lower blood pressure, etc.)
11. Do they have a Paired Kidney or a Domino Paired Kidney Exchange program?

12. Do they do blood donor incompatible transplants.
13. If you are sensitized, what program do they have to desensitize you?
14. Is there someone that can assist me with any financial issues I may have?
15. If you are using Medicare to pay for the transplant, what kind of help can they provide to support your effort to continue your prescription drugs after 3 years?
16. Who will be responsible for my follow-up medical care after my transplant has taken place, and for how long will you continue to come to the hospital for follow up?
17. How, and for how long will they follow up with your donor and what might not be covered under your insurance should the donor have any medical complications.
18. What is their policy on the use of steroids during the procedure and as part of your life-long medication plan?
19. Are there opportunities to participate in new drug trials?

### **How will I know that I am listed on the kidney transplant waiting list?**

Each hospital has their own criteria for listing patients. However, UNOS has developed listing guidelines. UNOS does not send patients written confirmation of their placement on the waiting list. Instead, patients should find out if they have been placed on the waiting list through their transplant hospital. If you have questions about your status on the list, you should ask the team at your transplant hospital.

## Matching Recipient & Donors

The terms “match”, “matching” or a “perfect match” are often misunderstood or misused when referring to a recipient and donor.

A clearer way of describing the evaluation process between a recipient and donor would be to use the terms, “suitable” and “compatible”. A suitable donor is someone that is healthy enough to donate. A donor is compatible when all the tests are finalized and a suitable donor is able to donate to their intended recipient.

The history of the term “match” comes from the 6 HLA antigens, (Human Leukocyte Antigens.) In the past, the recipients and donors 6 antigens needed to “match” in order for that donor and recipient transplant to be successful. The new anti rejection drugs are so effective, that there isn’t a statistical difference in success rates between a zero “match” and a 5 out of 6 “match.” Therefore, HLA matching typically is not a factor that determines whether someone is compatible. There is however, a benefit to having a “perfect match,” 6 out of 6 antigens. A “perfect match” results in a significantly longer survival of the donated kidney.

Donor/recipient compatibility is dependant on the following:

### BLOOD TYPE MATCHING

Scientists have known for many years that blood group matching is important in transfusion and it is equally important in kidney transplantation.

There are four major blood types. These types are simply noted as blood type A, B, AB and O. The positive or negative feature in blood typing is not a factor when determining compatibility between a donor and a recipient.

### Blood Type Compatibility Chart

Donor Can Donate to:		Recipient Can Receive From:		
Blood Type	Donate to	Recipient Blood Type	Recipient Blood Type	Can Receive Blood Type
O		A,B, AB, O	O	O (A)*
A		A or AB (O)*	A	A or O
B		B or AB	B	B or O
AB		AB	AB	A or B or AB or O

(Blood Type O is the **Universal Donor**: donors with O blood are compatible with any other blood type)

(Blood Type AB is the **Universal Recipient**: recipients with AB blood are compatible with any other blood type)

\* Recently, it has been discovered that some donors with blood type A may donate to a blood type O recipient. Person with blood type A or AB and someone 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.

## **PRA's - Panel Reactive Antibodies**

When it comes to pursuing a kidney transplant most people are thinking about finding a compatible donor. They don't realize that there is a test you need to take that will determine how easy or difficult it will be to find that compatible person. The test is called PRA.

PRA's, panel reactive antibodies is a blood test that measures the level of antibodies in the recipients blood. The more antibodies you have, the more difficult it will be to find a compatible donor. A person's PRA can be anywhere from 0% to 99%. Your PRA represents the percent of the U.S. population that the antibodies in your blood would react to and reject the kidney. For example, having a PRA of 25 means that 25% of the population will not be able to donate a kidney to you. The antibodies present in your blood would attack the transplanted kidney and can cause immediate rejection.

About 20% of the people who need a kidney transplant have high PRA's. Simply stated, having a high PRA will significantly limit the number of people that will be able to donate to you.

You can develop high PRA's from a blood transfusion, an earlier transplant or for some women, from being pregnant.

There are ways of lowering PRA's through a procedure called Plasmapheresis a blood-cleansing process that can lower the dangerous antibodies from the blood. Plasmapheresis is usually used when you have an incompatible living donor.

Plasmapheresis can also been used to allow blood-type incompatible donor/recipients to proceed with the transplant. Plasmapheresis can cost tens of thousands of dollars and are complex to administer.

If you've been told by a transplant center that you are too highly sensitized, (another term used to describe high PRA's,) to receive a transplant ask about Plasmapheresis. If they don't offer it there, speak to another transplant center.

## **CROSS MATCHING**

Cross matching is a very sensitive and final test performed on a kidney donor and a particular recipient. Laboratory techniques for cross matching 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 cross match 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 cross matching. It is now possible to better indentify a recipient who might reject an organ and thus avoid a transplant that might not succeed. Thus, improved kidney transplant outcomes may ensue because we can better determine and predict how the recipient may respond to the donated organ. Cross match testing, therefore, has evolved and improved long-term results.

Cross match testing, which involves several different phases and, as many as 10 to 15 different tests, comes down to a fairly simple final result. Either the cross match is positive or negative. A positive cross match means that the recipient has responded to the donor and that the transplant should not be carried out. A negative cross match means that the recipient has not responded to the donor and therefore transplantation should be safe. A positive cross match (not what you want,) essentially says that the recipient will respond to the donor organ by rejecting it and the operation should not be performed. A negative cross match says to the recipient, you are not likely to reject the donor organ and the operation should be performed. If we look at the cross match in this way, the positive and negative results make sense to all concerned.

A well matched kidney is one in which the blood type between the donor and recipient are compatible, the tissue typing well defined and hopefully well matched and all cross match studies are negative. Application of good matching studies in clinical kidney transplantation has allowed for excellent results using living donor and deceased donor organs and has permitted safe kidney transplantation for thousands of patients with end-stage renal failure.

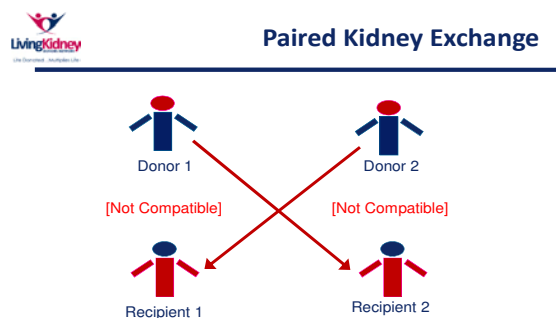
# Kidney Paired Donation

## Making Incompatible Donors Work

Kidney paired exchanges are becoming very common and an exciting option for kidney recipient and donor pairs who are not compatible with each other. Previously, people with kidney failure who had an incompatible donor were not able to benefit from the transplant being offered to them. However, kidney paired exchange programs are having a significant impact on the expanding options of living kidney transplants. Paired exchanges are now allowing transplants to occur between incompatible donor pairs and in a few unique ways.

### How Does a Kidney Paired Exchange Work?

A kidney paired exchange consists of two or more donor/recipient pairs who are not compatible with each other. Kidney paired exchanges are a major breakthrough in living donations and are revolutionizing living donor transplants by eliminating incompatibility as a barrier to donation and providing a way for recipients and their incompatible donor to be paired with another incompatible recipient and donor.

