Living Kidney Donors

There are several advantages for a transplant candidate receiving a living kidney transplant as opposed to receiving a kidney from a deceased donor. The major advantage is that the recipient does not have to wait as long for a transplant. The transplant can occur before the patient begins dialysis, becomes too ill to survive transplantation, or worse, passes away. Another advantage of living donor kidney transplantation is that it can give patients the chance to receive a transplant before the onset of debilitating complications of their kidney disease while waiting for a deceased donor. Finally, an advantage to the living donor approach is the emotional satisfaction donors and recipients feel when they are involved in such a life-sharing experience.

Although living kidney donation is considered safe, the operation does involve certain risks, including pain, infection, and in rare circumstances, death. This is a major operation and your potential donors should thoroughly discuss it with their family and family physician first, and then with the transplant team if evaluated. You will be able to find out exactly how many patients have been transplanted at the University of Michigan through living donation and the outcomes of these donors and recipients. This is available on the Scientific Registry of Transplant Recipients (SRTR) given to you at your evaluation. SRTR publishes organ transplant statistics and is produced each year by SRTR staff and staff of the national Organ Procurement and Transplantation Network (OPTN).

The Living Donor

Any healthy and willing adult can be considered for a living kidney donation. Donors must be at least 18 years old to donate to a specific recipient.

Some health circumstances may prevent an individual from donating a kidney. For instance, individuals with diabetes or cancer may not be eligible to donate. The transplant team will review the data on potential donors with a relevant health history before scheduling an evaluation appointment.

Obesity and past abdominal surgeries may also exclude a donor because of increased surgical risk.

Donors may not be paid or receive any financial incentives to donate. However, there are some costs that you, the recipient, may offer to help cover.

Living Donor Kidney Transplant Options

A living donor transplant may be your best opportunity for a kidney transplant. Please consider sharing your story with family and friends letting them know you need a transplant and that living donation is possible.

We offer multiple options for you to receive a Living Kidney. These include:

- **Direct Donation** from your donor if the donor is a match to you.
- Paired Kidney Donation. This program is offered to recipients whose possible donors are incompatible, either because of blood type incompatibility or because you have antibodies against the donor. In this program, donor and recipient pairs are matched with other pairs in the same situation. The donor from Pair 1 donates to the recipient from Pair 2, and the donor from Pair 2 donates to the recipient from Pair 1. In the simplest form, a 'swap' of kidneys. This program allows you, and another recipient, to still receive a living kidney donation. Your donor knows they have provided you with this gift through a different pathway.
- **Compatible Paired Donation.** Your donor may be a match to you, however, we may offer them the opportunity to go into our Paired Donation Program. The goal is to find additional matches and benefit multiple people who otherwise would not have the opportunity to receive a kidney from a living donor.
 - All compatible pairs will be reviewed and may be approved regarding enrollment in this program.
 - If you participate in this program your surgery will not be delayed. We take care to ensure that you are receiving a kidney of equal value.
- Non-Directed Donation. This is a person who wants to donate and has no recipient (altruistic). They are put in the paired program and it is possible when they donate a 'chain' of donations can be created.



And so on and so on...

The gift chain continues as long as there are suitable donors and compatible recipients. Our ultimate goal is that the recipient receives a kidney from a live donor as it allows the recipient to be transplanted sooner and provides the best long-term outcome. Please have any potential donors contact our office at **1-800-333-9013** even if you believe they are not compatible with you.

The Decision to Donate

Being a living donor can be a very rewarding experience. Living donation is a sharing of life, giving a part to someone in need. However, it is also a choice that only the donor can make.

Living Donor Advocate

The University of Michigan provides an independent living donor advocate (LDA) who participates in the care of living kidney donors. The LDA is knowledgeable of living organ donation, transplantation, medical ethics and informed consent, and has no responsibility in the care of kidney transplant recipients. The LDA meets with potential donors during their formal evaluations to help educate them about living donation and to try to ensure that they are able to make a decision about donation that is fully informed and free from pressure. The LDA participates in team discussions about living donors and has the authority to exclude any potential living donor if there is a belief that donation would not be in the best interest of the living donor. The LDA will remain available for assistance and consultation throughout the donor's evaluation, donation process and beyond.

Living Donors MUST Call the Transplant Center

Individuals who wish to be considered to donate a kidney **must** contact the transplant office to indicate their interest in donation; the office cannot initiate contact with potential donors until they declare their interest. Potential donors must self refer by providing the transplant team with your full name as their intended recipient.

