



Clinical Transplant Services

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OHSU Patient Label

Informed Consent for the Living Kidney Donor

Thank you for considering living kidney donation through Oregon Health and Science University (OHSU) transplant program. We look forward to working with you. You may find it helpful to review the meaning of some of the terms used in this consent.

- A “transplant candidate” is a person who needs an organ transplant. The transplant candidate must be on the national waiting list to receive an organ transplant from either a deceased donor or a living donor.
- The “intended recipient” is the person who you would like to receive your kidney.
- After a transplant candidate receives an organ from either a deceased donor or a living donor they are called a “transplant recipient” or “recipient.”
- If the living donor can name a specific recipient it is called a “directed donation.”
- If the living donor does not name a specific recipient it is an anonymous, altruistic or “non-directed donation.” Non-directed donors will be matched to a compatible transplant candidate on the waitlist.
- “Infectious diseases” are certain viral and sexually transmitted diseases that we will test you for because they can be passed on to your recipient through the transplanted kidney. For example: Tuberculosis (TB), HIV, Hepatitis C (HCV), Hepatitis B (HBV), and Syphilis.
- “BMI” stands for your body mass index. BMI is a measurement of body fat based on your height and weight. Combined with your current health and family history can help predict your risk of developing chronic diseases. The BMI is the tool we use to determine if you are able to donate a kidney based on your current weight.

The United Network for Organ Sharing (UNOS) monitors and directs all organ transplant in the United States of America. All transplant centers must abide by the rules and regulations set forth by UNOS. **UNOS has a toll-free patient services phone number: 1-888-894-6361**

Call this number to:

- Find the transplant center(s) in your area that do living kidney transplants.
- Learn more about organ donation and transplantation policies and data.
- Ask questions or report concerns or problems about your transplant center.

Why Kidney Transplantation?

Kidney transplantation is a good treatment option for transplant candidates who have end stage renal disease (ESRD) or kidney failure. The gift of a kidney from a living donor can significantly improve the health and lifestyle of the person receiving it. There are advantages for both you and your intended recipient if they receive a living kidney donation.

Benefits for the Recipient:

- Kidneys from a living donor usually last longer than deceased donor kidneys.
- Your recipient can get a transplant faster, shortening their time on the waitlist.
- It may prevent their need for dialysis or shorten their time on dialysis.
- Better genetic matching which reduces the chance of rejection.
- Improved quality and length of life for your recipient.
- The kidney from a living donor usually starts working immediately while a kidney from a deceased donor may take longer to start working.

Benefits for the Donor:

- Positive emotional experience from helping someone you care about get transplanted.
- More time with your loved one.
- The emotional rewards of seeing your loved one achieve a better quality and length of life.
- The surgery can be planned at a time convenient for both you, your support person and your recipient.
- Non-directed donors take great satisfaction from helping someone in need.

Being a kidney donor can be a very rewarding experience but it may not be a good choice for everyone. Our intent is to give you accurate and complete information about donation so that you can make a decision that feels right for you. Kidney donors must be in excellent health and be able to make an educated and voluntary decision to donate.

- All directed donors must be 21 years of age or older.
- All non-directed donors must be 25 years of age or older.
- You will undergo very extensive education, medical testing and a psychosocial screening to determine if donation is a safe choice for you. The results of your lab work, your age, your past and current health issues, current medications, and family history will be considered to make this decision.
- It is possible that if you have a very strong family history for kidney disease, diabetes or high blood pressure you may be declined because your risk of developing them later in life is too high. Nationwide, only 10-20% of people who express an interest in living kidney donation actually become donors.

It is important you understand that donating a kidney involves having a major surgery that will not benefit you medically. Because of this, it is very important that you are fully educated about all aspects of kidney donation. OHSU has a dedicated donor team that will help you to understand all this information and assist you through every phase of your evaluation including consent, medical and psychosocial evaluation, pre and post-operative care, and mandatory long-term follow up.