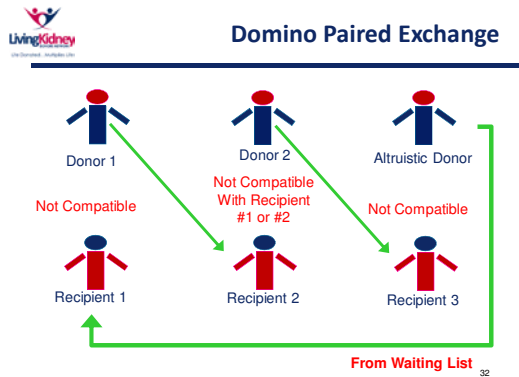


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In Pair 1, Donor 1 is not compatible with Recipient 1. In Pair 2, Donor 2 is not compatible with Recipient 2. However, Donor 1 is compatible with Recipient 2 and Donor 2 is compatible with Recipient 1. If you, your donor and the other pair are willing to participate in this “exchange,” a comprehensive evaluation process begins. The medical team will complete final medical tests and schedule the transplant on a date that works with everyone. Both transplants usually occur at the same day. This example used 2 pairs, but in fact any number of pairs is possible.

### Domino Kidney Paired Exchanges

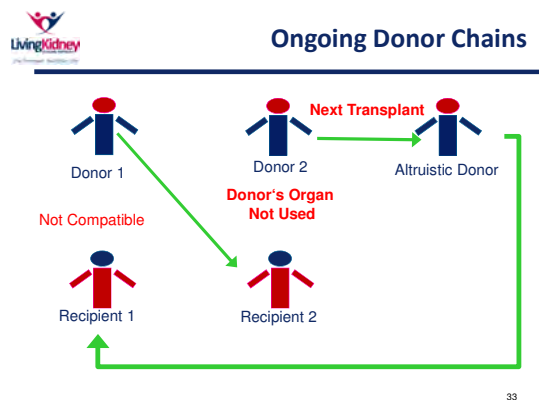
A domino kidney paired exchange starts with a non-directed or altruistic donor. Instead of just one person benefiting from their donation, this donor can allow many incompatible pairs to be transplanted. The difference in the example shown below from the “Kidney Paired Exchange” is that Donor #2 is not compatible with either recipient #1 or #2. As such, the altruistic donor allows the other pairs to be exchanged, and have the domino effect.



## Ongoing Donor Chains (Also called Never Ending Donor Chains)

Most recently, altruistic or non-directed donors have begun initiating donor chains which have the potential to facilitate thousands of additional living donor transplants.

In the example below, donor, #2 does not donate in this exchange. Donor #2 is referred to as the “bridge donor” for the next “chain”. Donor #2 functions in the same role as the altruistic donor in this example. This chain could continue, over and over again with a new bridge donor. This example uses 2 pairs and the altruistic donor, but any number of pairs could be transplanted.



## Compatible Paired Exchanges

Compatible donor/recipient pairs are being used to facilitate transplants with incompatible donor/recipient pairs. This benefits the compatible donor/recipient pair if the recipient receives a better HLA matched kidney, a kidney from a younger donor, or kidney that is a better size. The goal is to have all recipients benefit by participating in such an exchange. An ideal compatible donor/recipient pair is one where the donor is a blood type "O", and the potential recipient is blood type "A", "B", or "AB".

## Kidney Paired Exchange Programs

Many hospitals have their own kidney paired exchanges that they arrange within the incompatible pairs at their hospitals. The nature of kidney paired exchanges is that the likelihood of finding a compatible pair is increased when there are many incompatible pairs. There are organizations that “co-op” with other hospitals to increase the likelihood of being

“matched” with another incompatible pair. The following organizations have agreements with many hospitals in order to increase that likelihood.

National Kidney Registry [www.kidneyregistry.org](http://www.kidneyregistry.org) Contact: Diane Zocchia (631) 560-6836

The Alliance for Paired Donation [www.paireddonation.org](http://www.paireddonation.org) Contact: Laurie Reece 512-961-6199

The New England Paired Exchange Program [www.nepke.org](http://www.nepke.org) Contact: Ruthanne (800) 446-6362

## Medical Advocacy

Dealing with a chronic disease requires someone to acquire skills in self-advocacy. It is important for you to become your own medical advocate. You will need to speak up on your behalf. Don't be intimidated by the doctors or the nurses. They are there to diagnose and treat your condition, but they should also be there to explain the issues so you understand them. It is your responsibility to Advocate on your own behalf.

Having any debilitating illness, especially chronic kidney disease, (CKD) can make it very difficult to speak to the many doctors and nurses. You will need to speak with many people about matters that could be very personal, ones that are not easy to talk about, especially to virtual strangers. Also, repeating this information time and again can seem redundant and unnecessary. Your condition may be effecting how you feel, your ability to remember or recall the important facts may be frustrating.

In order to be informed about your condition and your options you need to be able to take part in the very discussions in planning for your treatment. It is your right, as much as it is your responsibility to be effective in communicating your condition and needs.

Ask to meet privately, or in a room where you feel comfortable. Don't be afraid to interrupt a doctor or nurse when they are speaking if you have a question. If you wait to ask, you may forget the question.

Let the doctors and nurses know that you have a list of questions to ask and you would like to review the ones that weren't addressed before they leave. Always come to an appointment with a list of questions, even if it is just one or two, write them down. In fact, you should use a separate notebook that is used only for medical questions and notes that are taken. You will have many appoints and keeping track of all of your questions, and answers will be very helpful.

Every time you have a medical test done, from a blood test to an MRI, a written record will be available. You should receive a copy of every report and keep track of the results.

Almost every medical situation or interaction can benefit from having an Advocate with you. It will give you a chance to consult on your questions about your health and to have your Advocate make sure that you've asked all your questions and your Advocate can listen to make sure you understand and remember the advice that is given.

Being an effective communicator, especially for your own health issues may not be easy, but is an essential part of experiencing positive results...and remember, being a good communicator usually means that you are a good listener too.

## Financial Side of Kidney Transplants

There are many ways to help pay for your kidney transplant. Private insurance, Medicare, Social Security, State programs, drug company assistance programs and private organizations all have programs that can help cover a kidney transplant. The recipients' insurance coverage usually pays for all medical costs for the recipient and the donor. **The recipient needs to pre-approve coverage prior to the procedure.** Your Transplant Coordinator should provide you with guidance on your coverage and other programs that are available

What is actually paid by insurance depends on your specific policy coverage plan. Your insurance policy manual or your insurance representative should explain any costs of transplant not covered by your insurance company—costs that you have to pay out of pocket. Some insurance policies may pay 100 percent of expenses, while others pay 80 percent or less.

There may be a cost to you if your insurance company does not approve the transplant at our center, or if your policy has limits on transplant services. Some insurance companies will only pay for a transplant if it is done at a center with which they have a contract.

The insurance benefits representative or your employee human resources department case manager are contacts who may be able to help you understand your specific coverage and limitations. Your insurance company phone number is usually on the back of your insurance identification card.

### Medicare – Part A & B

If you qualify for Medicare, Part A pays for inpatient hospital expenses and Part B pays for outpatient medical expenses. You must have Part A in order to receive Part B. Medicare Part B pays for most of the dialysis and transplant costs. There is a premium that you must pay for Part B coverage.

Medicare will pay for the anti-rejection medicines and other medical costs for three years. If you will use Medicare for your anti-rejection medicines you should speak to your social worker and start to make plans for when the Medicare coverage ends.

### Additional Programs

State medical assistance programs have different names. I.e. Medicaid, Public Aid or Public Assistance. Social Security benefits may be another way to receive some financial support. You can talk to your social worker to receive more information about financial assistance programs.

