

Kidney and Pancreas Transplant Program

Information for Potential Kidney Donors: What You Need to Know about Becoming a Kidney Donor



AMAZING
THINGS
ARE
HAPPENING
HERE



You have the power to *Donate Life*SM

Our Living Donor Program

INNOVATIVE AND HIGHLY
EXPERIENCED LIVING DONOR TEAM



Photo: Parents Brian and Evette
each donated a kidney to twin sons
Alan and Brian.

This booklet is designed to introduce you to the basic concepts of kidney donation. If you are thinking about being a donor for someone who needs a kidney transplant, we hope that you will find the booklet to be a useful resource.

At **NewYork-Presbyterian/Weill Cornell Transplant Center**, we have the **largest Living Donor Kidney Program** on the east

coast and third largest in the United States, along with on the top Kidney Paired Donation Programs. Although our focus is providing kidney transplant to patients in need, our living donor program is designed to protect you, the potential kidney donor. We have separate medical teams for the donor and the recipient. You will be assigned an independent living donor team to help you through the evaluation and donation process, and always look out for your best interests.

We have the
longest history of
kidney
transplantation in
New York,
performing New
York's first Kidney
transplant in 1963.

Who Can Be a Donor?

The majority of kidney donors have an established relationship with the person needing a kidney: a relative, spouse, friend, co-worker, or neighbor. However, there are also people who wish to donate a kidney to someone, but do not have a specific recipient in mind. **You must be at least 21 years old to be a living kidney donor at NewYork-Presbyterian/WeillCornell, but there is no upper age limit for being a donor.**

Here is a brief description of the types of donors:

- **Living Related:** Kidney transplants from a relative such as a parent, brother, sister, aunt, uncle, cousin or child.
- **Living Unrelated:** Kidney transplants from people unrelated to the recipient such as a husband, wife, partner, friend, co-worker, or neighbor.
- **Altruistic:** These donors want to donate a kidney but do not have a specific recipient in mind. There are several ways an altruistic donor can find someone to donate to, including joining registries of people who need a kidney but have an incompatible living donor.

What About My Health?

First and foremost, **we need to make sure that you are healthy enough to donate a kidney.** In particular, it is important to make sure that you do not currently have (or are at high risk for developing in the future) any diseases that could put you at risk for kidney problems of your own, including diabetes and uncontrolled high blood pressure. In addition, we need to make sure that you are healthy enough to undergo the surgery needed to remove the donated kidney.

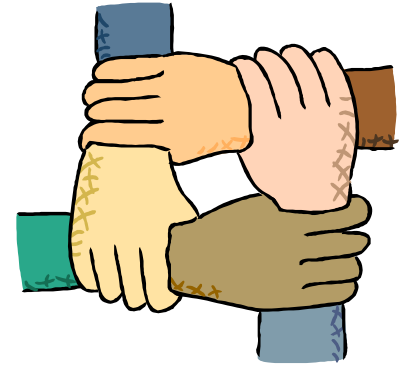
A complete list of the testing you will have if you decide to come forward as a potential donor can be found later in this booklet.

Please also visit our Living Donor Kidney Center Online at www.WeillCornellTransplant.org



What is Compatibility?

When coming forward as a donor, you may hear the term “**compatibility**” used quite often. This term simply means that we will be **determining if you will be a good donor for your intended recipient**. If you come forward as a potential donor for someone, several tests, described below, will be performed to assess your compatibility with the recipient.



Blood Type Compatibility

When looking at blood type compatibility, we use the same rules that are used for blood transfusion compatibility.

Donor With Blood Type:	Can Donate to	Patient with Blood Type:
A	—————→	A or AB
B	—————→	B or AB
AB	—————→	AB
O	—————→	A or B or AB or O

Antigen Matching

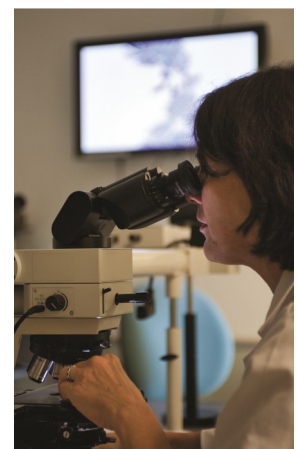
Each person has unique markers on the cells in their body called **antigens**. The antigens help the immune system know when a foreign cell enters the body (for example, through a blood transfusion or transplant). **There are 6 of these unique markers that we try to match when considering if someone will be a good donor for a specific recipient**. These antigens are inherited from your parents. For parent-to-child or child-to-parent transplant, there is always a 3 out of 6 match. For siblings, that match is 0, 3, or 6 out of 6 matches.