UNOS requires that you acknowledge and consent to all of the following information:

The Voluntary Nature of Donation:

- It is important to understand that your kidney is a gift. You must give it willingly without an expectation of a financial reward from your recipient or the Transplant Program.
- No one should exert influence over your decision to donate with coercion (pressure or guilt) or inducement (material incentive, for example: vacation, money, or property).
- You may not be offered or accept anything of value in exchange for your kidney, including but not limited to money, property, or vacations. It is a federal crime to sell a kidney, or for any person to knowingly acquire, obtain or otherwise transfer a human organ for anything of value. The law imposes a maximum \$50,000 fine and five years in prison for any violation.
- You are never “locked into” this decision. If your circumstances or feelings change, just let us know that you no longer want to donate. We are here to support you in the decision that is right for you. You can change your mind about donation at any time in the process up to and including the day of surgery. If you are uncomfortable telling your intended recipient that you do not want to donate your decision will be protected and confidential. Your recipient will only be told that OHSU determined you did not meet criteria.

What if you have a hard time deciding?

- Some people decide to donate quickly, on an emotional level, with few worries or concerns. Others really struggle with their decision. We encourage donors to take their time, think things over, be honest with themselves about their feelings and ask lots of questions. Sometimes discussing donation with your friends, family or physician may be helpful; of course, the donor team is always available as well.
- If you would like, we can arrange for you to speak with a previous donor to get the personal perspective of someone who has lived through donation. The only “right” decision regarding donation is one that you are comfortable with.
- Kidney donation is truly a gift. What happens to the kidney after surgery is out of your control. Your satisfaction will come from knowing that you gave your recipient the best opportunity for a longer and healthier life.

Confidentiality:

- OHSU takes your privacy and confidentiality very seriously. We will take all responsible and reasonable precautions to provide confidentiality for you and your recipient. Your donor evaluation is your private health information that is protected by the Health Insurance Portability and Accountability Act (HIPAA). We may need a signed consent to disclose certain information to your recipient’s team.
- Your recipient will not be updated about what stage you are at in your evaluation. We will notify your recipient once you are fully approved as a donor and you have confirmed you want to proceed with surgery.

Independent Living Donor Advocate:

OHSU is required to provide you with an Independent Living Donor Advocate (ILDA) who is not involved in the care of any transplant candidates or transplant recipients. Your ILDA’s role is to serve as your representative in the donor process. They will present your interests, preferences and perspective to the donor team.

Your ILDA will:

- Review all the elements of the informed consent.
- Answer additional questions you may have or refer you to another team member who can.
- Make sure that your rights as a donor are protected.
- Make sure there is no evidence of pressure, coercion or undue emotional responsibility towards your intended recipient.
- Make sure you have all reasonable supports in place (physical, emotional, financial).

Your ILDA is available to you at all times during your evaluation including your admission to the hospital for surgery, immediate post-operative period and your long-term follow-up period after donation. If you choose to withdraw as a donor, your ILDA will assist you with this.

The Risks of Evaluation and Donation:

OHSU is required to inform you that there are medical, psychosocial (emotional) and financial risks associated with living kidney donation. Being very overweight, of older age, having high blood pressure, smoking tobacco, doing recreational drugs, drinking excessive alcohol or having another medical condition could make you more likely to die or have a serious problem after donation. These risks may be temporary or permanent and include, but are not limited to, all of the following:

- Potential Medical Risks:
 - Being allergic to dye/medication that is used in testing and having a bad reaction.
 - Discovery of an infectious disease that the hospital staff must report to local, state or federal health authorities.
 - Discovery of a serious medical condition that could create the need for unexpected decisions by the transplant team or require more medical tests or treatment that *you will have to pay for*.
 - Discovery of a genetic health risk factor or issue that you did not know about.
- Potential Surgical Risks:
 - It is reported that 3-6% of donors develop complications following surgery such as an abdominal hernia, infections, blood clots, the need for a blood transfusion, pneumonia, temporary or permanent nerve injury, bowel obstruction, acute kidney failure, the need for dialysis or a kidney transplant in the immediate post-operative period.
 - Every donor will have scars, pain and fatigue to varying degrees after surgery. Fatigue can be significant and prolonged for many donors.
 - A donor may have abdominal symptoms like constipation, bloating and nausea or urinary symptoms such as urinary retention post-operatively.
 - A donor nephrectomy involves the same risks typical of any major surgery including death. The risk of dying with donor surgery is reported as 3 in 10,000. The morbidity and mortality of the living donor is impacted by donor age, obesity, hypertension and other pre-existing conditions.