The following organizations have helped transplant recipients with the future cost of their anti rejection drugs:

### Financial Support

#### National Living Donor Assistance Center (NLDAC)

2461 S. Clark Street, Suite 640  
Arlington, VA 22202

703.414.1600

This program provides financial assistance to those who want to donate an organ, priority is given to individuals not otherwise able to afford the travel and subsistence expenses associated with living organ donation.

**National Foundation for Transplants**

1102 Brookfield, Ste. 200  
Memphis, TN 38119  
Contact: Janice Hill  
(800) 489-3863, (901) 684-1697  
(901) 684-1128  
[jhill@transplants.org](mailto:jhill@transplants.org)  
[www.transplants.org](http://www.transplants.org)

NFT helps establish fundraising campaigns in patient communities.

**National Transplant Assistance Fund**

150 N. Radnor Chester Road  
Suite F-120  
Radnor, PA 19087  
(610) 535-6105, (800) 642-8399  
(610) 535-6106  
[lsamson@transplantfund.org](mailto:lsamson@transplantfund.org)  
[www.transplantfund.org](http://www.transplantfund.org)

**Nielsen Organ Transplant Foundation**

Provides financial assistance to pre- and post-transplant patients in the NE Florida area.  
580 W. 8th St.  
Jacksonville, FL 32209  
(904) 244-9823  
[www.notf.org](http://www.notf.org)

**National Foundation for Transplants**

1102 Brookfield, Ste. 200  
Memphis, TN 38119  
Contact: Janice Hill  
(800) 489-3863, (901) 684-1697  
(901) 684-1128  
[jhill@transplants.org](mailto:jhill@transplants.org)  
[www.transplants.org](http://www.transplants.org)

**American Kidney Fund**

6110 Executive Blvd., Ste. 1010  
Rockville, MD 20852  
Phone Number (800) 638-8299

Web Address: [www.akfinc.org](http://www.akfinc.org)

**Georgia Transplant Foundation (GTF)**

6600 Peachtree Dunwoody Road  
600 Embassy Row, Suite 250  
Atlanta, GA 30328  
866.428.9411

GTF is focused on providing both financial and educational assistance during a time that is often overwhelming for those undergoing or waiting for a transplant.

**This was developed by UNOS**

<http://www.transplantliving.org/beforethetransplant/finance/directory.aspx>

**This information was developed by the National Kidney Foundation**

<http://www.kidney.org/transplantation/livingdonors/pdf/FinancialResourcesLivingDonation.pdf>

**Prescription Drug Assistance**

Patient assistance programs for prescribed immunosuppressive medications are available by contacting:

**Roche Patient Assistance Program (Cellcept)**

(800) 772-5790

**Novartis Patient Assistance Program (Cyclosporine)**

(888) 455-6655

**Novartis Transplant Reimbursement Information (Neoral)**

(877) 952-1000

**Astellas Patient Assistance Program (Prograf)**

(800) 477-6472

**Abbott Patient Assistance Program (Gengraf)**

(800) 633-9110

**Wyeth** <http://www.wyeth.com>

**Needy Meds** <http://www.needymeds.com/>

**Transplant Foundation, Inc** <http://transplantfoundation.org/>

**The Medicine Program** <http://www.themedicineprogram.com/>

## **Donor Leave Laws**

In 1999 Congress passed legislation granting federal employees 30 days paid leave if they serve as organ donors. The leave does not affect annual or sick leave which the employees may have already accrued. Some states have begun to replicate the legislation, making such leave available to state employees. Wisconsin, for example, enacted organ donor leave legislation in May 2000, granting state employees 30 day paid leave to facilitate living organ donation. Maryland followed suit, enacting donor leave legislation in October. The states of Delaware, New York, Texas, and Virginia have had legislation introduced addressing state organ donor leave.

## **State Leave Laws Related to Medical Donors**

State laws are constantly changing. You should check the current federal and state laws. The following information should be helpful, but you'll need to confirm what the status is in your state.

## The United Network for Organ Sharing (UNOS)

UNOS' main responsibility is to coordinate the transplant waiting lists and to facilitate the deceased donor transplants. However, they are developing policies for living donation and may start to play a larger role in setting living donation policies.

UNOS coordinates the nation's organ transplant system, providing vital services to meet the needs of men, women and children awaiting lifesaving organ transplants. Based in Richmond, Va., UNOS is a private, nonprofit membership organization. UNOS members encompass every transplant hospital, tissue matching laboratory and organ procurement organization in the United States, as well as voluntary health and professional societies, ethicists, transplant patients and organ donor advocates.

Under contract with the U.S. Department of Health and Human Services' Health Services & Resources Administration (HRSA), the United Network for Organ Sharing (UNOS) maintains a centralized computer network linking all organ procurement organizations, (OPO's) and transplant centers. This computer network is accessible 24 hours a day, seven days a week, with organ placement specialists in the UNOS Organ Center always available to answer questions.

After being referred by a doctor, a transplant center evaluates the possible transplant. The transplant center runs a number of tests and considers the patient's mental and physical health, as well as his or her social support system. If the center determines that the patient is a transplant candidate, they will add the patient's medical profile to the national patient waiting list for organ transplant. The patient is **not** placed on a ranked list at that time. Rather, the patient's name is added to the "pool" of patients waiting.

When a deceased organ donor is identified, a transplant coordinator from an OPO's accesses the UNOS computer. Each patient in the "pool" is matched by the computer against the donor characteristics. The computer then generates a ranked list of patients for each organ that is procured from that donor in ranked order according to organ allocation policies. Factors affecting ranking may include tissue match, blood type, length of time on the waiting list, immune status and the distance between the potential recipient and the donor. For heart, liver, and intestines, the potential recipient's degree of medical urgency is also considered. Therefore, the computer generates a differently ranked list of patients for each donor organ matched.

The organ is offered to the transplant team of the first person on the list. Often, the top patient will **not** get the organ for one of several reasons. When a patient is selected, he or she must be available, healthy enough to undergo major surgery, and willing to be transplanted immediately. Also, a laboratory test to measure compatibility between the donor and recipient may be necessary. For example, patients with high antibody levels often prove incompatible to the donor organ and **cannot** receive the organ because the patient's immune system would reject it.

Once a patient is selected and contacted and all testing is complete, surgery is scheduled and the transplant takes place.

# Pursuing a Living Kidney Transplant

## Getting Started Suggestions

There are many reasons why someone who is in need of a kidney transplant does not pursue a living kidney transplant. The two most common obstacles are, not knowing all the facts about living donation and apprehension about asking someone to donate. Learning about living kidney transplants is the first step to success, second is to develop a clear message letting other people know about your need. The more knowledge you have about living kidney donation, the more likely you'll be willing to discuss your need with other people.

Kidney donation is a Gift of Love, and Gifts are given, not asked for. Every donor/recipient story is unique. However, when polled, donors say that they offered to donate after hearing about their family member or friend's situation. However, someone who might be willing to donate is unable to do so unless they know about your need.

