

Living Kidney Donor Evaluation Education



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Organ Donation>Living Donor Eval Presentations

(Revised 1/14/2022)



Thank You!

First & foremost, the ChristianaCare Transplant Team would like to THANK YOU for considering giving the gift of Living Kidney Donation!





Our Responsibility to Donors... "First Do No Harm"

As a team we do all that we can to ensure donors are not harmed in order to help the recipient.





Informed Consent

Definition: Consent by a patient to a surgical or medical procedure after achieving an understanding of the relevant medical facts and the risks involved.

- Your responsibility is to ask questions until you understand.
- Our responsibility is to answer questions until you understand.







Living Donation is the best option for a transplant candidate, but it is <u>not</u> their only option. Other options include:

- \checkmark Dialysis, either hemodialysis or peritoneal dialysis
- ✓ Waiting for a deceased donor kidney off the UNOS list. (Note: A kidney may become available for the recipient before the living donor evaluation is complete or living donor surgery occurs.)
- \checkmark The transplant candidate may have another donor being evaluated





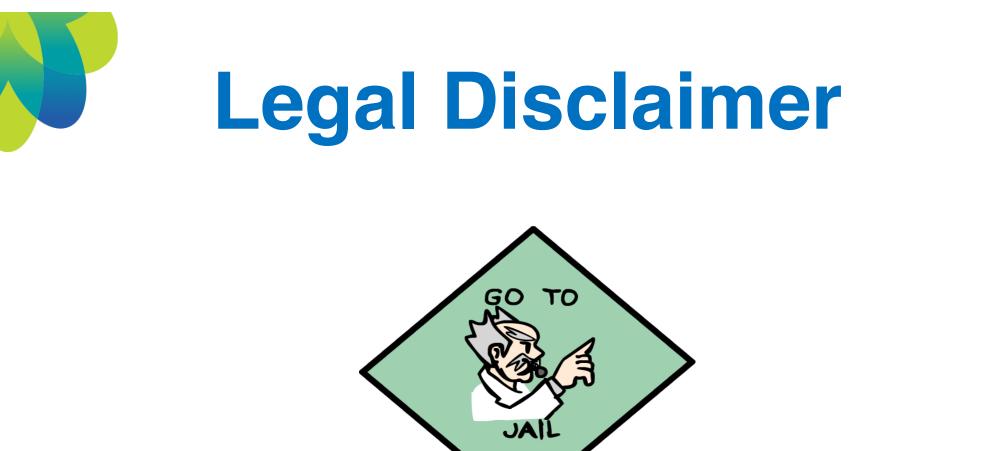
Our Commitment to Potential Living Donors

Potential Living Kidney Donors will receive a thorough medical and psychosocial evaluation.



- 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 health authorities.
- The ChristianaCare Kidney Transplant Program will take all reasonable precautions to provide confidentiality for the both the donor and the recipient.
- The ChristianaCare Kidney Transplant Program must provide an (ILDA) Independent Living Donor Advocate to the donor in accordance with Federal standards.





It is a federal crime for any person to knowingly acquire, obtain or otherwise transfer any human organ for valuable consideration.



Your Rights & Responsibilities

- You must be willing to donate.
- Your willingness to donate must be without inducement (payment or promises) or coercion (threats).
- You ask questions if there is something you do not understand.
- You will be provided with an (ILDA) Independent Living Donor Advocate to assist you with the donation process and protect your rights.
- You must understand that it is your right to decline to donate at any time.

If you should decide not to donate, you will be offered the opportunity to discontinue the process at any time in a way that is protected and confidential.



Our Responsibility

- To ensure you are willing to donate without inducement or coercion.
- To make sure all your questions have been answered to your satisfaction.
- To provide you with an (ILDA) Independent Living Donor Advocate.
- To ensure you are healthy enough and it is safe for you to donate to the best of our ability (minimize risk).
- To ensure that there is nothing in your medical workup that would harm the recipient by accepting your kidney.



Risks Associated with Living Donation

- Medical and Surgical Risks may be temporary or permanent.
- There may be psychological and financial risks also.
- These are rare, but the informed consent process includes discussions regarding risks.
- Please ask questions of any team members about any concerns that you have.