Although matching can be important (for example, a 6 out of 6 match is known to be superior to other matches), it is not critical to the success of transplantation. In fact, many transplants that we perform have a 0 out of 6 match, and the recipients do well. **Therefore, when you receive your match results, remember that the match is not a critical factor in determining your compatibility.**

Crossmatch Compatibility

During the **crossmatch**, your blood is mixed with the blood of your potential recipient to determine if you are compatible. Some people who need a transplant may have developed antibodies in their blood that react against the blood of their donor. These antibodies may have developed as a result of blood transfusion, prior transplant, and/or pregnancy. This reaction is known as a “**positive crossmatch**.”

If the crossmatch is positive, we will look at how strong the reaction is. Remember that **just because there is a positive crossmatch does not mean that you will no longer be considered a potential donor**. There may be other options available.



What Are the Options When a Donor and Recipient Are Not Compatible?

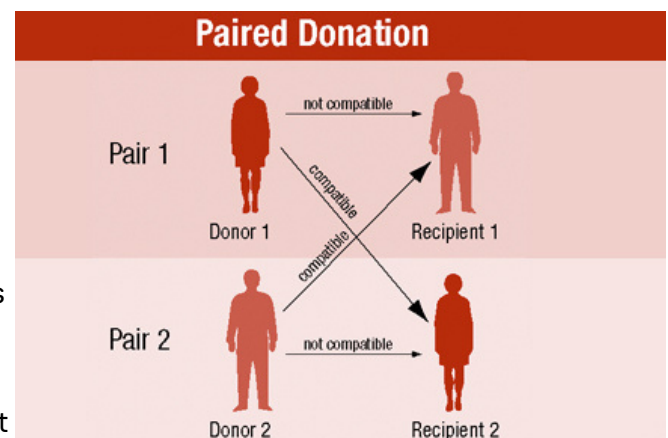
The need for transplantable organs is critical. Over 550,000 people in the U.S. have end-stage kidney disease requiring dialysis and/or transplant. However, the number of deceased donors available to provide organs for transplant is not growing at the same rate. The best way to increase the number of organ donors is through living donation. ***If you are tested to be a donor but are not compatible, it is important to remember that there are other options, which are briefly outlined below and on Page 5.***



The Donor Paired Exchanged Program:

Approximately **one-third of patients** that need a kidney transplant who come forward **with potential living donors will be incompatible with their donor(s)**. This amounts to a large number of people who need a kidney and have a willing donor whose kidney doesn't "match" them. One way to help solve this problem is to enter the incompatible donor and recipient into a **larger pool of other incompatible donor and recipient pairs**. Then, patients are matched to donors with whom they are compatible. One such pool is the National Kidney Registry, with whom NYP-Weill Cornell has been able to transplant 75% of our incompatible donor/recipient pairs at Weill Cornell. One benefit is that the recipient avoids the additional therapy needed for positive crossmatch or ABO incompatible transplants.

NYP-Weill Cornell is also one of a few transplant centers to be selected to participate in the Kidney Paired Donation Pilot Program of the United Network for Organ Sharing (UNOS), whose goal is to develop a national matching program and which has the potential to greatly benefit incompatible donor/recipient pairs. We expect this to significantly increase transplant opportunities for patients listed at our program.



Our transplant team is one of the most experienced in the U.S. in working with living donor kidney transplant chains. By working with pools like the National Kidney Registry, we have been able to transplant over 75% of our incompatible recipient pairs.



One benefit to donor paired exchange is that the recipient avoids the additional therapy needed for positive crossmatch or ABO incompatible transplants, which is described on Page 5. In addition, compatible pairs may also choose to participate in donor paired exchange in order to find a better genetic or age match for the recipient, or to avoid antibodies that may be harmful to the kidney in the long-term.