### Developing Your Game Plan

1. Learn as much as you can about the living kidney donation process. The more you know about living kidney donation, the easier it will be to talk about your situation.
2. Form a team of people that will help you. The more people helping you achieve your goal the better your chances are of being successful. If you are not prepared to be the team leader, a family member or friend could help.
  - a. Personal Advocates – Friends and family members that will help spread the word about your need.
  - b. Medical Advocates – Someone who will be with you during your medical appointments.
  - c. Medical Team – Doctors, nurses, social workers. They are there to answer your questions.
3. Develop a list of people and organizations that you want to contact.
4. If someone from the media wants to write a story about you, be prepared and provide them with some written material about your condition. Reach out to local newspapers or schools and churches that have newsletters. They might be interested in writing "your story."
5. Online groups, Facebook etc. are outlets where your story could appear.
6. Know what you'll say when you meet people. You are always given the opportunity to let others know about your need....every day you are asked, "how are you," or "what's new." If you are prepared, you'll be able to tell "your story."
7. Many people "get lucky" when they let others know about their condition. **"Luck Happens when Preparation Opportunity."**

### Telling "Your Story" don't "Ask" someone to donate:

1. The first few people you speak to will probably be the hardest as you struggle with the words. Speak from your heart. Find a person who will listen with support and encouragement, then role play with that person until you feel comfortable conveying your message.
2. Start talking to family members and friends. Get comfortable telling your story.

## Reaching Out

1. Most people say that it gets easier each time you speak to someone else. Be open and honest. Speak from your heart. The more people you speak to not only increases the likelihood that someone will offer to learn more about your situation, but will also increase the number of people that you could lean on for support.
2. It is important when talking to family members, that you do not pressure anyone to donate. The decision to donate is a personal one, any outside pressure is inappropriate and may cause long lasting personal and family problems. Also, you should make it clear to anyone who shows an interest in donating that they can change their mind at any time and you will respect and accept that decision.
3. Local radio and television stations may be interested in doing a story about you. Many media companies have a “Health Editor” who may already know, (from reading other stories,) about the challenges facing people who need a kidney transplant. A local story will not only reinforce to the people who already know about your situation, but could also reach other people who you know, but are still unaware of your condition.
4. To help media outlets show an interest in you, write out “your story.”
5. Schools, churches, community centers, not-for-profit and many other organizations have newsletters. They may be interested in writing a story about you.
6. Reach out to your place of worship and to other organizations. The clergyman can inform the congregation of your need. You may want to post information on their bulletin board.
7. Using the internet and email isn’t for everyone. Understand the risks and rewards from using these mediums.

## When Someone Offers to Donate, What’s the Next Step?

The first thing you’ll want to do is thank that person. You will want to express to them that at any time and for any reason if they feel that they do not want to continue with the process that they will always have that option. There’s a chance that someone that offers to donate may not be medically suitable to be a donor. If someone is not suitable, they could still help you by advocating on your behalf. You could provide them with the name of the donor transplant coordinator at your hospital to discuss the evaluation process.

Just because one person offers to be a donor doesn’t mean you stop the process of reaching out. You want to have backups in case that person doesn’t work out. It might take a month or more for someone to be evaluated. Don’t lose that time should they not be a suitable donor, healthy enough to donate. Also, ask your hospital about their evaluation process. There isn’t a national standard for evaluating donors. Each hospital has their own policy.

## What To Do First

The old saying, “every journey starts with the first step” has meaning for you and your journey. Your first step should be a small one. Don’t try to accomplish too much. Take small steps, or even just one step. Choose one new idea and try it out. Gain some confidence and momentum with a few small successes, then move on to another. Share your successes and challenges with others. Support them, and they’ll support you too.

# Communicating Your Need

## Talking Points for Discussing Living Kidney Donation

Most people feel comfortable talking about topics they are familiar with and where they have some personal knowledge. The more you know about a certain subject, the easier it is to talk about it. The same holds true with telling people about your need for a kidney transplant. The more you know about living kidney donations, the easier it will be to talk about your condition.

Speak from your heart. If the words you are expressing are not sincere, the person you are speaking to will know.

Practice what you want to say to someone. Find a person who will listen with support and encouragement, then role play with that person until you feel comfortable conveying your message.

The following talking points should help you develop what you want to say about your condition.

### Primary Topics

- Briefly, tell your story, how you came to be in need a transplant, your current physical condition
- Why you need a transplant...how it will help
- The Waiting List
- Benefits of a Transplant & Living Donation
- Most healthy people can Donate

### Secondary Topics

- Talk about “matching”, and how it has changed.
- An overview of the surgical procedures
- Make sure you allow the person to ask questions...if they interrupt, give them the chance to speak and wait to finish your point
- If they start asking questions about living donation in a way that makes you think they might be interested, make it clear that you are not asking for an answer now
- When someone offers to be a donor, or to be tested, you want to let them know that at any time they could change their mind and that they will not owe you an explanation why. That you’ve just decided it is not for you at this time.

### Elevator Speech Guidelines

The term, “Elevator Speech” is used to describe a situation where you know that you might only have 30 seconds to minute to convey a message, you’ll need to make just a few points to highlight your situation with the hope that you might have an opportunity to expand on the conversation at some other time or the person you are talking to decides to ask more

questions. Your goal should be to make 2 or 3 quick points that will be of interest to the listener. Sometimes an Elevator Speech immediately develops into a full conversation.

Following are some guidelines to help you create a brief communication regarding your transplant needs:

- Basic background on your health condition.
- Explain why you need a transplant; how it will help.
- Describe waiting list times or how your health will likely deteriorate the longer you wait.
- Appreciate their interest, wish them well.

When the listener seems particularly interested, you can add some of this detail:

- Many people are healthy enough to donate. (Provide more information about living donation if there seems to be an interest.)
- Benefits of receiving a kidney from a living donor as compared to one from a deceased donor
- An overview of the surgical procedures
- Make sure you allow the person to ask questions...if they interrupt, give them the chance to speak. (Offer to share materials later)
- If their comments make you think they might be interested in donation, make it clear that you are not asking for an answer now, that you are grateful that they want to learn more.

## Links to Other Organizations

### Educational

Transplant Experience

[www.transplantexperience.com](http://www.transplantexperience.com)

Transplant Living

[www.transplantliving.org](http://www.transplantliving.org)

American Association of Kidney Patients

[www.aakp.org](http://www.aakp.org)

Living Organ Donor Advocate Program

<http://www.lodap.com/>

Living Donors Online

[www.livingdonorsonline.org/general.htm](http://www.livingdonorsonline.org/general.htm)

TransWeb

[www.transweb.org](http://www.transweb.org)

A nonprofit educational web site about transplantation and donation

National Kidney Foundation

[www.kidney.org/transplantation/livingDonors/about.cfm](http://www.kidney.org/transplantation/livingDonors/about.cfm)

Transplant Recipients International Organization, Inc

[www.trioweb.org](http://www.trioweb.org)

Transplant Success

<http://www.transplantsuccess.org/index.html>

American Society of Transplantation

[www.a-s-t.org](http://www.a-s-t.org)

National Donor Memorial

[www.donormemorial.org](http://www.donormemorial.org)

How Transplants Work

<http://health.howstuffworks.com/organ-transplant.htm>

Transplant [Success promotes organ donation awareness through shared personal experiences](http://www.transplantsuccess.org/)

<http://www.transplantsuccess.org/>

### You Tube Videos

Altruistic Donor Interview

[http://www.youtube.com/watch?v=TeKsX1\\_kT9k&feature=channel](http://www.youtube.com/watch?v=TeKsX1_kT9k&feature=channel)

## **Inspirational Film**

<http://decisiontodonate.com/>

## **Paired Kidney Exchange Programs**

National Kidney Registry

[www.kidneyregistry.org](http://www.kidneyregistry.org)

## **Governmental & other Informational Web Sites**

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

[www.unos.org](http://www.unos.org)

U.S National Institutes for Health

<http://clinicaltrials.gov/>

NIH has developed this site to provide patients, family members and members of the public current information about clinical research studies.

