University of Washington Medical Center Living Kidney Donor Program
PATIENT ACKNOWLEDGEMENT FOR MEDICAL/SURGICAL EVALUATION AS A LIVING KIDNEY DONOR

I have been given the option to undergo medical, surgical and psychosocial evaluation to determine if I am a candidate for donating one of my kidneys for transplant to a designated recipient. This process is called living kidney donation.

Living kidney donation involves three phases. The first phase is a thorough medical and surgical evaluation to determine if I am a suitable living kidney donor. If it is determined that I am approved as a suitable donor and I agree to continue, I will enter into the second phase. In the second phase, I will undergo surgery for the removal of one of my kidneys for transplant in a designated recipient. The third phase is post-donation follow up care.

Because I have no obvious medical conditions that would make it impossible for me to be a living kidney donor, I have been given the option to proceed with the living donor evaluation. I understand that my willingness to participate in the medical, surgical and psychosocial evaluation for living kidney donation does not guarantee that I will be able to donate or obligate me to donate my organ for transplantation.

I understand that my donation is voluntary. I understand that I may discontinue the donor evaluation process and decline to donate at any time, and my choice not to donate will be protected and confidential.

Confidentiality
I understand that this transplant center will take all reasonable precautions to provide confidentiality for me and the recipient. If I wish to share my medical information, I will sign a hospital release of information form. The transplant candidate’s information is also confidential. They may have risk factors for increased illness and death that are not disclosed to me.

EVALUATION PROCESS
Length of Medical Evaluation Process
My medical evaluation as a potential living donor will be coordinated if my preliminary screening is acceptable by the Living Donor team at UWMC. I understand that this medical, surgical and psychosocial evaluation process may take 2 to 6 months to complete. I understand that this process will include a 30-day cooling off period which starts at the beginning of HLA testing so I may further consider living kidney donation/surgery before making a decision to donate. I am aware that a deceased donor kidney might become available for the recipient before the donor evaluation is completed or transplant occurs.

Living Donor Team Members:
An Independent Donor Advocate (IDA), a licensed clinical social worker, must be provided to me throughout the donation process and recovery period to promote my best interest and advocate for my rights. The IDA is independent of the recipient’s care team. The IDA will assist me with obtaining and understanding information regarding the medical, psychological and financial risks associated with being a living donor. The IDA will be available to me to discuss any concerns or questions I may have throughout the donor evaluation and

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Patient Initial
post-donation. The IDA will make sure that I feel comfortable moving forward with the living donation process and that I do not feel any pressure to donate. The IDA will be my voice at the donor selection conference.

The Nurse Transplant Coordinator provides medical education through all three phases of the donation process. The nurse coordinator facilitates the medical and surgical work-up, the surgery and follow up care. Meeting with the nurse coordinator is intended to provide me with an opportunity to ask questions and to become fully informed about the process, testing that is needed and results of testing preformed.

The Scheduler coordinates testing, procedures and appointments for my evaluation. The scheduling coordinator provides detailed instructions about testing, procedures and appointments that are performed at outside facilities and at University of Washington Medical Center.

A Transplant Surgeon meets with me to discuss whether donation is an option for me, based on the results of my testing. The surgeon will also discuss the significance of having the surgery, the donation procedure itself, the risks of the surgery and the possible complications during my recovery period and after my donation.

A Transplant Nephrologist meets with me and determines if I am a good medical candidate for donation. The nephrologist will review my medical history and ask many questions about my health and what infections I may have been exposed to. The nephrologist will review my family history to determine if I am a suitable candidate for donation. After donation, the nephrologist follows my kidney function for two years.

The Social Worker, a licensed clinical transplant social worker, will complete a full psychosocial evaluation, including review of my mental health and alcohol and drug use. The purpose of this evaluation is to determine if I understand the emotional, financial and physical stress I may experience as a kidney donor. This interview will also allow me to become acquainted with the support systems available at the UWMC. The social worker can also recommend options for assistance with expenses not covered as part of the donation (e.g., housing and transportation). Support of the transplant social worker will be available throughout the living kidney donor process to help with stress-related problems to me and my family.

A Psychiatrist/Psychologist may conduct a more in-depth psychiatric evaluation and assessment. Some patients with a history of drug or alcohol abuse may be required to participate in a rehabilitation program and/or to abstain from substance use prior to and after donor surgery.

A Registered Dietitian performs a nutritional assessment and provides nutritional education for kidney health.

A Transplant Pharmacist performs a medication review, discusses allergies and provides pharmacological education for future kidney health.