This matching process has greatly increased the ability of patients with willing but incompatible donors to receive a transplant.

Photo: When he found out he was an incompatible donor for his mother, Corey donated a kidney through the Kidney Paired Donation Program, enabling her to receive a kidney in return, as part of a chain.

What Are the Options When a Donor and Recipient Are Not Compatible? Continued.

Compatible Pairs and Paired Exchange Swap Program

As explained above a compatible pair is a donor and recipient that are biologically "compatible" but want to find a better match through a paired exchange swap. An improved match between the donor and patient will increase the chance that the transplanted kidney will function better and last longer.

A mother who has a biological child as a donor should always consider paired exchange because the mother may have donor specific antibodies (DSAs) against the child's paternal antigens. These DSAs can negatively impact the transplant outcome.

Compatible pairs can also benefit from participating in swaps by finding a better matched donor which will increase the chances that the transplanted kidney will function better and last longer. Generally the improvement in the match from a swap is driven by a better HLA match or a younger donor. A better HLA match is also correlated with lower patient mortality over time because a good HLA match will reduce the number of antibodies created from mismatched antigens, and make it easier for patients to be retransplanted in the future.

Another benefit derived when compatible pairs participate in swaps is that other patients with incompatible donors are helped because a compatible pair will generally facilitate between one and ten additional transplants. In other

The Advanced Donation Program (ADP)

A kidney paired exchange separated in time, when a donor donates as part of the ADP, either a Standard Voucher or Family Vouchers will be provided based on the situation:

- When a donor donates for an intended recipient who will likely need a transplant within the next year, a Standard Voucher will be provided for that one recipient. Standard Vouchers can also be provided when a chain breaks and a donor continues with their donation to keep a portion of their chain on schedule, even though their paired recipient has been removed from that chain.
- When a donor donates for intended recipient who will not likely need a transplant within the next year, Family Voucher will be provided for up to five intended recipients.

Both types of ADP vouchers allow donors to donate their kidney before an intended recipient receives, or even needs, a kidney transplant.

Transplanting Patients Who Have a Positive Crossmatch with Their Donor:

As mentioned earlier, some patients have developed antibodies which cause them to have a reaction against their donor. In some cases, we can **reduce the antibodies** and **improve the crossmatch** results by treating the patient who needs the kidney with medications and/or treatments that can decrease antibody levels. If antibody levels are sufficiently reduced and the crossmatch results improve, the transplant may be able to go forward.

Blood Type Incompatible Transplants:

For certain combinations of blood types, the incompatibility can be reduced by treating the person who needs the transplant with a treatment similar to what is described above for positive cross match transplants, and the transplant may be able to go forward.

Transplant from a Deceased Donor:

Even if a patient needing a transplant has potential living donors, all patients are placed on the waiting list for a deceased donor kidney (transplant from someone who has died and donated their organs) once they are determined to be eligible for a kidney transplant. That way, the **patient can begin to accumulate waiting time in case the living donor(s) is incompatible** and the options listed above are not feasible.



How Do I Become a Donor?

The first step is to complete the registration process at www.cornell.donorscreen.org. Based on your responses to the questions asked during the registration process, you will be contacted by a member of the donor team, who will discuss your eligibility for proceeding with the work-up process. You can also call (212)746-3922.

Please understand, we will not call you—we do not want you to feel pressured into making this commitment. When you are ready, please call us. You will be asked routine questions (name, address, date of birth, social security #) and a brief medical history will be taken. You can then arrange to have the required testing done (initial testing may be done locally if you live far away).



The NYP/Weill Cornell Transplant Clinic, is located in the brand new David H. Koch Building on the 9th floor.

Step 1

- Register Online at www.cornell.donorscreen.org
- We will contact you to schedule compatibility testing
- Come to our center to have blood drawn: determination of blood type, antigen profile, and crossmatch are performed
- Blood work can be done locally if donor lives out of state

Once you receive the results of these tests from us, **you are responsible for telling your potential recipient the results** if and when you choose. **To protect your privacy, we will not disclose this information to your potential recipient.** If you are compatible and decide to move forward, **you must contact us** at (212) 746-3922 to arrange to come in for additional testing to determine that you and your kidneys are healthy enough for donation. You will receive a comprehensive medical evaluation that is likely more thorough than any other you have had in the past. In consideration of you becoming a donor, we believe it is our responsibility to protect your current and future well-being.