Clinical Trials Listing Service

<http://www.centerwatch.com/>

National Clinical Trials Listing Service. A for-profit company providing industry, patient and public clinical research information.

U.S. Government Site on Organ Donation

[www.organdonor.gov](http://www.organdonor.gov)

Medicare

[www.medicare.gov](http://www.medicare.gov)

## **Online Communities**

Transplant Buddies

<http://www.transplantbuddies.org>

Matching Donors

[www.matchingdonors.com](http://www.matchingdonors.com)

Living Donors Online

[www.livingdonorsonline.org](http://www.livingdonorsonline.org)

## **FAQ's**

### **Who can donate?**

Donors are often a close relative such as a parent, brother or sister, son or daughter but may also be individuals who are not related but have an established emotional relationship with the recipient such as a partner or close friend. Sometimes a donor and a recipient may be incompatible with each other because of blood group or tissue-type and in this case it may be possible for them to be paired with another donor and recipient in the same situation. This means that each recipient will benefit from a transplant that they would otherwise not have had (this is called paired donation). Donors may also offer to give a kidney to someone who is on the waiting list for a transplant but whom they have never met before (this is called non-directed altruistic donation).

### **How will I know if I am suitable to donate?**

You will have a thorough medical and surgical and psychological assessment to establish that you are fit and healthy to donate. A number of people who wish to donate find that they are not able to do so because health problems are discovered through the assessment process. Members of the healthcare team involved in your assessment include counselors, coordinators and social workers.

### **Are there any risks to me?**

All operations carry some risk and this is no different for living donation. Donors are at risk of infections (eg chest, wound or urine) and, more rarely, bleeding or blood clots. There is a very small risk of death for the donor: this is estimated at 1 in 10,000 for this operation.

### **Are there any long-term risks?**

There is a possibility of a rise in blood pressure and excess protein in your urine. However studies have shown that there is no long-term effect on the health of the donor or your remaining kidney.

### **Am I at greater risk of developing kidney failure?**

You are at no greater risk of developing kidney failure after donating than anyone in the general population.

### **Will it shorten my lifespan?**

Studies have shown that donors live longer than the average population. This is because donors are selected on the basis of good health and are thoroughly screened prior to donation.

### **Will I have to change my lifestyle after donating?**

No. You should lead a normal healthy life as before.

### **Will donating my kidney affect a future pregnancy or fathering a child?**

The small amount of data available shows that, having donated one kidney, there is no evidence to suggest an increased risk of complications during pregnancy. A man's fertility will not be affected.

### **What if I live in a different part of the county from the person I am donating to?**

You can still donate. The transplant team can arrange for your donor assessment to take place at a hospital near you if that is more convenient for you. Usually the donation will take place in the hospital where the person you are donating to is cared for. However, different arrangements can be made depending upon individual circumstances for both the donor and recipient. There are organizations that could help you with the travel and living expenses.

### **How long does the donor assessment process take?**

This varies. You should check with your hospital. In general, this will take at two to six weeks. There is variation depending upon where you live and what tests you may require. Wherever possible, the assessment is tailored to your needs and commitments.

### **How much time will I need to take off work?**

Most transplant centers will try to arrange the tests before the operation around your work schedule to minimize disruption to your job. It is sometimes possible to arrange for some of this to be done locally if the donor lives a long way from the transplant center. The operation and recovery period varies depending on surgery, your individual recovery and the type of work you will be resuming. Many people that have a desk job are back to work in three weeks. If you job is physically demanding, you might need six weeks or more to fully recover.

### **How long will I be in hospital?**

This varies depending on your individual recovery. Many donors only spend one day in the hospital. It is not uncommon for someone to have to spend 2 or 3 days in the hospital to recover.

### **Will I need to take any medication after donating?**

You will need to take some painkillers immediately after the operation and during the recovery period. However, you will not need any long-term medication as a result of kidney donation.

### **What about follow-up?**

You would usually be seen by the transplant team between two and six weeks after donation.

### **Do some donors have trouble making the decision?**

Some people make the decision easily. Others go through some soul searching before deciding. Being afraid of donating a kidney or feeling guilty about not wanting to donate is quite normal. The only "right" decision is the one that makes you, the potential donor, feel comfortable. Finding out more information about living donation and what it involves may help you with this decision.

**Can I speak to somebody who has donated?**

Your coordinator at your local transplant center should be able to arrange this for you.

**Suppose I decide against being a donor?**

You have the right to withdraw your offer at any time and you would be supported in your decision by the transplant team.

# The Legal Side of Donation

## National Organ Transplant Act (NOTA)

### Background

**Rationale.** To ensure an equitable distribution of organs for transplant, Congress established a regionalized system of organ distribution in 1984. However, despite this system, by the mid-1990's, more than 4,000 potential transplant patients still died each year waiting for organs. With the objective of increasing cadaveric organ transplants, further rules were developed to ensure that families of dying patients were better informed about the potential benefits of organ donations.

**Statutory Authority.** The National Organ Transplant Act of 1984 created the Organ Procurement and Transplantation Network (OPTN); two major sets of amendments have been enacted subsequently. The most recent set of final rules for OPTN were issued April 2, 1998 (63 FR 16296) and became effective on July 1, 1998. There are parallel state laws governing organ transplants, but the most recent rules for OPTN for the first time included a preemption provision so that states could not interfere with OPTN policies that require organ sharing across state lines. Rules regarding hospital notification of families of potential donors were issued on June 22, 1998 (63 FR 33856) and became effective August 21, 1998.

**Key Elements.** OPTN provides a regionalized system of organ distribution using a system of Organ Procurement Organizations (OPOs) which by law have a monopoly in the geographic areas they cover. A central feature of the National Organ Transplant Act of 1984 was a prohibition on the buying or selling of human organs for transplantation; in contrast, most state laws governing organ donations contained no such prohibition (Kaserman and Barnett 2002). The notification regulations require hospitals to have an agreement with an Organ Procurement Organization (OPO) under which the hospital would contact the OPO about patients who die or whose death is imminent in the hospital (42 CFR Part 482). The rule further requires hospitals to notify the family of each potential donors of their option to donate tissue or organs and to educate staff about these issues.

**Scope.** The rules regarding organ transplants and notification of potential donor families cover all hospitals participating in Medicare, nearly 4,900 short-term general hospitals nationwide.

**Enforcement.** OPTN is a private, not-for-profit organization designated by the Secretary of Health and Human Services; regulations provide for specified representation of various groups on the Board of Directors. Funding for OPTN is provided through HRSA's Office of Special Programs. However, CMS also is indirectly responsible for enforcement of these rules, since the standard Medicare Conditions of Participation for hospitals require them to establish arrangements with their local OPO and notify families of potential donors. Failure to comply with these rules thus would jeopardize Medicare and Medicaid funding for transplant hospitals. In addition, buying or selling organs is designated as a felony offense.

## Theoretical Impact

Costs. The ban on organ sales reduces the number of organs available for transplant and results in the death or worse health status for those who otherwise might have benefited from these organs. The notification rules impose process requirements on all hospitals. The rules are designed to increase organ donations; this increases the annual number of transplants performed, thereby increasing costs for hospital and physician services.