**Physical Examination and Laboratory Tests**

I will undergo a thorough physical examination that includes, but is not necessarily limited to: a complete medical history, kidney function testing (24-hour urine collections and/or nuclear scan), histocompatibility testing, blood tests, including HIV and Hepatitis, as well as electrocardiogram (EKG) and chest x-ray. Depending upon my past medical history, additional tests may be needed. If the results of these tests are acceptable, I will undergo further tests to measure the size, blood supply and condition of my kidney.
Abdominal CT Scan
I will undergo a CT scan, which is a special x-ray that includes injection of a contrast dye for detailed imaging of my kidneys. The surgeon will use the CT scan to determine which kidney will be removed for donation and the best surgical method (laparoscopic or open) for the donor nephrectomy (surgery for the removal of my kidney). This is a low risk procedure with contrast dye that may include an allergic reaction. If you have had any allergies to dye, shellfish, eggs or iodine, you must inform us so we can request radiology review and prepare appropriately.

Test Results
The results of all tests will be discussed with me. If it is determined that I am a suitable candidate for living kidney donation, I will be asked to carefully, once again, consider my decision to be a living kidney donor.

Risks of Donor Evaluation
I understand that during the evaluation process I may be found to have a condition that may or may not be treatable. Risks of medical testing may include results that bring unexpected decisions for you and the medical team. Discovery of infections, serious medical conditions, adverse genetic findings or malignancies could be uncovered by evaluation. This may result in additional testing and treatments that may be the financial responsibility of the donor or donor’s insurance. Testing could reveal positive results for infections that must be reported by law to other health care agencies. Health information obtained during the evaluation is subject to the same regulations as all records and could reveal conditions that must be reported to local, state, or federal public health authorities. HLA testing may expose unexpected identity or family relationships. Any infectious disease or malignancy pertinent to acute recipient care discovered during the first two years of post-operative follow-up care will be disclosed to me, the recipient’s transplant center, UNOS, and may need to be reported to local, state or federal public health authorities.

Future Risks of Kidney Donation
In a healthy patient, the remaining kidney has been shown to increase in size and has the ability to provide sufficient kidney function for the remainder of my life. Risk of end stage renal disease (ESRD) does not exceed that of members of general population with the same demographic profile. There exists, however, a long-term risk of developing end stage kidney failure after donating a kidney; this has been estimated to be as high as 0.5%. The specific risk of developing end stage kidney failure as a consequence of donating a kidney at individual programs is not yet available. Generally, chronic kidney disease (CKD) develops in mid-life (40-50 years old) and ESRD develops after age 60. The evaluation of a young potential donor cannot predict lifetime risk of CKD or ESRD. Future obesity, high blood pressure and other medical conditions can lead to increased risk of illness and death. Donors may be at a higher risk for CKD if there is sustained damage to the remaining kidney. The development of CKD and progression to ESRD may be more rapid with only one kidney. ESRD requires dialysis and/or transplantation. Current practice is to prioritize prior living kidney donors who become kidney transplant candidates.

Psychosocial Risks
I understand that potential psychosocial risks related to donation include the following: problems with body image; post-surgery depression or anxiety; anxiety related to dependence on others; feelings of guilt; feelings of emotional distress or bereavement if the transplant recipient experiences any recurrent disease or in the event of
the transplant recipient’s death; feeling of distress if donor’s lifestyle is impacted; and post-traumatic stress disorder (PTSD).

**SURGICAL PROCEDURE**

**Donor Nephrectomy Surgery**
The surgical removal of one of the kidneys for transplant is called a donor nephrectomy surgery. A donor nephrectomy in a healthy individual carries less risk than when it is done for treatment of a diseased kidney. Donor nephrectomy can be performed safely, but as with any major surgery there are minor and major risks including the risk of death either from anesthesia or surgery.

**Procedure**
The donor nephrectomy entails the surgical removal of one of my kidneys to transplant in a designated recipient. One of my kidneys will be removed using either a laparoscopic or open surgical procedure. Although most of our nephrectomies are through the laparoscopic approach, some are done by open procedure, either because of donor choice or anatomical considerations. With the laparoscopic approach, there are typically 3 to 5 small incisions (1 to 2cm) and one larger incision (7 to 8cm) to remove the kidney. For the open approach, there is one incision (8 to 9cm). There exists the possibility that an intended laparoscopic approach may require conversion to the open approach requiring a larger surgical incision. This occurs in less than 2% of the living donor procedures. This center does not recover extra vessels from a living kidney donor for transplantation.

**Procedural Risks**
The overall frequency of major complications when this operation is performed in a healthy person and by trained surgeons is expected to be minimal. As with any surgery, the administration of general anesthesia carries a small risk for a healthy person. In general, complications can occur immediately following surgery or later in the course of life. In most cases, these symptoms are temporary but in rare cases they can become permanent.

Immediate complications include pain, prolonged bowel symptoms such as nausea, vomiting, bloating, constipation and developing bowel obstruction, DVT (deep vein thrombosis), bleeding, blood clots and pulmonary embolism. Scarring, fatigue, infection, as well as injury to the blood vessels, kidney and surrounding organs could also be a complication. Damage to nerves may occur. This can happen from direct contact within the abdomen or from pressure or positioning of the arms, legs or back during the surgery. Nerve damage can cause numbness, weakness, paralysis and/or pain. The risk of death from nephrectomy in the published medical literature ranges from 0.02 – 0.04% with the most successful outcomes in those patients that are in good health prior to surgery. Some donors report feeling emptiness or occasional ‘twinges’ of discomfort in the area where the kidney was removed. There may also be unexpected complications not listed above.

