OCHSNER MULTI-ORGAN TRANSPLANT CENTER

LIVING KIDNEY DONOR EDUCATION, INFORMATION, & COMMUNITY RESOURCE HANDBOOK

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Introduction

Welcome to the Ochsner Kidney Transplant Program!

Choosing to donate a kidney and give the "gift of life" is one of the most meaningful things anyone can do. Becoming a living donor offers a loved one or friend an alternative to remaining on the national transplant waiting list to receive an organ from a deceased donor. While living donation is not for everyone, it can be rewarding to know an opportunity for a better quality of life has been given to someone else.

This book explains certain issues and answers many common questions about living donation. We encourage you to share the information contained in this important handbook with any family members, friends, or caregivers who will be involved with your medical treatment and recovery. By knowing the facts, you and your family can make an educated decision, one that you can feel comfortable with, now and in the future.

You will meet several members of our team who will evaluate and educate you on living kidney donation as a treatment option for your family/friend's disease process. To qualify as a living donor, you must be physically fit, in good general health, and free from high blood pressure, diabetes, cancer, kidney disease and heart disease.

You will be scheduled for several diagnostic tests to determine your level of physical and mental health. Once the results of all testing are available, the Transplant Committee will review your case and determine if you are a suitable kidney donor for the patient awaiting a transplant.

It is also important to know, that you may change your mind at <u>any time</u> during the process. Your decision and reasons are kept confidential.

We provide you with the most up to date and cutting-edge care; however, we will need your assistance. Please make every effort to keep all appointments as scheduled.
If you cannot keep your appointments, please call in advance to reschedule**.**

If there is anything we may do to help you through this process, please contact us at (504) 842-3925 or (800) 928-1635.

The members of your team include:

Living Donor Coordinator: <u>Rebecca Guillera, RN</u>

Kidney Transplant Social Worker: <u>504-842-3925</u>

Patient Service Associate: <u>504-842-3925</u>

Donor Advocate <u>504-842-3541</u>

Treatment Options for Kidney Failure

Your kidneys are 2 bean-shaped organs located behind your stomach in the middle of your back, on either side of your spine. Kidneys perform some of the most important jobs in your body including:

- Filtering and removing waste by producing urine
- Helping to regulate blood pressure
- Cleaning and controlling the amount of blood in your body
- Keeping the body's balance of water, salt and acid constant
- Making hormones that help bone marrow produce red blood cells

If something happens to abnormally change the away the kidneys work, it is usually because of a condition that has been attacking the kidneys for a long time. Some conditions which can injure the kidneys are diabetes, high blood pressure, infection, cysts, and kidney stones. These can lead to chronic kidney disease which affects both kidneys. Sometimes you can be born with a problem that affects the kidney or have a problem that runs in your family. There may be no symptoms of kidney disease until you have had it for a while.

When the kidneys are not working correctly, the body's waste and excess fluids build up, causing harm to your body. Some signs of kidney disease are:

- Fluid retention – puffiness in the face, swelling of hands and feet
- A change in urination – amount, frequency, painful or difficult
- Shortness of Breath
- Mental confusion
- Abnormal blood or urine test results
- Tiredness

If kidney disease has not been diagnosed or treated early enough, or if you have not responded to treatment, the disease may progress to end stage kidney failure (ESRD). At this point, the kidneys have stopped working and you will need treatment to survive. Treatment options for kidney failure include:

- Hemodialysis
- Peritoneal Dialysis
- Kidney Transplantation (from a living or deceased donor)

Kidney transplant is considered a treatment for kidney disease, it is not a cure. Transplant recipients may lead a more normal life, free from dialysis. However, they will have to take medications and have frequent follow-up care for the life of the transplant. There are side effects to both dialysis and transplant. Understand, if you choose not to become a kidney donor, your recipient has other options.

Benefits of Living Kidney Donation

- The gift of a kidney can save the life of a transplant candidate. There is about a 3 to 5 year wait for a deceased donor kidney. Data shows that approximately 1 out of 20 patients die each year from kidney disease as they wait for a donor kidney. Living donation may also help to avoid the potential health complications which occur when a recipient is on dialysis for a long period of time.

- The experience of providing this gift to a person in need can serve as a very positive aspect of donation. Many donors report that they feel good about improving another person's life.
- Transplant's can greatly improve recipients' health and quality of life, allowing them to return to normal activities.