- Potential Psychosocial/Emotional Risks:
 - It is reported that 30% of living donors experience emotional problems after surgery. This includes problems with body image, changes to the living donor's lifestyle as a result of donation, depression, anxiety, emotional distress or grief.
 - Depression and anxiety are reported even when they had never experienced them before the surgery. This is more common if the donor or recipient experience medical problems such as surgical complications, inadequate support from friends and family, recurrent kidney disease or death after surgery.
 - Emotional reactions are usually short-term. Please reach out to us if you experience any difficulty adjusting after donation, or if unanticipated feelings take you by surprise. The living donor team is always available for support working through these issues.

- Potential Financial Impacts of Donation:
 - Your medical testing, the surgery, the hospital stay and your post-operative check-up are covered by your recipient's insurance. If your donor testing reveals a condition that would need further evaluation or treatment independent of donation (if it is needed for your own health whether you were going to donate or not), it will be billed to your own insurance.
 - We don't require you to have health insurance to donate but we strongly encourage you to have and keep health insurance for life.
 - The cost of travel (gas, airline or train tickets), short-term housing, childcare costs and lost wages from time off work are not reimbursed by OHSU. Other resources to help cover some of these costs may be available. The donor team will discuss this with you in detail.
 - Some donors have reported loss of employment or income related to donation. It is essential that you discuss donation with your Human Resources (HR) department or with your immediate supervisor if you do not have a HR contact. You need to know what benefits are available to you after donation surgery and whether your job will be secure after donation.
 - Difficulty obtaining future employment. You can engage in most occupations after donation, however, the military, law enforcement or fire departments might disqualify you or restrict your duties. We recommend donors speak with their supervisor early in the donor process regarding any impact donation may have on their career.
 - Negative impact on your ability to obtain, afford or maintain health insurance, disability insurance and life insurance. We advise every potential donor to contact all of their insurance carriers and ask if donation would impact their eligibility or premiums and whether they would cover any complications of donation.
 - OHSU does not cover the costs of future health problems or complications from the donor surgery. Future health problems or complications you experience will not be covered by the recipient's insurance unless they are specifically related to the donation surgery. Even if your complications are related to donation surgery the cost of them may only be covered for a limited time frame; after which you would be responsible for all the costs related to your issue.
 - We highly encourage you to discuss a benefit called Medicare part B with your recipient. It is a benefit they will automatically qualify for at the time of surgery. We do not require your recipient to have Medicare part B. If they do have it all the costs of your post-operative complications will be covered for life. Your social worker, ILDA and living donor coordinator (LDC) will discuss this option in more detail.

Evaluation Process:

- Once you are approved to begin medical testing your LDC will order tests and discuss the results with you. The order of testing may vary based on any number of factors related to either you or your recipient, your LDC will discuss this with you.
- If you do not live close to OHSU, the first part of your testing can be done locally at a lab or hospital close to your home. Your final day of testing and evaluation will be at OHSU.

General Medical Testing:

- Blood and urine tests to look at your kidney, pancreas and liver function.
- ABO to determine your blood type. You don't necessarily need to have the same blood type as your recipient.
- Tests to check for "pre-diabetes" and diabetes.
- Blood tests and a "crossmatch" to see if you and your recipient are "compatible". The crossmatch will determine if your recipient can accept your kidney. The crossmatch will be repeated within a week of your actual donation surgery to make sure that your recipient can still accept your kidney.
- Testing for infectious diseases that can be passed on to your recipient through your kidney. For example: tuberculosis, syphilis, HIV, hepatitis C, hepatitis B (these tests are repeated a few weeks before surgery). Some positive test results are required to be reported to local, state or federal public health authorities.
- Depending on your personal and family medical history, we may get additional tests or consultations before or after you travel to OHSU for your final day of testing. Be prepared that the need for additional testing or consultations can arise at any stage of your evaluation.
- If there is more than one potential living donor for a particular transplant candidate, OHSU will assist them in choosing the "best" donor to proceed with.

Final Evaluation at OHSU:

The final day of evaluation is a full day of testing and interviews at OHSU from 8:00 am to 4:00 pm. Your LDC will schedule this and provide you with detailed instructions. If you are traveling from out of town your LDC will help you with logistics and accommodations. It is not required but highly encouraged that you to bring your support person with you to your evaluation. Your evaluation will include:

- Blood and urine tests to confirm kidney, pancreas and liver function.
- Chest X-ray to evaluate your lung health.
- Electrocardiogram (EKG or ECG), to look for heart disease.
- A computed tomography (CT) scan of your abdomen to check for abnormalities. This test will show us the size of your kidneys and "map" the blood vessels that feed your kidneys. It will help your surgeon decide which surgical approach is the safest option for you. This test requires the use of intravenous (IV) contrast. All donors feel hot, flushed and like they have to pee. This is a normal and expected reaction to the IV contrast. An allergic reaction such as hives, rash, or shortness of breath may occur. In the event of an allergic reaction, you would receive treatment and contrast would be added to your allergy list.
- In addition to these tests you will meet with the entire living donor team in person.
- A nutritionist will assess your diet and nutrition and educate you regarding dietary health after donation.