Referral Phase

- Interview/Screening with Living Donor Nurse Coordinator
- Interview/Screening with ILDA (Independent Living Donor Advocate)
- Information Packet with signed consents/medical release received back from potential donors



- Preliminary lab screening (blood type/compatibility, rules out diabetes, checks basic kidney function)
- Attend Nursing Education session on Living Donation
- Telehealth visit with Transplant Nephrologist



Evaluation Office Visit in Transplant Clinic

Meet the team

- Nephrologist- Medical evaluation
- Living Donor Coordinator
- Social Worker psychosocial evaluation
- Dietician
- Financial Coordinator



- Meet the Independent Living Donor Advocate (ILDA)
 - The ILDA you will meet in office may be different than the one you spoke with on the phone



Evaluation Lab Work

Blood Typing

- The first blood type for this was done in the referral phase. It let us know if you were blood type compatible with your recipient.
- If you are compatible, you can donate to your recipient.
- If you are not compatible, we will discuss paired donation with both you and the recipient.
- Paired donation may also be discussed with compatible pairs for certain situations.
- HLA typing & Crossmatch



- Your blood is also tested to see if the recipient has any antibodies or "fighter cells" against your tissue (kidney)
- If Compatible, you can donate directly to your recipient
- If incompatible, we will discuss paired donation with both you and the recipient



Evaluation Lab Work

- Complete Blood Count (CBC)
- Chemistry panel, Lipid panel, & coagulation testing
- Drug Screen
- Urinalysis and Urine Culture
- Infectious Disease Testing
 - HIV Tuberculosis
 - Hepatitis
 Chicken Pox
 - EBV Herpes
 - CMV
 Toxoplasmosis
 - Syphilis
- Other testing may be ordered based on your medical history.







Evaluation

Testing (Scheduled at your convenience)

Cardiac Testing, including cardiology consult if necessary

- EKG, Echocardiogram, Stress Test (males > 40 years old & females> 50 years old)
- Chest X Ray
- Renal Scan
- CT Angio
- Health Maintenance testing
 - Completed by donors with their own doctors
 - Colonoscopy, Gyn with Pap, & Mammogram
- Additional testing may be requested on an individual basis.

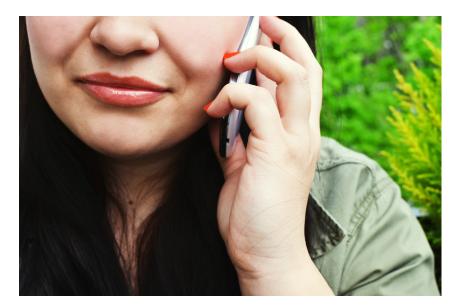






Evaluation Additional Information

- If there are > 3 months of inactivity/no response during your evaluation, the Living Donor Coordinator will end your living donor evaluation.
- Potential Living Donors are required to followup every 6 months between initial evaluation and donation with the Nephrologist, Social Worker, & Independent Donor Advocate.



Please stay in contact with your coordinator if you wish to continue with your donor evaluation.



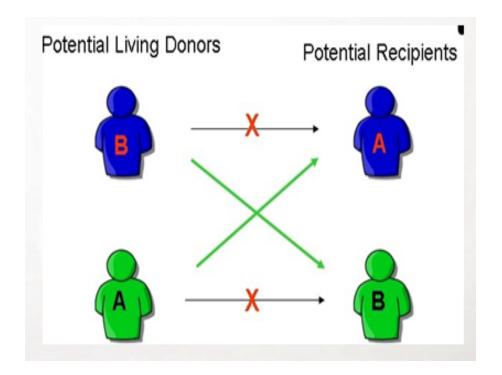


- You are able to opt out of the Donor Evaluation Process <u>at any time</u> and your reasons for doing so will be kept confidential.
- Your test results will be reported directly and only to you.
- We will not discuss your evaluation status or test results with the recipient, but you may if you wish.
- The Transplant Team will not discuss recipient information with you This includes the degree of tissue typing match.



Paired Kidney Donation

An alternative option given to those who are not directly compatible with their recipient.