Step 2

- You will collect your urine over the course of 24 hours, which will allow us to check the health of your kidneys (*called a 24 hr hour urine collection*) and blood tests will be performed
- Meeting with the donor team (*Transplant coordinator, physician, social worker, living donor advocate, financial specialist &/or psychiatrist*)
- Electrocardiogram (*electrical tracing of heart activity*)
- Chest x-ray to make sure your lungs are healthy
- CT scan with 3D reconstruction to create a detailed anatomical road map of your kidneys to allow for the donor surgeon to visualize the blood supply to your kidneys



Justin donated his kidney to his father Jay.

Other tests may be necessary based on your age, gender, and medical history:

Women

- Pap smear
- Mammogram (if over age 40 or strong family history of breast cancer)

Men

- PSA to check for prostate cancer if over age 50

All

- Colonoscopy if over age 45
- Stress test and echocardiogram if history of high blood pressure or as determined by your team



Step 3

If all the testing done during Step 2 show that you may still be a donor, we will set the date for the transplant (as long as your recipient has also been cleared for transplant and you still wish to be a donor), and you will come back one week prior to the scheduled transplant for the following:

- Final Crossmatch to confirm that there is no reaction when you & your recipient's blood are mixed
- Meet with your surgeon
- Visit the hospital to complete pre-operative paperwork
- Repeat blood tests to check for HIV, hepatitis C, and hepatitis B



Informed Consent

During your evaluation, your team will take you through the informed consent process, which should help you all aspects of the donation process, including the risks and benefits. Your consent to be a donor is completely voluntary. You should never feel pressured to be a donor, and you have the right to delay or stop the donation process at any time. The reasons behind your decision will be kept confidential. Talk in detail with your family members and close friends. Talk to other living donors (we can connect you with others who have donated through our program).

Please see the back of this booklet and visit our website: www.WeillCornellTransplant.org for a comprehensive list of resources.



Independent Donor Advocate Team

As you move through the living donor evaluation process, our priority is to keep your best interests in mind. You will meet with an **Independent Donor Advocate (IDA) team**, who will assist you through the donation process. This team is separate from the potential transplant recipient's medical team. The IDA's responsibilities include, but are not limited to:

- Promoting the best interests of the potential donor
- Advocating for the rights of the potential donor
- Assisting the potential donor in getting and understanding information regarding the:
 - 1) Consent process
 - 2) Evaluation process
 - 3) Surgical procedure
 - 4) Medical and psychosocial risks
 - 5) Importance of post-donation follow-up

Your Independent Donor Team can address any questions you have. We always encourage you to be honest with the IDA team and other transplant center staff about your feelings or concerns about being a donor.



Living Donor Mentor Program

We offer opportunities for potential living donors to connect via phone with living donors who have been through the donation process. This provides the chance to ask questions and hear feedback from those with firsthand experience with living donation. Talk to your social worker or your Independent Donor Advocate Team if you are interested in connecting with other living donors.



What are the Risks Associated with Being a Kidney Donor?

If you are considering being a kidney donor, it is very important that you understand the risks associated with donation. Please note that there has been little national systematic long-term data collection on the long-term risks of living donation. Based on the limited information that is available, long-term risks are considered to be low. Please note that the risks will be different for every donor and your donor team will inform you of any risks specific to you after your evaluation. **Please do not hesitate to ask questions if you do not understand some of the risks or if you would like more information.**

Short-term Risks:

- You may experience emotions such as anxiousness, guilt, and peer pressure when you are considering being a donor
- The risk of this surgery is similar to other minimally invasive procedures (such as gallbladder removal) that require you to undergo general anesthesia
- You may experience one or more of the following after your surgery: pain, bleeding, reaction to anesthesia, and infection. Other complications that are more rare include blood clots, pneumonia, injury to surrounding tissue or other organs, and in 0.003% of cases, death.