- A social worker will talk to you about your social history, substance use history, how you cope with stress and your expectations about the surgery and recovery. They will assess your ability to make an informed decision, your social and financial support, and discuss some possible complicated emotional responses to donation.
- A donor surgeon will perform a history and physical exam to assess your risks with surgery; he will discuss those risks as well as the two operative procedures and recovery times with you.
- An independent nephrologist (kidney specialist) will also perform a history and physical exam, assess your long-term medical risks after donation and discuss those with you.
- A pharmacist will assess your past and current medication use and educate you regarding medications to avoid after donation.
- Your ILDA will review your understanding of the informed consent and the evaluation. They will explain the surgery and recovery in detail and talk about the lifestyle modifications required after donation. Your ILDA will also assess your comfort with donation and willingness to proceed.
- If you are a non-directed donor or do not know your recipient well, a psychiatric evaluation will be required as part of your evaluation. A psychiatrist experienced in living kidney donation will assess your psychiatric history, coping, motivation, relationship history with your intended recipient, if applicable, for evidence of coercion. Your LDC will discuss this with you if it is required for your evaluation.

After your full evaluation is completed, the entire donor team will meet to review the test results and information collected throughout your evaluation to determine if donation is a safe choice for you. Your LDC will notify you by phone of the team's decision to accept you or decline you as a donor. Please be aware that the need for additional tests or consults can arise after the full day at OHSU. You may be declined as a donor at any stage in the process. We have a responsibility to explain our decision to you, but the donor team's decision is final. If you are approved as a donor your LDC will discuss the next steps with you and educate you about the surgery and recovery period in detail.

Timeline:

- On average, it takes two to three months to complete your donor testing and another few weeks before your surgery is scheduled. Some donors may progress faster than this. Please be aware that the evaluation process may take longer if either you or your recipient have issues that need to be resolved before scheduling surgery. There may also be unanticipated events that occur that are out of the donor team's control that will delay scheduling surgery. Your LDC will discuss any changes to your expected timeline with you if necessary.
- We cannot pick a date or schedule your surgery until both you and your intended recipient have completed all required testing, are accepted by the team and approved for surgery. There is flexibility in scheduling surgery to accommodate for the preferences of you, your support person and your intended recipient.

Support Person Requirements:

- OHSU requires that you have a dedicated support person available to you for two full weeks after surgery. This individual will assist you in your recovery and perform many daily tasks for you such as: driving, shopping, cooking, cleaning, and household chores. This person must be available to you 24 hours a day and be completely separate from your recipient's support plan.

- This is especially important if the transplant is taking place between family members. It is okay for you to have more than one support person as long as someone is always there to assist you. Donors who have good support both physically and emotionally after surgery have better outcomes. This is a non-negotiable requirement and your LDC and ILDA will discuss this in more detail with you.

What will surgery involve?

Donating a kidney by elective nephrectomy is major surgery that requires general anesthesia. OHSU does two types of donor surgery, an open or “traditional” surgery, and a less invasive hand-assisted laparoscopic nephrectomy. Your surgeon will decide which procedure you will have based on your preference as well as the CT scan done at OHSU that will show the anatomy of your kidneys.

Most of our donors qualify for the less invasive hand-assisted laparoscopic nephrectomy. Please be aware there is a very rare risk that we will plan for you to have the laparoscopic surgery but an unexpected emergency would require that we open you up to the traditional surgery. Our surgeons will do whatever is needed to keep you safe and remove your kidney safely.

The recovery times for each surgery are quite different. It is important for you and your support person to consider whether you have enough time off of work and/or school and adequate financial resources to accommodate both surgical options. Your LDC and donor surgeons will discuss all surgical options and risks with you in great detail.