Paired Kidney Donation Programs

- There are multiple Paired Kidney Donation Programs.
- ChristianaCare is affiliated with:
 - The National Kidney Registry (NKR): www.kidneyregistry.org.
 - The UNOS Kidney Paired Donation Program.
- Participation in Paired Donation is optional.
 - Both donor and recipient have to agree in order to be placed in a paired donor program.
 - There is a separate consent form for Paired Donation.
- Per National Kidney Registry regulations, Living Donors who are in the evaluation phase for >1 year will have to repeat most evaluation testing.



Risks/Benefits for being Evaluated for Living Donation

- Allergic reactions to the contrast dye
- Some of the infectious disease testing we do must be reported if positive – however, this also means you can get treatment.



- Some testing may show that you have a serious medical condition that needs to be corrected or followed.
- Thorough consultations and follow-up by our transplant multi-disciplinary team
- Some testing may identify adverse genetic findings unknown to the donor. (Discovery of certain abnormalities may require more testing at donor's expense.)



Decision to Accept Donor

- First, the donor must meet the basic criteria of the ChristianaCare Kidney Transplant Program
- If you can donate directly to your recipient & they are cleared for transplant, we will schedule surgery at <u>your</u> convenience.
- If you can donate, but not to your recipient, and you BOTH agree to being entered into the paired donation program, we will enroll you both.
- If we find that you are not a candidate for donation according to our criteria, we can refuse you as a donor.
- If you are declined as a candidate & still wish to pursue donation, you can be evaluated by another program with different criteria.



Decision to Accept Donor

- Deciding if a donor may donate a kidney is a decision by the <u>entire</u> ChristianaCare Transplant team.
- The Living Donor Coordinator will present the donor case to the Transplant team at a meeting where the decision will be made about the donor's ability to donate.
- The (ILDA) Independent Living Donor Advocate will support and represent your decision to donate & has full veto authority to end evaluation at any time.





Why is it a Team Decision to accept me as a Donor?



- Each team member is responsible for ensuring that you are healthy enough to donate.
- Each team member has a certain set of skills and knowledge to ensure as much as possible that donation will not harm you.
 - The Independent Advocate will support your desire to either donate or not donate



Once Evaluation Completed...

When the entire medical, surgical, and psychosocial examinations are complete, and the Transplant Team votes in favor of an individual proceeding to surgery--you are in the **Pre-Operative Phase**.





Pre-Operative Testing

Pre-Op testing will begin 2 weeks prior to the scheduled donation date.



Infectious Disease testing will be repeated 2 weeks before surgery. It is imperative that you do not participate in high-risk behaviors that could change your status.

Final Crossmatch will also be repeated at 2 weeks before surgery.

- Your prior confirmed compatible crossmatch done during the evaluation does not guarantee that this final crossmatch will indicate compatibility with your recipient. *This is rare but possible.*
- If final crossmatch is incompatible, you cannot donate directly to your recipient.



Pre-Operative Appointments

Two weeks prior to surgery, donor must have the following appointments:

(Appointments can be in our Office Clinic or via Telehealth)

- Pharmacist visit
- Social Worker visit



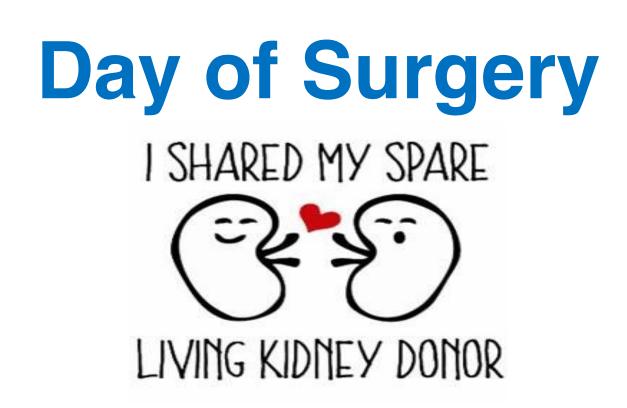


Pre-Operative Day (Day before Surgery)

- Appointment in the Transplant Office Clinic
 - Sign Surgical Consents
 - See Surgeon
 - Confirm that you have not been involved in any recent high-risk behaviors
- EKG
- CXR (Chest x-ray) if not done within the last year
- Lab work
- Review instructions for admission to hospital
- Any questions you have will be answered.
- You have the right to change your mind about donation in a way that will be kept confidential.