- With living donation, the transplant is scheduled at a convenient time for the donor and recipient, avoiding the stress and uncertainty of being on the waiting list. We can also assure the recipient and donor are prepared and in the best health, both physically and mentally.

- A kidney donated by a blood relative is usually a better genetic match which may result in a better chance for success. When well-matched to the donor organ, the recipient is often able to take lower doses of anti-rejection medication.

- The donor surgery and recipient transplant can happen almost simultaneously with very little damage to the organ, because it is not outside the body for long. Usually the donor kidney will begin to work immediately once transplanted.

- Kidneys from living donors usually have a longer life span

- A living donor removes the recipient from the national transplant waiting list, therefore, helping many others.

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Living Donor Evaluation

Donors must be chosen carefully to avoid outcomes which are medically and psychologically unsatisfactory for both the donor and recipient. The evaluation is a 2 to 3-day process to help ensure that you will not be harmed by donating, and that you are healthy and will remain healthy after donation. We will ensure that you understand all aspects of the donation process, including the risks and benefits. Your consent to become a donor is completely voluntary. You should never feel pressured to become a donor. You have the right to delay or stop the donation process at any time.

It is important to fully consider how donation may affect your physical and emotional health, as well as your family life, financial situation, and current and future health and life insurance status. Speak with your transplant team, use the resources available, ask questions, and voice concerns.

If you do not live in the local New Orleans area, you may want to decide to stay in the area for your evaluation. Refer to page 17 for several options which may meet your needs while you are undergoing your pre-donation evaluation, surgery, and recovery.

During your evaluation you will meet with all members of the transplant team.

- The Transplant Nephrologist/Physician Assistant will take a detailed medical history and perform a physical assessment.
- The Transplant Surgeon will also take a history but will be looking at your abdomen to see if there are any scars, masses, hernias or other abnormalities that would not allow for the donation to take place. He will also discuss the donor surgery with you.
- The Donor Advocate is an independent person, not affiliated with the transplant team. Their role is to represent and advise you. They ensure that the donor's decision is informed and free from coercion and that your rights are protected.
- The Clinical Transplant Nurse Coordinator serves as your primary contact by teaching about the process and answering questions related to donation. She will also organize your evaluation. This includes coordinating the tests and consultations needed for a complete evaluation.
- The Social Worker will meet with you alone and perhaps with your family members to complete a thorough assessment. This is an opportunity for the social worker to get to know you, identify any concerns or needs you may have, assess your support system, insurance, and financial situation, as well as link you to any necessary resources. The social worker will be asking you questions that may seem personal. Please recognize that there may be sensitive issues which need to be addressed. The social worker may arrange to meet with you alone without your family to ensure open communication between you and the social worker.
    - If you are experiencing feelings of pressure, coercion, or obligation to donate, please talk with your Transplant Social Worker immediately. This may be a reason not to donate. Receiving compensation for organ donation is illegal. Compliance with the law is required.

The following are tests which you will undergo during your medical evaluation.

The following are risks that may be associated with the evaluation of a donor: allergic reaction to contrast, discovery of reportable infections, discovery of serious medical conditions, discovery of adverse genetic findings unknown to the donor, and discovery of certain abnormalities that will require more testing at the donor's expense.

Blood Typing: The donor and recipient must have compatible blood types, but do not need to be an exact blood type match.

Tissue Typing: This blood test checks the tissue (DNA) match between six codes on the donor and recipient cells. Tissue typing between the donor and recipient does not need to match to have a successful transplant.

Crossmatching: A blood test done to determine how the recipient will react to your organ.

> Antibody is a protein substance made by the body's immune system in response to an antigen (a foreign substance; for example, a transplanted organ, blood transfusion, virus, or pregnancy). Antibodies can attack the transplanted organ. The white blood cells of the donor and the serum of the recipient are mixed to see if there are antibodies in the recipient that react with the antigens of the donor.

A "positive" crossmatch means that your kidney will not match with recipient. A "negative" crossmatch means that your kidney is compatible with the recipient and they may proceed with the medical evaluation.

This test is performed prior to the medical evaluation and again within 7 days of transplant.

Urine Tests: Urine is collected for 24 hours to look at your kidney function. A single sample is also obtained to check for protein and infection in the urine. Special 24-hour urine testing is done if you have a history of kidney stones.

Blood Tests: Blood tests are taken to check for infectious diseases, blood count, cholesterol, and basic chemistries, which give information on the functioning of the kidneys/ liver.
If you have a close blood relative with diabetes, you will also have a glucose tolerance test, which screens for diabetes.