<u>Surgical Approach</u>	<u>Open/traditional</u>	<u>Laparoscopic</u>
Time in the OR	about 4 hours	about 4-6 hours
Incisions/scars	one, about 8 inches	one about 4 inches plus two about 1inch
Hospital stay	about 3-4 days	2-4 days
Return to desk job	about 3-4 weeks	about 3-4 weeks
Return to manual	about 12 weeks	about 6 weeks

The Surgery Process:

- Your LDC will schedule the surgery.
- You are required to stop tobacco and all other products that contain nicotine for at least four weeks before and after surgery. We require a negative nicotine screen before we will schedule surgery. Smoking increases your risk of life-threatening respiratory complications with anesthesia and post-surgical complications such as slow wound healing, pneumonia and blood clots.
- The day before surgery we will perform another crossmatch (compatibility testing) to make sure your intended recipient can still accept your kidney. We will also repeat testing for the infectious diseases can be passed on to your recipient through the transplanted kidney within a few weeks of surgery.
- You will be scheduled for a pre-operative clinic appointment the day before surgery. You will be given instructions about where to go and certain medications to pick up before your appointment if indicated.

At Your Pre-Operative Appointment:

- Your LDC will review the instructions for your surgical prep, how to check in for your surgery and the plan for post-operative education with your support person.
- Your ILDA will meet with you to reinforce the critical elements of informed consents, donor education, that you are free of coercion, and still wish to proceed with donation. The ILDA may recommend that surgery be postponed if there are any concerns.
- Your surgeon will review the plan for your expected surgery and details about your recovery. Long term follow-up requirements will be reviewed at this time.

After Surgery:

- You will spend two to three nights in the hospital. You will have IV fluids for two to three days until you are able to drink and eat sufficiently. You will have a catheter to drain urine for the first day or so. You will be encouraged to get out of bed and start moving soon after your surgery to speed your recovery.
- Your ILDA, LDC, social worker, surgeon, pharmacist and a dietitian will all come visit you in the hospital. Each member of the team will come to your room and provide you and your support person with detailed instructions on how to care for yourself after donation. They will provide you with information on how to reach your transplant team after hours and on the weekend and review the long-term follow-up requirements with you.
- If you live locally or within a few hours of OHSU you may recover at home. If you live out of state or more than a few hours from OHSU you will be required to stay near Portland for two full weeks after surgery.
- Your post-operative appointment will be two weeks after the surgery. If you live far away and have been staying locally you may return home after this appointment as long as the healing and recovery are on track and going well. We will collect blood and urine before your appointment to check your kidney function.
- Once you go home you will need to allow yourself enough time off work or school to rest and heal. Get plenty of rest. Do not perform strenuous activities that strain the muscles of your back, sides, or abdomen until week six (laparoscopic) or week 12 (open).
- You may be able to return to a desk job or remote work after three to four weeks. You can resume a more physically demanding job after 6-12 weeks depending on which surgery you had. Be patient with yourself. Remember that you are recovering from a major surgery and it may take one to six months before you are fully healed.
- Activity restrictions and post-surgical instructions help reduce your risk of serious complications like an abdominal hernia. Call your LDC or ILDA if you have any concerns regarding your recovery.
- Do not drive a car or operate machinery while you are taking narcotic pain medicine. Most donors resume driving three to four weeks after surgery.
- If you experience complications related to donation, OHSU will be available for evaluation and treatment. If it is not feasible for you to be treated at OHSU, our team will be available to your local care providers for consultation.

Physical Activity:

- We hope and expect donors will return to their pre-donation level of energy and to enjoy all your favorite activities. After recovery you can participate in most sports although we do advise against “extreme sports.” This includes high impact college or professional level sports. Please avoid activities that might put your kidney at risk for repeated physical impact or traumatic injury, for example: boxing, wrestling, sparring martial arts, wild horseback riding, roller derby. Remember that you only have one remaining kidney, take good care of it!

Long-Term Follow-up with OHSU:

- OHSU is required to report certain health information about you to UNOS at specific time intervals after your surgery. We want to ensure you are doing well and that your kidneys are functioning. It is important that you are comfortable committing to the mandatory follow-up testing. Information gathered from these follow-up calls improves the quality of OHSU’s living kidney donor education.
- Currently the mandatory reporting is at 6, 12 and 24 months after donation. You do not need to come back to see the team in person. Your LDC will contact you at these time points to order a blood and urine test to check your kidney function.
- Your LDC will do an interview with you. This takes 5-10 minutes to complete by phone. You will be asked to provide us with a current weight and blood pressure at these time points.
- If you live far away you may do the follow-up lab tests near your home. OHSU will order and pay for the testing at 6, 12 and 24 months after donation. We recommend you continue to get the same studies done every year with your own doctor starting 3 years after donating. Stay up to date on all your annual labs and age appropriate routine health maintenance so any changes can be detected and addressed early.