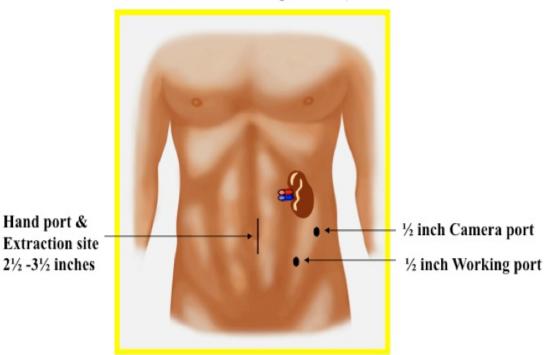
- Normal arrival around 0600 to Surgical Admissions Unit
- Pre-Op Labs, Covid19 test, IV placed
- You will have blood tubes drawn that will be archived/stored for 10 years to be used in the event that the recipient develops a disease that requires investigation



Donation Surgery

Hand Assisted Laparoscopic Donor Nephrectomy

(a variation of the Laparoscopic Donor Nephrectomy that some centers perform)









Inpatient Hospital Stay & Discharge

- Typical length of stay in the hospital is 2-3 days.
- Donors are kept in the hospital until pain & nausea is controlled, you are walking about, urinating without issues, and have evidence of bowel function.



You will have an omce visit in our clinic about i week after discharge from hospital.



Donor Post Op Follow-up Visits

- Follow up Consultations with our Transplant Team are a <u>BENEFIT</u> to all our Living Kidney Donors
- Certain Donor Followup visits are MANDATORY by UNOS

Follow Up

- Appointments are scheduled at the following intervals or as needed.
 - 1 week post discharge (Post Op visit) Per our policy
 - 1 month post donation (Return to work discussion) per our policy
 - 6 months post donation Mandatory per UNOS regulations
 - 1 year post donation Mandatory per UNOS regulations
 - 2 years post donation Mandatory per UNOS regulations
 - Annual visits/labs as requested by physician or Donor

*The 6-month, 1 yr. & 2 yr. f/u visits can be done via Telehealth



Important to Know about Variations to HIPPA

- Any infectious disease or malignancy occurring within 2 years in the donor that could affect the recipient, will be disclosed to the recipient's transplant program and reported through the OPTN Improving Patient Safety Portal.
- Certain infectious diseases that are identified during care must be reported to local, state, or federal public health authorities. ChristianaCare will follow this mandate.



Potential Medical Risks

- Decreased kidney function See next slide
- Acute kidney failure and the need for dialysis or kidney transplant for the living donor in the immediate post op period.
- Kidney failure and the need for chronic dialysis on kidney transplant for the donor.
- Females: Potential risk for pre-eclampsia or gestational hypertension in pregnancies post donation. (Risk increases from 4% in general population to 8% for Living Kidney Donors)





Post Donation Kidney Function

- On average, donors will have 25-35% permanent loss of kidney function post donation.
- Donors may be at higher risk for CKD (*Chronic Kidney Disease*) if they sustain damage to the remaining kidney.
- Development of CKD and progression to ESRD (*End Stage Renal Disease*) may be more rapid with only 1 kidney.
- Donor risks must be interpreted based on known epidemiology of both CKD or ESRD.
- Medical evaluation of young potential donors cannot predict lifetime risk.



Post Donation Kidney Function

Although risk of ESRD for living donors does not exceed that of the general population with the same demographic profile, risk of ESRD for living kidney donors may exceed that of healthy non-donors with medical characteristics similar to living kidney donors.

(Dialysis or Transplant is required when reaching ESRD)

Prior living kidney donors who become kidney transplant candidates receive list prioritization on the UNOS deceased donor list.

(If the Living Donor donated through the NKR Paired Exchange they are prioritized for a Living Kidney transplant.)