The **Living Kidney Organ Donation Clarification Act** (H.R. 710: Charlie W. *Norwood* Living Organ Donation Act.) amended the National Organ Transplant Act to provide that a 'paired donation' of kidneys is not considered a human organ transfer for a value consideration. The bill was identical to [S.487](#) that passed the Senate by Unanimous Consent on February 15, 2007.

A paired donation is when: Person 'A' needs a kidney. Person 'B' has a kidney to spare but it is not compatible with Person 'A'. Person 'B's kidney is, however, compatible with Person 'C' and Person 'C's kidney is compatible with Person 'A'. So, Person 'B' donates a kidney to Person C who then donates a compatible kidney to Person A.

This process has been proven successful in providing more kidney transplants when compatible kidneys are in short supply compared to demand. The bill essentially makes the swaps less expensive by considering it "not a transfer for value consideration."<sup>31</sup>

The bill passed the House on March 2, 2007 in a vote of 422 to 0.

## **LKDN Webinars & Get-Togethers**

The LKDN Webinars educates people in need of a kidney transplant so they understand the facts about living donation and teaches them the skills to effectively communicate their need to family members and friends. The webinars are online meetings that are available to anyone who has a broadband internet connection. These are free programs that allow participants to see the presentation material and to hear the facilitator either through their PC's speaker or via the phone. Questions could be asked live, during the presentation.

When you host a LKDN Get-Together, you ask friends and family members if they would like to help you let others know about your situation. For those that want to help, you invite them to come to your house so they could learn more about living donation. The presentation to your "advocates," is similar to the information given in the webinar program. The get-togethers are live, or online. It has been shown, that group education of patients with family members and friends can increase the number of living kidney donations. The advocates can provide invaluable support and can significantly increase the number of people who become aware of their friend or family members need. The webinars and get-togethers are taught by kidney transplant recipients and donors. Peer assisted learning has proven to be a very effective model.

The information presented for the webinar and get-together is divided into two main segments; the first focuses on educating everyone about living donation. The second reviews effective communication techniques that they could use for letting people know about their need.

### **Educational Component**

Individuals in need of a kidney transplant, and their advocates, will have more confidence to talk about living kidney donation if they are knowledgeable about the topic.

### **Communications/Group Interactions**

Having the knowledge about living kidney transplants is important, combining that with good communication skills will increase the likelihood of success. Having support from people you know is very helpful to the person in need of the transplant. In fact, it is motivating for the whole group knowing that they have joined forces to achieve a common goal.

After a webinar or get-together, participants will have the knowledge of the transplant process along with the verbal skills to be effective in speaking to others. They will also know that they can call upon one of the other advocates with any questions that might develop.

**Blogs:** [www.lkdnblog.blogspot.com](http://www.lkdnblog.blogspot.com)

**Here are some selected blogs:**

**What's my PRA? It's one of the first questions you should ask when pursuing a Kidney Transplant**

When it comes to needing a kidney transplant most people are thinking about finding a compatible donor. They don't realize that there is a test you need to take that will determine how easy or difficult it will be to find that person. The test is called PRA.

PRA's are "panel reactive antibodies." A blood test measures the level of antibodies in your blood. The more antibodies you have, the more difficult it will be to find a compatible donor. A person's PRA can be anywhere from 0% to 99%. Your PRA represents the percent of the U.S. population that the antibodies in your blood would react negatively to. For example, having a PRA of 25 means that about 25% of the population will not be able to donate a kidney to you. The antibodies present in your blood would attack the transplanted kidney and can cause immediate rejection. About 20% of the people who need a kidney transplant have high PRA's. Simply stated, having a high PRA will significantly limit the number of people that will be able to donate to you.

You can develop high PRA's from a blood transfusion, or an earlier transplant or from being pregnant.

There are ways of lowering PRA's through a procedure called Plasmapheresis a blood-cleansing process that can eliminate the dangerous antibodies from the blood. Plasmapheresis is used only in cases in which the patient has a live donor.

Plasmapheresis can also be used to allow blood-type incompatible donor/recipients to proceed with the transplant. Plasmapheresis can cost tens of thousands of dollars more than conventional transplants and are complex to administer.

If you've been told by a transplant center that you are too highly sensitized, (another term used to describe high PRA's,) to receive a transplant ask about Plasmapheresis. If they don't offer it there, speak to another transplant center.

**"Matching" and Kidney Transplants - Myths and Misconceptions**

The use of the terms "match", "matching" or a "perfect match" are often misunderstood or misused when referring to a recipient and donor.

A more accurate way of describing the evaluation process is to use the terms, "suitable" and "compatible". A suitable donor is someone that is healthy enough to donate. A donor is compatible when all the tests are finalized for the recipient and donor and it is shown that the prospective donor is able to donate to their recipient. When people say they are a "match",

they usually mean that they are compatible to the recipient.

Generally, a recipient and donor aren't "matched" until they know that the donor is suitable and compatible.

The term "match" references the 6 HLA's (Human Leukocyte Antigens.) Before antirejection medications, 6 out of 6 antigens needed to match in order for the transplant to be successful. The new anti rejection drugs are so effective, that there isn't a statistical difference in success rates between a zero match and a 5 out of 6 match. Therefore, HLA matching typically is not a factor that determines whether someone is compatible. There is however, a benefit to having a "perfect match," 6 out of 6 antigens since the life of the transplanted kidney survives significantly longer. (On average, 28 years instead of 18 years for a 0 - 5 match,)

Donor and recipient matching is divided into three distinct areas: blood type matching, tissue type matching, (the HLA referenced above,) and cross matching.

Transplants are being done when donor and recipient have different blood types. A procedure called plasmapheresis on the recipient makes this possible. (Plasmapheresis will be a topic of another blog.)

Cross matching is a very sensitive and final test performed on a kidney donor and their recipient. The basic cross match test involves a mixing of the donors and recipients cells and serum to determine whether or not the recipient of a kidney will respond to the transplanted organ by attempting to reject it. A positive cross match means that the recipient has responded to the donor and that the transplant should not be carried out. A negative cross match means that the recipient has not responded to the donor and therefore transplantation should be safe.

While this language may appear a bit backwards, the cross match is the test indicating a "go" or "no go" for the transplant.

Either way hearing that there's a "match" is usually Great News!!

## Newsletter

### The Heart of the Matter

*Helping you Achieve a Successful Living Kidney Transplant*

#### The “Pinking” of American

It seems the whole world is focused on breast cancer, pink ribbons are everywhere, baseball player’s bats are pink, football players are wearing pink cleats, let alone what the women are doing to promote breast cancer awareness. With all these advocates, it’s no wonder we are living in a virtually pink world.

This is a great achievement and an excellent demonstration of what a successful public awareness campaign can do. The Susan B. Komen Foundation has done an outstanding job of humanizing the face of this disease and drawing attention to the cause.

You can take this example and bring it down to the personal level, by telling people about your condition and having friends and family member, your advocates spread the word about your need. After all, the only way someone can offer to donate is if they are knowledgeable about living kidney donation and aware of your situation.

There are many options for spreading the word. As in the “pinking” example, the more advocates you have, the more likely that you will reach someone who offers to donate.

Here are a few ideas on how you and your advocates can spread the word:

- Write an email or letter to the people you know explaining why you need a kidney transplant. (See [http://lkdn.org/letter\\_from\\_friend.html](http://lkdn.org/letter_from_friend.html) for an example)
- When you, (or your advocates) are asked, “what’s new,” let them know!
- You can get creative, as when I met someone who wore a pin that said, “Ask me why I need a Kidney Transplant”.
- Does your school, place of worship or other organization have a newsletter? Ask them if they would be interested in writing a story about you.
- Here’s an example of a letter that was sent to members of the congregation after their religious leader mentioned this persons need for a kidney transplant. (See [http://lkdn.org/letter\\_religious.html](http://lkdn.org/letter_religious.html))
- Local TV, radio or newspapers write stories all the time about people who need a kidney transplant.