There are three methods to have potential donors initiate contact with the donor office:

- Telephone. 800-333-9013.
- **Online.** Our online form to start the process of being evaluated as a donor can be found at **www.uofmhealth.org/transplant**. Go to the kidney and pancreas section. The form can be found within the living kidney donation section. It is available under the heading 'Are You Interested in Donating a Kidney?
- Email. Request a Living Donor intake form at txp-donors@med.umich.edu.

Frequently Asked Questions for Living Donors

What are the risks of donating a kidney?

The complication rate for donating a kidney is around seven percent. As with any abdominal operation, there is risk for complications. The majority of these complications are minor. If there are more serious complications, they can usually be treated and rarely have any long-term effects. The complications include but are not limited to:

- Wound infections
- Urinary tract infection
- Pneumonia
- Blood clot
- Pulmonary embolus (clot in the lung)
- Incisional hernia
- Injury to the abdominal structures (large intestine, spleen or pancreas)
- Death (the chance of dying from a complication of the donor operation is one in 3,000)

How long will a donor be in the hospital?

The length of the hospitalization varies by individual, but most donors are generally in the hospital for one day.

How will this be paid for?

Living donors are not responsible for the cost of their donation work up, hospitalization or the costs of complications that are directly related to the surgery. These services are covered by the Transplant Center. If a donor receives a bill for these services, they should contact the kidney financial specialist at **(734) 936-7779**.

Donors will be responsible for their lost wages, cost of travel to and from the hospital for pre-donation visits, admission and post-transplant procedures. Most medical insurers do not reimburse for these items. Donors are also responsible for the diagnosis and treatment of medical conditions that could develop after donation that are **not** directly related to the donation surgery.

The National Living Donor Assistance Center (NLDAC) may help with travel expenses for donors who qualify based on financial need. The transplant donor coordinator can provide information on this program. A donor candidate and intended recipient each need to complete paperwork and provide financial statements to assess the financial need for funds. It takes approximately four weeks to apply for funds, receive approval and receive a card for travel funds. These funds can be used for all travel to MI Medicine (MM), lodging, parking, and meals for the donor and one additional person. If a donor plans to apply for, and use these funds to come to evaluation, it will be necessary to plan ahead to have it approved prior to their appointment. Visit the NLDAC website at **www.livingdonorassistance.org** for further information.

When can donors return to work?

Donors should anticipate being out of work for four to eight weeks after their surgery to give their body time to continue healing itself properly. In some cases, donors may be able to return to non-active work sooner, but it is recommended that they plan to be out for four to eight weeks. Their return-to-work release date will be dependent upon the type of work they do. They are advised not to drive until seen at their post-op visit following the nephrectomy (removal of the kidney) or while on narcotic pain medications. They will not be able to lift greater than 10 pounds for six weeks to reduce the risk of an incision hernia.

Is a living donor transplant better than a transplant from a deceased person?

Yes, a living donor transplant is almost always better than a transplant from a deceased person because the anticipated graft or transplanted kidney survival is longer and the transplant is planned.

Can a female donor have children? Will donating prevent them from getting pregnant or having a healthy baby?

Living donation is not a reason to avoid future pregnancies. We recommend that donors discuss donating with their OB/GYN .

The remaining pages are resources to explore living donation along with samples of ways to help you find a donor. Please contact the donor office with any questions at (800) 333-9013.



To view online streaming:

- 1) Visit: <u>https://exploretransplant.org/explore-transplant-education/</u>
- 2) Click on: View Explore Transplant education materials & videos
- 3) Enter Login: ETELD2018_MI
- 4) Enter Password: UofMI2018!





Living Kidney Donor Fact Sheet

Types of Living Kidney Donation:

- Compatible Living Donation
 - \checkmark The donor and recipient are compatible by blood type and tissue typing.
- Incompatible Paired Kidney Exchange
 - The donor and recipient are incompatible by either blood or tissue typing. Pairs are enrolled in programs that look for alternate matches participating with multiple centers nationwide.
- Compatible Paired Kidney Exchange
 - Compatible pairs cleared for surgery have agreed to enrollment in the Michigan Medicine Paired Donation Program in search of alternate matches. This would allow the potential opportunity for your recipient to find a more suitable donor for him or her while also providing the chance at transplant for someone who otherwise may not had this opportunity.