Every Year After OHSU Monitoring is Completed:

- Monitor your weight and blood pressure.
- Check a blood chemistry panel to look at your kidney function.
- Check a urine microscopic exam to check for protein in your urine.
- Remember that leading a healthy lifestyle with regular exercise, good nutrition, a moderate protein diet, avoiding herbal supplements, maintaining good blood pressure and a healthy weight will help your remaining kidney work at its best.

Recipient Considerations:

- There are alternative procedures and treatments for your intended recipient including dialysis, other potential living donors and receiving a transplant from a deceased donor (the waiting list). There is no “cure” for kidney failure at this time. Each of these treatment options comes with its own risks.
- A kidney transplant is considered the best treatment choice for people with kidney failure who are determined by their transplant center to be healthy enough to have a transplant surgery. Transplant often results in a longer and more enjoyable life than long-term dialysis.
- OHSU determines recipient candidacy for transplantation based on existing center- specific guidelines or practices as well as their clinical judgment. Every transplant candidate undergoes extensive testing and evaluation to decide if getting a transplant is a safe option for them.

- A deceased donor organ may become available for the recipient candidate before your evaluation is complete or prior to the living donor surgery. Your recipient may become ill or have other unanticipated delays that make your evaluation longer or require us to stop the donor evaluation.
- Your transplant candidate's medical information is also protected by HIPAA privacy laws. OHSU will take all responsible and reasonable precautions to provide confidentiality for you and your recipient. We may need a signed consent to disclose certain information to you.
- A transplant candidate may have an increased likelihood of a "bad outcome" (medical and/or surgical complications) that will NOT be disclosed to the donor. These risks may limit how long your kidney lasts in the recipient and require them to need another transplant sooner. These risks include but are not limited to: rejection of the kidney (graft failure), delayed graft function (the kidney taking longer to work) that would require continued dialysis after transplant or death that might exceed local or national averages (but do not prohibit transplantation).
- Recipients will need to take anti-rejection medications for the rest of their life. These medications can have some very significant side effects and makes them more susceptible to certain infections and cancer that may limit how long your kidney lasts and require them to need another transplant sooner.

Donor Considerations:

- OHSU may decline you as a living donor. There are no "universal" selection criteria for living donors; each transplant center decides to accept or decline a donor based on its own best medical judgment. You have the right to pursue donation at a different transplant center if OHSU declines you. Your intended recipient may request a referral to a different program if you are declined and they disagree with the team's decision.
- You may be required to lose weight before starting your donor evaluation or before scheduling surgery. Donors who do not meet weight criteria will be declined. Your LDC will discuss this requirement in detail with you if indicated.
- You may be required to quit tobacco, hormone replacements, certain over the counter drugs or prescription medications prior to surgery. You will be required to have a negative nicotine or drug screen prior to scheduling surgery. If you are unsuccessful in quitting any substance as required you would not be able to donate.
- For purposes of ensuring that the correct kidney is transplanted into your recipient certain information about you will be put in your recipient's chart at the time of surgery. This may include any or all of the following information: your name, date of birth, blood type, tissue typing, whether you have had certain viruses in the past and the UNOS Donor ID number that is assigned to you.
- As required by UNOS policy, OHSU will obtain a blood sample for storage within 24 hours of the transplant surgery. This sample will be stored by the Laboratory of Immunogenetics and Histocompatibility for 10 years following transplant surgery.
- If you are diagnosed with any infectious disease or malignancy (cancer) within the first two years following your donation report it to OHSU. These health issues have the potential to impact your recipient's treatment plan and will be disclosed to your recipient or your recipient's transplant hospital if your kidney was donated through the paired exchange. We are required to report these findings to UNOS through the Patient Safety Portal.