The more knowledge you have about living donation, the easier it will be to talk about your need. Learn as much as you can about living donation and educate your Advocates.

Recently, home get-togethers have demonstrated to be very effective at helping people become successful at pursuing living donation. (See [www.lkdn.org/ktx\\_get\\_togethers.pdf](http://www.lkdn.org/ktx_get_togethers.pdf).) The

materials used in the Living Kidney Donors Network Workshop have been modified for these personal get-togethers. Here's how they work:

- If you live in Illinois, Wisconsin or Indiana, a LKDN representative will come into your home to facilitate a private get-together. See [http://lkdn.org/home\\_get\\_togethers.pdf](http://lkdn.org/home_get_togethers.pdf) for more information about these home get-togethers.
- Where travel isn't practical, a LKDN representative will coordinate a virtual, (via the internet,) meeting. See [http://lkdn.org/virtual\\_get\\_togethers.pdf](http://lkdn.org/virtual_get_togethers.pdf) for more information about these virtual get-togethers.

There is no cost to you for hosting a LKDN Get-Together, whether at your home or is held virtually through the internet. You are encouraged to invite friends and family members to attend. Let them know that you would like them to be one of your advocates, to help spread the word about your need for a kidney transplant. Ask them to come to learn more about living kidney donation and how to speak to other people about your need. The get-togethers are taught by recipients and donors, people who have been through the process. Peer assisted learning has proven to be a very effective model.

If you are interested in having a LKDN Get-Together, please email me. I will schedule a time to discuss the get-together in more detail with you.

I've written two articles that are being published by the AAKP, (American Association of Kidney Patients,) and have been picked up by other organizations. They are available on the website:

- How Do We Increase the Number of Kidney Transplants
  - [http://lkdn.org/aakp\\_mag\\_article.html](http://lkdn.org/aakp_mag_article.html)
- In Pursuit of a Living Kidney Transplant...It's About Your Donor Finding You
  - [http://lkdn.org/donor\\_finding\\_you.pdf](http://lkdn.org/donor_finding_you.pdf)

I have started a blog that provides up to date information on helping you through the living donation process. I welcome your feedback and suggestions. You could go to the blog and register to receive updates at [www.lkdnblog.blogspot.com](http://www.lkdnblog.blogspot.com) or send an email to [info@lkdn.org](mailto:info@lkdn.org), write Blog in the Subject line and you will be notified when a new entry is posted.

Stay healthy and keep a positive attitude....your donor will find you!

December 2009

## Supporting Documents

### Draft Letter

This letter is designed come from a friend or family member of the person who is in need of a transplant. It could be rewritten to come from the person who needs the transplant.

Dear (Personalize letter if possible,)

I am writing to you about my, (i.e. friend, brother,) Jim. It's to let you know about his current health challenge, and how you can help. This is not an easy letter for me to write, but I know that without sending this, someone who might be interested in helping won't have that opportunity.

Jim is a wonderful person. (You could talk about the work that Jim does, his family, the volunteer work he has done, his involvement with the community, anything that could connect Jim with other people.)

Jim suffers from kidney failure. (Give a brief history of Jim's health challenges. Mention if Jim's on dialysis, had a previous transplant, how long he's been waiting, how many other people have tried to help etc. You could even include a picture of Jim that you think others would like to see. If Jim has made many positive lifestyle changes, mention them. If you are unable to donate, explain why.)

Mention the long wait for a deceased donor and the benefits of receiving a kidney from a living donor. (The wait for a deceased donor is 5+ years and a kidney from a living donor lasts almost twice as long as one from a deceased donor.)

If Jim isn't on dialysis, talk about how difficult it is to have a normal life while being on kidney dialysis, if he is on dialysis, you could describe the routine.

Be as straight forward as possible, "***Jim needs a new kidney, and we hope you will consider being tested to be a donor.***"

I know this is a big request. But I make it on behalf of someone who devotes every day of his life to making a difference to his family and friends.

***If you can help, please do. If you know anyone who might, please forward this on.*** Forwarding this to your family, friends, work, school, congregation, or any other communities you belong to would be most gratefully appreciated.

If you would like to learn more about living kidney donation, please feel free to call me. I want to be as helpful as possible. You could also call Jim's transplant coordinator, (Susan Smith at 555-1212,) and have a confidential conversation and get answers to any questions you have. At first, you don't even have to disclose who you are interested in helping, just that it is one of Susan's patients.)

Thank you so much!

## **Draft Letter**

(It is common for the leader of a religious organization to speak about one of their congregants need for a kidney transplant. After one such situation, the individual followed up with this letter. You could make changes to reflect your personal situation.)

Dear,

This is probably the most difficult letter I've written. You see, I am in need of a kidney transplant, and I need to let my friends and family know about my condition.

I went on the kidney transplant waiting list three months ago. Recently, I have had to start dialysis, and I go to the dialysis clinic 3 days a week. I'm hooked up to the machine for three and a half hours. By the time I travel to and come home, I've spent most of my day, and when I do get home I'm often very tired. Being on dialysis is physically and emotionally draining.

Kidney failure runs in my family. Aside from my kidneys I am in good health. I've been very active in my community, volunteering at my Church and at the local school. I've had more than 10 people genuinely offer to be tested to donate – but almost all of them had the wrong blood type and several were ruled out for health reasons.

I am pursuing a living donor for two main reasons, (but there are many others,) kidneys from living donors last, on average, twice as long as kidneys from deceased donors and the waiting list for a deceased donor kidney could be more than 5 years. Most people can donate who don't have high blood pressure, cardiac problems or some other medical condition.

Here's some basic information about kidney donation:

- We are born with an extra kidney – you only need one to live a full, healthy, long life.
- The majority of the donor surgery is done laproscopically, with tiny incisions.
- The recuperation period is generally 2 weeks for those with a desk job and 6 weeks for those whose job entails heavy lifting.
- The surgery would be done at a hospital that has some of the best surgeons in the country.
- All medical expenses would be paid by my insurance benefits.
- Most donors say if they had another extra kidney they would donate again in a heartbeat and that it is one of the best experiences of their life.

Would you please consider giving the Gift of Love and hope? Please call me and I will send you an information packet that will help you make a well-informed decision. Or, if you would like to explore this in more detail before you let me know about your decision, you could call the ABC Hospital and ask for Sue Smith, my Transplant Coordinator. You could let them know about your interest in being a living donor to one of their patients, and you will not have to disclose my name at this time.

Thanks for your support and concern.

## LKDN Published Articles – AAKP Magazine - Renalife

### How Do We Increase the Number of Kidney Transplants The Answer is Right Under Our Noses

If someone you know needed a life saving kidney transplant, would you be willing to donate one of your kidneys to them? More than 16 people a day answer that question with a resounding YES. Understanding why someone chooses to donate, and how they found out about the recipient's need, could be the answer to a growing problem faced by doctors, hospitals and kidney patients.

There are more than 80,000 people in the US waiting for a kidney transplant from a deceased donor, and most stay on the waiting list for more than 5 years. Conservatively, that number is expected to grow to more than 100,000 in the next three years. Their health seriously deteriorates while they wait for a kidney to become available. In 2008 more than 4,700 people died waiting for a kidney from a deceased donor. This tragedy is avoidable with increased awareness of the need and available options.