Long-term complications include hernia, chronic nerve injury, chronic pain, fatigue, decrease in kidney function and in rare cases, End Stage Renal Disease (ESRD).
Blood Transfusions
The risk of substantial blood loss during donor nephrectomy surgery is approximately 0-2%. This may necessitate a blood transfusion. I acknowledge that I will be asked to agree to a blood transfusion with the risks associated if my doctors determine it is necessary.

Recovery Period
The in-hospital recovery period for donor nephrectomy in a healthy person is approximately 2 to 4 days. In addition, I should expect a recovery period at home of approximately 4 to 6 weeks. Should I experience surgical or postoperative complications, the recovery period may be longer. Removal of one kidney will cause a temporary reduction in overall kidney function, but I should not experience any noticeable side effects. On the average, kidney donors will have 25-35% permanent loss of kidney function at donation.

Follow Up Care after Donation
For the continued health of my kidney, I commit to be followed by the UWMC for 2 years after donation, and longer if needed. I will be asked to attend follow up appointments at 12 days, 6 months, 1 year, and 2 years after the donation. If it is not possible for me to attend follow-up appointments at UWMC, it will be necessary to have yearly physical examinations with my primary care physician and laboratory testing which would include serum creatinine and urine testing. I will be asked to sign a release of records from my primary care physician in order to help follow my progress after donation. UWMC requests that I notify them if any medical issues occur which may be related to my donor surgery.

Financial Costs/ Risks
I understand that during the evaluation process I may be found to have a condition that needs further evaluation and treatment. Treatment for any conditions will be my responsibility. Additionally, I understand that the evaluation or donation could affect my future ability to obtain, maintain or afford health, disability or life insurance and my lifetime maximum benefit.

Donation may result in loss of employment or income or have a negative impact on the ability to obtain future employment. I may be responsible for travel, housing, child-care costs and lost wages related to the donation.

Following donation, I will also be responsible for obtaining yearly lab testing and physicals with UWMC or my primary care physician. I will be requested to return to UWMC at six months, one-year and two-years following donation. I understand that medical expenses related to any complications arising from my living donation surgical procedure will be billed to my recipients’ insurance per Medicare guidelines. It is important to know that these complications must relate directly to the donation surgery and not any other health conditions. Not all charges are covered by the recipient’s insurance. If questions surface, the financial counselor team will assist me clarify the concerns.

The sale or purchase of human organs is a federal crime. It is unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for the use in human transplantation.

Patient Initial
NOTIFICATION OF TRANSPLANT PROGRAM INACTIVATION (CLOSURE)

If any event were to occur that might impact our ability to provide transplant services, our staff will attempt to contact you regarding the type of program inactivation (closure) in a timely manner. This would be rare, but may include lack of required physician coverage, operational changes requiring temporary cessation of transplantation or a natural disaster. The inactivation may be short-term or long-term.

If the event is unplanned, the center’s disaster call list will be initiated once inactivation is determined. The designated individual(s) would initiate notification of patients. We would use whatever means is available to contact you, such as telephone, email, text or mail. If the disaster is severe, we will make arrangements for an out-of-the-hospital agency to assist us with the notification.

UNITED NETWORK for ORGAN SHARING (UNOS)

UNOS is the national agency that helps to keep track of all transplant outcomes. Prior to having my kidney removed and transplanted into the intended recipient, I understand that I will be registered into UNOS as a living kidney donor. The purpose of my registration is to track my health along with the health of all other living kidney donors after donation. This center is required to submit health information about me at 6 months, 1 year, and 2 years post donation.

The United Network for Organ Sharing provides a toll-free patient services line to help transplant candidates, recipients, and family members understand organ allocation practices and transplantation data. This "Patient Information Letter" from the United Network for Organ Sharing (UNOS) has been provided to you at your clinic visit. It describes the services and information offered to patients by UNOS and the Organ Procurement and Transplantation Network.

National and Transplant Center-Specific Outcomes

Statistics about survival after kidney transplant are available from the Scientific Registry of Transplant Recipients (SRTR). We will give you a handout with details regarding these statistics. You can also review these statistics at www.srtr.org.

ALTERNATIVES

If I do not wish to be a living donor, your intended recipient will continue to receive care by the kidney transplant team at UWMC. The recipient will continue to be eligible for deceased donor transplantation, plus other living donors can be evaluated.

If the UWMC living donor program determines I am not eligible to donate, I can be evaluated by another transplant program with different selection criteria.

This agreement acknowledges that the enclosed detailed information regarding living kidney donation has been provided to me. I have read the information and been given opportunity to ask questions. I understand the information that has been given to me. I would like to proceed with the evaluation process.

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LIVING KIDNEY DONOR PROGRAM EVAL ACKNOWLEDGEMENT
PAGE 6 OF 6