After Donation:

- Emotions may be strong after donation, including anxiousness, regret, anger, and depression. Your donated kidney may not function in the recipient after it is transplanted.
- It is very rare to develop kidney problems after donation, however, it is possible, especially if you develop high blood pressure or diabetes
- Financial issues may develop after donation
 - If you experience any complications after donation, you and/or your recipient's insurance may not cover the costs associated with those medical bills
 - You may face extra expenses related to child care needs, transportation, and housing, and may have lost wages during your recovery period
 - You could have difficulty obtaining health or life insurance if you apply after donation, therefore it is important for you to **clarify, and if necessary, optimize your health insurance situation prior to donation**

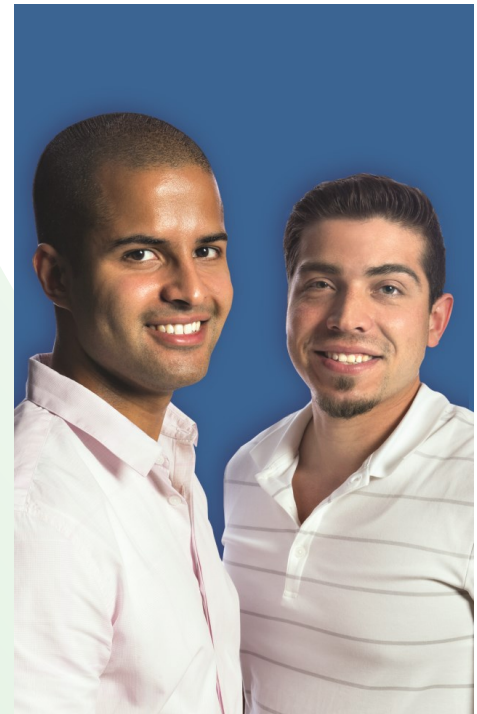


Photo: Ariel (left) donated to his cousin-in-law, Roberto.

What are the Benefits of Being a Kidney Donor?

The opportunity to help someone lead a more normal life with improved quality is a wonderful gift that the donor offers to their recipient. Donors feel good about themselves when performing such a selfless act. **Living donation generally gives the recipient a kidney that will function better and last longer than a deceased donor transplant.** This also allows the patient to get a transplant much more quickly than remaining on the waiting list, and may provide emotional benefit to the donor.



Photo: Susan donated a kidney to her son, Damien.



Photo: Daryl was an altruistic kidney donor, starting a chain of 5 kidney transplants by donating to a stranger.

Many advances have been made since the days when an open surgery was needed to remove the donated kidney. **Today's minimally invasive surgery to remove the kidney allows a much shorter hospital stay and overall recovery time for the donor.** Studies have shown that over the long-term, donors do not experience deterioration in the function of their remaining kidney. Female donors can also have successful pregnancies after donation.

Our History & Outcomes of Living Donation



Photo: Steve (right) donated a kidney to his brother, Anthony.

In 2019, our Kidney Transplant Program had the largest volume of transplants in the history of our program. Our Living Donor Kidney Transplant volumes are # 1 on the East Coast!

We are proud to have excellent outcomes after living donor kidney transplants.

What Should I Expect During the Surgery and for My Recovery?

Kidney donation is a **minimally invasive surgery**, which means that several small incisions are made, and the instruments used by the surgeon are placed through those incisions and used to remove your kidney (called a nephrectomy). It is known as a "laparoscopic" surgery because a camera is one of the instruments used by the surgeon.

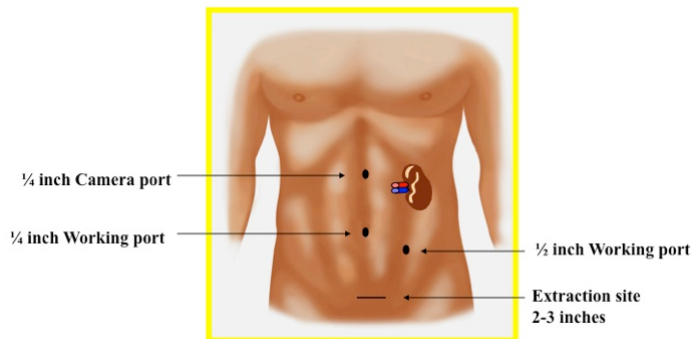
The small incisions allow you to recover faster with minimal scarring. As part of the evolution of this technique, NYP/Weill Cornell is now one of the first centers in the New York Tri-State area to perform a "single-port" nephrectomy, in which only one incision is required for the donor operation, which can further reduce scarring.