Additional Considerations for Non-Directed Donors:

- If you are a non-directed (anonymous) donor, you are donating to someone you do not know or do not know well and there are some additional considerations. The donor team will discuss them with you in detail.
- You are required to have health insurance before beginning your evaluation.
- As a non-directed donor, you can choose to enter a national Paired Exchange Program, start a transplant chain within OHSU or donate to a recipient on the OHSU deceased donor waiting list. You cannot influence who will receive your kidney. You will have no say as to the race, sex, gender, age, religion or any other demographics or characteristics of your recipient.
- There are strict confidentiality and communication guidelines. Both your identity and the identity of your recipient are kept confidential. While all responsible and reasonable measures will be taken to maintain confidentiality and to protect your identities, there is a risk your recipient may learn of your identity or you of theirs.
- Some non-directed donors do not want to know anything about their recipient or what happens to their kidney. Their satisfaction comes simply from knowing they tried to help someone live a better life. Many donors hope for a relationship with the recipient or to hear from them after donation to know “how they helped someone.” It is very important you understand that you have *no guarantee* of ever hearing from your recipient or knowing the outcome of your gift.
- Communication between you and your recipient must be welcomed and wanted by *both* of you. There are strict rules regarding the timeline and nature of communication after donation. These will be explained to you in full detail. You must agree to and consent to the communication rules prior to surgery.

Long-Term Health Considerations:

- Kidney function is permanently reduced after donation. On average, a donor has a 25%-35% permanent loss in kidney function. Donation does not affect your life expectancy unless you develop other medical problems after donation.
- The medical evaluation of a young donor cannot accurately predict the lifetime risk of developing Chronic Kidney Disease (CKD) or kidney failure. This is because CKD generally doesn't develop until mid-life (40 or 50 years of age) and kidney failure generally develops after the age of 60.
- Your risk of having kidney failure later in your life is not any higher than it is for someone in the general population of a similar age, sex or race. However, you do have a slightly increased risk of kidney failure than healthy people who are not donors.
- Donors may be at higher risk of developing CKD or kidney failure if they sustain damage to or cancer in their one remaining kidney. You may progress to kidney failure faster and need dialysis or your own kidney transplant sooner because you only have one kidney.
- High blood pressure is one of the leading causes of kidney failure. Regular monitoring of your blood pressure is crucial after donation because it is a “silent disease”. This means you will not have symptoms or feel bad until significant damage has been done to your kidney. You can check your blood pressure at the pharmacy, fire station, doctor's office or you may purchase a blood pressure cuff to keep at home (use an arm cuff, not a wrist cuff). Because you have an increased risk of developing high blood pressure after donation, we recommend that you measure your blood pressure regularly, at least a few times year and let your doctor know if it is getting higher. Uncontrolled high blood pressure can lead to kidney failure.

- Dialysis or transplant would be required if you developed kidney failure after donation. Current UNOS practice is to prioritize prior living kidney donors on the deceased donor waitlist, if they later need a kidney themselves.
- There is no evidence that donating a kidney impacts the donor's ability to have children. The risks of pre-eclampsia or gestational hypertension (high blood pressure with pregnancy) are increased after donation. We recommend that woman do not donate for one year after having a baby and wait for one year after donation surgery before becoming pregnant. We also recommend that donors discuss pregnancy with their own physician before becoming pregnant and get early, regular pre-natal care.

Long-Term Lifestyle Changes After Donation:

- We recommend that you eat a moderate protein diet after donation. This means you only need to eat 80% of your protein needs based on your weight. Protein is processed through the kidneys so the more you eat the harder they work. Limiting protein can reduce the demand on your one remaining kidney. Your LDC will help you calculate your post donation protein goals.
- Plant proteins, such as tofu, beans, lentils, nuts and seeds are "gentler" on your kidneys. Enjoy them! Avoid high protein diets. As long as you enjoy a variety of foods, with one or two protein sources at each meal, you do not need any special high protein shakes or powders.
- Limit sodium to 2300mg a day to keep your blood pressure under control. Avoid adding salt to your food when cooking or adding salt to it at the table. Avoid heavily salted nuts.
- Your kidneys love water! Staying well hydrated supports the kidney and general metabolic health. It is recommended you drink a minimum of 80 oz (equal to 10 cups) of water a day. All decaffeinated fluids can count towards that fluid goal.
- You may drink caffeine in moderation such as a cup or two of coffee or caffeinated tea in the morning or an occasional soda but you cannot count them towards your fluid goal. Be aware some sodas contain sodium so read the labels and limit them. Excessive caffeine intake can be dehydrating, if you drink more than a few caffeinated beverages a day you should drink an extra glass of water. It is recommended you avoid all "energy drinks" for life as they are dehydrating and can be extremely harmful to the kidneys.
- Avoid all herbal and dietary supplements after donation. It is better to get all your vitamins and minerals from food sources. It is okay to drink herbal teas (chamomile, mint, ginger etc...) and cook with spices, but avoid all herbs in a pill or tincture (liquid) form as they are concentrated and can be harmful to the kidneys.
- It is important to maintain a healthy weight after donation and aim for a healthy BMI. Being overweight increases your risk of surgical complications and many negative health outcomes including but not limited to kidney disease, high blood pressure, heart disease, type 2 diabetes and certain cancers. Avoid high protein diets, diet pills and laxatives for weight control they can significantly harm your one remaining kidney. Use a healthy diet and exercise to lose weight.