Medical advances have enabled far easier living donor/recipient matches, (no longer requiring only "related" donors), and laparoscopic procedures often allow the donor to return home 24 to 48 hours after surgery. Paired kidney exchange programs are having a significant impact in facilitating transplants between incompatible pairs. (In a paired kidney exchange, an incompatible donor will donate their kidney to another recipient who also has an incompatible donor.) Research shows that kidney donors have the lifespan, hypertension and overall wellness rates comparable to the general population.

Given all the medical advances, reduced risks, and the documented benefits of living donors, the number of living kidney transplants should be increasing. However, they are not. There have been fewer living kidney transplants in each of the past 4 years, a cumulative decrease of over 11%. This is a baffling and disturbing trend, especially to experts in the field who recognize the tremendous advantages of living kidney donations.

The good news is that 6,000 living kidney transplants are performed every year - offering life saving benefits to patients and their loved ones. The challenge is finding a way to increase that number.

Hospital transplant programs inform their patients about the importance of finding a living donor. Most patients don't have any idea how to even **start** the conversation with family or friends. The fear of asking someone to donate is the number one reason given for not pursuing living donation. In truth, patients rarely need to ask directly. Most living donors say they

volunteered to donate once they heard about their family member or friend's need. When kidney patients realize that they do not have to ask directly, they become more comfortable in discussing their situation openly with everyone they know – exponentially increasing their chances of finding a living donor.

It is critical to develop better education and communication programs to help kidney patients spread the word about their need for a transplant. We must also educate the public about the need for living donors, and the process of donation. Having accurate and detailed information makes a person more likely to become a donor when they hear that a friend or family member is in need.

Rather than trying to build on the success of the current living kidney option, the transplant community is focusing on three other solutions: increasing the number of deceased donor kidneys, exploring a financial compensation model for donors, and trying to move to a system of “presumed consent” for deceased donations.

Any proposal for compensating donors is vigorously opposed by medical ethicists and many other groups. Each side's opinions have been hotly debated, but it is unlikely that the two opposing camps will resolve their differences any time soon.

Changing our current donor system to one of “presumed consent” is also controversial. Every person, upon death, would be considered a donor unless they specifically “opted out.” Again, this type of sweeping change is unlikely to be implemented in the near future.

The current focus is almost exclusively on increasing the number of deceased donor organs. Millions of dollars are being spent by governmental agencies, private and nonprofit organizations to encourage people to register as organ donor. While these efforts are commendable, and should be continued, increasing the number of deceased donor organs will not be enough to meet the current level of need. In fact, the number of deceased donor transplants has decreased in each of the past three years.

Clearly, it would make sense to reallocate some of these resources to help expand the number of living kidney donations, with educational programs for those who need a kidney transplant and for the general public. Not only is there a virtually unlimited supply of kidneys from living donors, it is the medically preferred option. A kidney from a living donor lasts almost twice as long as a kidney from deceased donors and it is a safe, successful and cost-effective option.

Increasing the number of living kidney donors is the **only way** to reduce the current 5+ year wait for a kidney transplant, and eventually eliminate the waiting list altogether. The solution is “right under our noses.” I believe that educational programs for people who need a kidney transplant and a public awareness campaigns will increase the number of living kidney transplants.

When surveyed after the transplant, living donors are quick to respond that they would donate again, without hesitation. They are happy with the decision they made, and say they feel a

unique kind of pride and contentment - seeing firsthand what a profound impact their gift has had on another human being. A joy that confirms that it is better to give than receive.

When you hear of a friend or family member who needs a kidney transplant, consider being a living donor. Living donors save lives. Give the greatest gift of all....Life Donated, can Multiply Life.

## **LKDN Published Article - AAKP Magazine - Renalife**

### **In Pursuit of a Living Kidney Transplant; It's About Your Donor Finding You!**

When someone in need of a kidney transplant is instructed to “find a living donor”, one of their first thoughts is, “how am I going to ask someone to donate a kidney to me?”

In reality, most living donors say they volunteered to donate once they heard about their family member or friend's need. Health care professionals need to advise their patients: rather than “ask” someone to donate, just let them know about your situation. Although it's a subtle difference, it could have a significant impact on a patient's willingness and state of mind about pursuing living donation.

How do you start the quest to have the donor find you? It's very important to start by learning as much as you can about living kidney donation. The more you know, the more confident you'll be when discussing the subject and informing others. You will likely be the person to educate your donor about the process. Therefore the more accurate information you provide, the more you will dispel some of the myths and misconceptions surrounding living donation.

There are many resources you can seek to gain information about living kidney donation. Start with your transplant hospital and meet with the coordinator of their living donation program to learn how they can help you. For additional information about pursuing living kidney donation, visit [www.lkdn.org](http://www.lkdn.org).

Once armed with knowledge about living kidney donation, you'll then need to effectively communicate your need and the information you've learned. If you have initial unease discussing the subject, then practice and rehearse what you want to say with a confidante such as a family member or friend who can also become an advocate on your behalf. Advocates are often the ones to educate the person who ends up being your donor.

When letting others know about your need, speak from your heart, make it personal, tell your story. You and your advocates need to be positive. Tell others how you envision your life improving after the transplant. And remember, you are not asking outright for anyone to donate.

- Technology has changed the way we communicate. Some people use less personal channels such as the internet to reach out and let others know about their need. A word of caution, some transplant hospitals are not receptive to these less personal outlets, so you should speak to your transplant hospital about their living donor policies. There's no substitute for "high touch" personal channels, "high tech" electronic channels come with risks and many people have been disappointed after months of email contact when communication stops, so pursue these cautiously.
- "High touch" and personal channels abound. There are many success stories of donors coming from places of worship, schools, reunions or local media feature stories. The only limit in reaching out is your comfort level of letting others know about your need.
- There are myths and misconceptions about living donation that you may confront and need to dispel. One of the most common myths is that only a close relative can be a match and be able to donate. Medical advances have enabled a much easier matching process of donor and recipient. The need of a "perfect match" no longer exists. New anti-rejections drugs have allowed a much wider range of people to become donors.

For example, in 1998, 77% of the living kidney donors were from close blood relatives. By 2008, only 57% of the living kidney transplants came from close blood relatives and this trend should continue. Also important is the fact that medical procedures have advanced dramatically. Today, donors' surgery often uses the minimally invasive laparoscopic procedure which allows many donors to return home within 1 to 3 days after surgery.

- The emergence of paired kidney exchange programs has also had an impact in facilitating transplants between incompatible pairs. A paired kidney exchange occurs when two or more incompatible pairs of recipients and donors donate or swap between each other.

The laparoscopic procedure is still considered major surgery and as such, the surgical risk, emotional and psychological implications need to be taken into consideration. When properly screened, the surgical risks for the donor are not high, and trained social workers speak with the recipient and donor to make sure the donor is donating for the right reason and is not under any pressure to donate.

Letting people know about your need for a kidney transplant may at first seem overwhelming. However, once you get started it's often not as difficult as you might imagine. Develop a plan and start slowly. The more people you speak to, the easier it will get and the greater your chances will become of a donor finding you. Donors often come from the most unlikely connections, and as such, reach out to everyone you know. As a final word of encouragement, in the U.S. there are more than 16 successful living kidney transplants performed every day. Perhaps the next happy ending will be yours!