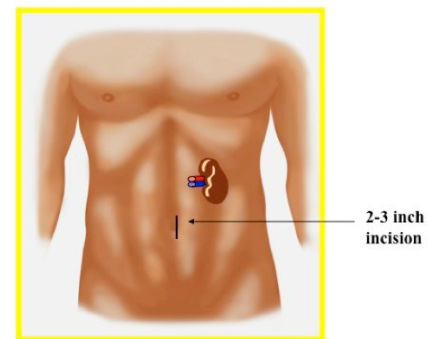
The Surgery & Your Hospital Stay:

- The surgery to remove your kidney generally takes 2 to 3 hours
- You can expect to be up and walking within a few hours after surgery
- You can also expect to be able to eat several hours after surgery (liquids first, then solid food)
- The usual hospital stay is 1 to 2 days after the surgery

Laparoscopic Donor Nephrectomy (the way the donor surgery is currently performed)

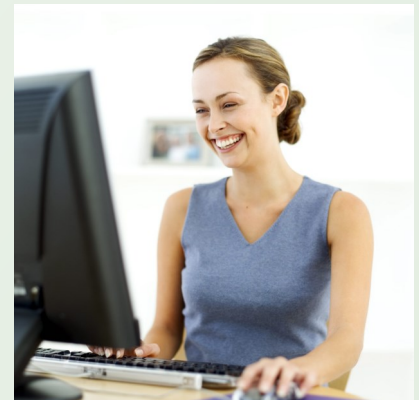


Single Incision Donor Nephrectomy



Your Recovery:

- Most donors can return to full normal activity and go back to work 2 to 4 weeks after their surgery



Follow-Up After Donation:

- The United Network for Organ Sharing (UNOS) requires that all living kidney donors return for follow-up at 6 months, 1 year, and 2 years after donation. At these brief visits, we will take blood and urine so that we can follow the function of your remaining kidney. If you live out of state, you can have the testing done at your local doctor's office, who can then send the results to us.

Donor Resources

The following websites may be of interest to people wishing to learn more about being a kidney donor:

Transplant Living Website	www.transplantliving.org
National Kidney Foundation	www.kidney.org/transplantation/livingdonors
Living Donors Online	www.livingdonorsonline.org
National Kidney Registry	www.kidneyregistry.org
United Network for Organ	www.unos.org/living-donation
Sharing Donate Life America	www.donatelife.net

It is important that donors have health insurance. The following are a few insurance options available in New York State; please discuss options further with your Social Worker:

Medicaid www.Medicaid.gov 1-800-541-2831

Health insurance that helps many people who can't afford medical care to pay for some or all of their medical bills. You must meet certain requirements, including financial ones, to be eligible for Medicaid which are determined by each state.

New York State of Health www.nystateofhealth.ny.gov 1-855-355-5777

An organized marketplace designed to help individuals, families, and small businesses shop for and enroll in health insurance options. The Marketplace also helps individuals check their eligibility for health insurance programs like Medicaid and sign up for these programs if they are eligible.

The following are resources available for Living Donor Financial Assistance; if interested, please discuss further with your Social Worker:

The National Living Donor Assistance Center www.livingdonorassistance.org 1-888-870-5002

Covers some of the travel and non-medical expenses incurred by individuals being evaluated for or undergoing living donation. There are eligibility requirements and an application process. Eligibility is based partially on recipient's finances and priority will be given to those donors who cannot otherwise afford the expenses.

American Kidney Fund www.kidneyfund.org 1- 800-638-8299

Provides a one time grant within three months after donation to assist with transportation and loss of wages for donors.

Contact Us:

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Transplant Program
NewYork-Presbyterian
Weill Cornell Medicine Transplant Center
525 East 68th Street
New York, NY 10065

Telephone: 212.746.3099
Email: transplant@med.cornell.edu
Website: www.WeillCornellTransplant.org

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