Alcohol, Tobacco and Recreational Drugs:

- Avoid all tobacco products and vaping. We strongly discourage tobacco and nicotine products in any form. There are numerous negative health outcomes and they are particularly harmful for kidneys.

- Avoid all recreational drugs including but not limited to marijuana, cocaine, molly (ecstasy), heroin, CBD, kratom, methamphetamines and LSD (acid).
- Alcohol intake should not exceed healthy guidelines for the general population. This is limited to one drink a day for women and two a day for men. Exceeding healthy guidelines for alcohol puts you at higher risk for hypertension, it can impair the kidneys ability to filter blood and lead to other negative health outcomes.

Treatments and Medications:

- After donation, IV dye for tests such as CT scans should be avoided if possible. If they are necessary, you should be well hydrated before and after the study.
- It is essential to avoid non-steroidal anti-inflammatory drugs (NSAIDs) for life. Avoid over the counter, prescribed, or combination drugs that contain NSAID medications such as ibuprofen, Aleve, aspirin, Bayer, naproxen, Mobic, Motrin, etc. They are very hard on the kidneys and can cause long term damage. It is okay to use a topical NSAID cream or “patch” on sore muscles which are “kidney friendly”. Taking a baby aspirin a day (81mg) is fine. You should NOT use NSAIDs in large doses for extended periods of time as they may harm your remaining kidney.
- Read drug labels and make sure all your future healthcare providers know you only have one kidney so they can select the safest medications, tests, treatments and procedures for you.
- Do not take vitamins that are not medically indicated for you. A multivitamin should have no more than 100% of the recommended daily allowance (RDA) for any ingredient. Always check with your doctor or consult OHSU transplant team **before** starting any new product.

Other Issues:

- You have been provided with national and OHSU specific one- and three-year kidney transplant recipient patient survival as well as one- and three-year graft (transplanted kidney) survival. These statistics are also available at the Scientific Registry of Transplant Recipients (SRTR) web site: <http://www.ustransplant.org/csr/current/csrDefault.aspx>.
- If your kidney is donated through the paired exchange at another hospital, we will provide you with their SRTR data in addition to national one-year patient and organ survival. In the unlikely event that in a paired exchange we don’t know which hospital transplanted your kidney we will provide you with the most current national one-year patient and organ survival.
- OHSU is in good standing with the Center for Medicare and Medicaid Services (CMS) and has no unmet requirements. If a transplant is not performed at a Medicare approved transplant center, it could affect the recipient’s ability to access transplant benefits through Medicare. If your kidney is donated through the paired exchange at another hospital we will provide you with information about any CMS requirement not being met by that hospital.

I understand that if I have concerns or grievances about the OHSU Transplant Center I can discuss them with my Independent Living Donor Advocate, the supervisor of the transplant program, the **OHSU Patient Advocate Office 503-494-7959 or UNOS 888- 894-6361**



Clinical Transplant Services

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Toll free: 800/452-1369 x 8500 - Fax: 503/494-4492

OHSU Patient Label

I have read and considered everything in this informed consent. I wish to continue in the process of evaluation as a potential living kidney donor. I understand that signing this consent does not in any way obligate me to donate and that I can change my mind about donation at any time without penalty for doing so.

Potential living kidney donor signature/date

Witness signature/date

Printed name

Printed witness name

I am on-site at Oregon Health and Science University completing my evaluation as a living kidney donor. I have reviewed the above, have had an opportunity to ask questions and had them answered and wish to continue in the donor process.

Potential living kidney donor signature/date

ILDA signature/date

Printed name

Printed witness name