Potential Surgical Risks

- Abdominal or bowel symptoms such as bloating, nausea, and developing bowel obstruction.
- Scars, hernia, wound infection, blood clots, pneumonia, nerve injury, pain, fatigue, and other consequences of any surgical procedure.
- Morbidity (lack of health and well being) and mortality (death) of the donor may be impacted by existing medical conditions such as, but not limited to hypertension or obesity.
- Death (The risk of death from this procedure ranges in the literature from 0.03% to 0.06%. In comparison, the risk of death from a standard appendectomy is 0.7%.)



Potential Psychological Risks

- About 30 % of donors experience some degree of depression after they donate.
- Problems with body image.
- Feelings of emotional distress or bereavement if recipient experiences any recurrent disease or in the event of the recipient's death.
- Impact of donation on the donor's lifestyle

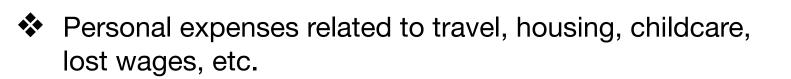






Potential Financial Risks

- Loss of employment or income during recovery.
- Negative impact on the ability to obtain future employment.
- Need for life-long medical followup.



- Negative impact on the ability to obtain, maintain, or afford health, disability, and life insurance.
- Future health problems experienced may not be covered by the recipient's insurance.





It's your kidney until you give it away (We cannot share recipient outcomes with you!)

The recovery hospital cannot share information with the donor about the recipient unless the recipient gives permission. This includes:

- The reasons for a recipient's increased likelihood of adverse outcomes.
 - ✓ Graft Failure
 - \checkmark Complications
 - ✓ Death
- Personal health information collected during the transplant candidate's evaluation, which is confidential and protected under privacy law.

We cannot share recipient test results, etc. with you, the donor.



Recipient Privacy



- Transplant hospitals have criteria for accepting patients to be recipients based on existing hospital specific guidelines or practices and clinical judgement.
- Any transplant candidate may have an increased likelihood of adverse outcomes that exceed local or national averages, do not necessarily prohibit transplantation, and these are not disclosed to the living donor.
- In other words, some transplant candidates may be riskier than others for adverse outcomes, but still meet the transplant hospital's criteria for being transplanted.



SRTR Data

(Scientific Registry of Transplant Recipients)



- UNOS collects and manages all data that pertain to the patient waiting list, organ donation and matching, and transplantation occurring on the OPTN, the nation's organ transplant network.
- This information provides information on a transplant program's outcomes for both transplant recipients and donors.
- All Transplant Programs have to share this data with their potential donors.



Sharing SRTR Data

If the recovery hospital and recipient hospital are the same:

(Both Donor & Recipient are having surgery at Christiana Care)

ChristianaCare must provide the potential donor data from the most recent SRTR center specific reports for our center:

- \checkmark National 1 year patient and graft survival rates
- \checkmark Hospital's 1 year patient and graft survival rates
- \checkmark Notification about all CMS outcome requirements not being met by the transplant hospital.

If the recovery hospital is not the same AND the recipient hospital is known:

(Donor is at Christiana Care and the recipient is having surgery at another hospital-occurs frequently in paired donation)

ChristianaCare must provide the potential donor data from the most recent SRTR center-specific reports:

- \checkmark National 1 year patient and graft survival rates
- \checkmark Recipient hospital's 1 year patient and graft survival rates
- ✓ Notification of all CMS outcome requirements not being met by the recipient hospital

If the recovery hospital and the recipient hospital will not be the same and the recipient hospital is not known:

(Donor is at ChristianaCare and the recipient is having surgery at another hospital and that hospital is unknown)

ChristianaCare must provide the living donor with national transplant recipient outcomes from the most recent SRTR reports, including national 1 year patient and transplanted organ survival.



Social MEDIA Stay Connected with Us!

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Other Post Clicks	100	Other Post Clicks	35	Other Post Clicks	19	Saves	0	Saves	1	Saves







- Receive important messages from transplant team
- Get updates on patient events
- Please provide your email to our staff today or scan this QR code!





QUESTIONS?

Please remember that informed consent is a process and not just a signature on a page. Please ask questions and make sure you understand the answers.

Again, we would like to thank you for your inquiry about living kidney donation.



The ChristianaCare Transplant Team