Resources for Living Kidney Donation:

- Transplants at Michigan Medicine <u>http://www.med.umich.edu/pdf/kidney-transplant/Living-Donor.pdf</u>
- University of Michigan Transplant Center website http://www.uofmhealth.org/transplant
- http://wearetransplant.com- We are Transplant
- www.kidney.org- National Kidney Foundation
- www.ustransplant.org- USTransplant.org: Supporting the transplant community
- https://www.unos.org- United Network for Organ Sharing (UNOS)

Steps to Living Kidney Donation:

- Contact the Living Donor Office 800-333-9013, complete initial intake and determine eligibility
- Review any records if requested to determine if donor is eligible to proceed with evaluation
- Obtain verification of blood type and complete further compatibility testing if needed
- Complete a Formal Evaluation- *may* consist of 3 different appointments that will be at Michigan Medicine unless specified elsewhere
- Complete Cancer Screening according to the American Cancer Society Guidelines. *Note: this is considered general health maintenance and should be covered by the donor's insurance.*

Financial Perspective:

Expenses related to living donation evaluation process for Living Donors are covered by the Transplant Center. However, we are unable to reimburse donors for lost wages, traveling or lodging costs. One of the programs we work with is the National Living Donor Assistance Program. This is a federal program that may be able to provide assistance with costs associated with Living Donation. Attached you will find more information about this program as well as additional living donor financial resources

Post-Donation and Recovery:

Donors are generally discharged from the hospital within 24 hours after surgery. Expected recovery may vary from 4-6 weeks after donation depending on the type of employment and lifestyle of the donor. A 2-week post-operative appointment will be scheduled at Michigan Medicine to determine expected clearance to return to daily activities. We request that you do not drive until you are seen at this post-operative appointment and given clearance to drive. You will be required to have a support person to help you during the post donation recovery.

Could you send a letter or email? Here are some words to start you off.

Dear_____,

I'm asking for your help to spread the word.

I have kidney disease, and my kidneys have stopped working. My doctors want me to consider getting a kidney transplant, which will give me my best chance of living a longer life. It would also give me more freedom and energy.



I could get a transplant within the next year if someone decides to donate a kidney to me. Living donors don't have to be related to me. Also, living donors can't donate if they have diabetes, high blood pressure, or kidney problems.

If you want to help share my need for a donor with your family and friends, I would appreciate it. It can be hard to bring this up with people myself. It's possible that one of them, or someone they know, would want to help me or someone else. If you want to learn more, please go to **exploretransplant.org**.

Finally, I want to ask you to consider becoming a donor for me. I know this is a personal decision that isn't right for everyone. If you want to learn more, the website I mentioned above has videos of actual living donors telling their stories. Please know that if you don't want to consider living donation, I understand and respect your decision.

If you want more information about living donation, please contact my transplant center, ______, at ______. They'll be glad to answer your questions.

Thank you for taking the time to read this and for caring about me.

Sincerely,

Other words I would add:_





Prescription for Donating Your Kidney



Are you interested in being a living donor?

1st Step: Contact the University of Michigan Transplant Center at 1-800-333-9013 to speak with a living donor coordinator or go online to complete a screening questionnaire. Please visit www.uofmhealth.org/transplant and go to the kidney and pancreas section. The form can be found within the living and paired kidney donation section.



Resources to learn more



A guide for patients, family, and friends

Learn about kidney disease and treatment options:

American Association of Kidney Patients aakp.org

Explore Transplant exploretransplant.org

Kidney School kidneyschool.org

Living Donors Online livingdonorsonline.org

National Kidney Foundation kidney.org

PKD Foundation pkdcure.org

Renal Support Network rsnhope.org

Renewal life-renewal.org

Transplant Recipients International Organization (TRIO) trioweb.org United Network for Organ Sharing (UNOS) unos.org

UNOS Transplant Living transplantliving.org/kidney

U.S. Department of Health & Human Services organdonor.gov

Find a transplant center near you:

Organ Procurement and Transplantation Network (OPTN) optn.transplant.hrsa.gov

For help paying for a transplant:

American Kidney Fund kidneyfund.org

American Transplant Foundation americantransplantfoundation.org

National Foundation for Transplants transplants.org

National Living Donor Assistance Center livingdonorassistance.org Learn about donor exchange programs:

Alliance for Paired Donation paireddonation.org

Living Donation California livingdonationcalifornia.org

National Kidney Registry kidneyregistry.org

United Network for Organ Sharing (UNOS) unos.org/donation/kidney-paired-donation Learn about Medicare coverage and dialysis:

Centers for Medicare & Medicaid Services (CMS) cms.gov/center/esrd.asp