Chest X-Rays: A chest X-Ray is performed to screen for lung disease.

Electrocardiogram (EKG): An EKG is performed to screen for heart disease. An exercise stress test will be performed if you are 40 years or older.

CT Arteriogram: This test involves injecting a liquid that is visible under X-Ray into the blood vessels to view the organ to be donated. This enables the physicians to examine the kidney and its blood supply prior to surgery.

Psychiatric Evaluation: After meeting with the social worker, you may be referred for a psychiatric and/or neuropsych evaluation. If a person is donating to an unrelated person, who is not a spouse, they will undergo a psychiatric evaluation.

Female Examinations: For all female donors, a complete gynecological examination and Pap smear is required. This can be done with your physician or if you have had this completed in the last year, you

can have the medical records sent to us. For females 40 years and older, a mammogram is also required. Again, if you have had this done in the last year, records can be sent to us for use.

Colonoscopy: A colonoscopy will be required on all donors age 45 or older. If this has been obtained with your own physician, please have the records sent to us.

Additional tests may be required depending on your medical history and physical examination.

The results of your testing will be kept confidential under the Health Insurance Portability and Accountability Act of 1996 (HIPPA).

The recipient will not have access to your personal information or test results.

Review of Tests

Once the results of all tests are available, the Transplant Selection Committee, which consists of all members of the transplant team, will review your case. The committee, after reviewing all information, will determine if you are approved to donate.

You will receive a phone call from the living donor coordinator once the review is complete and the committee has made their decision.

If you are not approved as a donor, you may choose to be evaluated by another transplant program that may have different selection criteria.

Living Kidney Donor Selection Criteria

Any person over 18 years of age meeting the following criteria may be considered a potential living kidney donor:

1. Overall good general health.
2. Able to understand the risks and benefits of donation
3. Has acceptable kidney function and anatomy as determined during the living donor evaluation process.

Absolute Contraindications

1. Diabetes mellitus.
2. Evidence of kidney disease, for example:
   a. GFR < 80 ml/min
   b. Proteinuria > 300 mg/24 hours.
   c. Small kidneys
3. Active infections until resolved.
4. Current pregnancy.
5. BMI >33
6. Acute malignancy
7. History of Melanoma
8. Financial inducement or evidence of coercion
9. Uncontrolled diagnosable psychiatric conditions requiring treatment before donation, including any evidence of suicidality.
10. Uncontrolled hypertension or history of hypertension with evidence of end organ damage

Relative Contraindications will be considered on a case-by-case basis, considering donor's age and other health concerns:

1. If the right kidney is going to be used for donation, then BMI must be <30.
2. Impaired glucose tolerance on 2-hour Glucose Tolerance Test
3. History of malignancy.
4. Current substance abuse.
5. Hypertension requiring more than one medication to control.
6. Kidney stones without treatable cause.
7. Any medical condition that, in the opinion of the transplant team, may increase the risk of a decline in the donor's health.
8. Proteinuria 150-300 mg/24 hours

Pre – op Testing and Hospital Admission

Preparing for Surgery (pre-op)

Once you are approved as a living kidney donor for your recipient, your Transplant Coordinator will discuss surgery dates with you. Keep in mind, this process moves at the pace in which you need. Surgery will be scheduled for the day you request, and pre-operative appointments will be scheduled the 1-2 weeks before the surgery date.

During pre-op you will have the following appointments:

- Blood testing to check kidney function and the final crossmatch will be obtained
- Transplant Nephrologist will provide medical clearance for surgery
- Transplant Surgeon will review surgical procedure and obtain consent for surgery
- Transplant Coordinator will provide instructions for the day of surgery
- Transplant Social Worker will discuss your understanding, your ability to choose not to donate, and assure caregivers, financial, and other plans are in place.
- Anesthesia physician will obtain information and review details of surgical anesthesia

Smoking must be stopped eight weeks before surgery. Smokers have an increased risk of cardiovascular (heart) and pulmonary (lung) complications with any surgery. The transplant team recommends that all donors refrain from tobacco use after organ donation to prevent long term health problems related to smoking.

Females taking oral birth control pills or hormone pills will need to discontinue four to six weeks before surgery. Birth control pills can increase the risk of blood clots after surgery.

Keep in mind, several events could happen that may change the date of the transplant.

- The recipient's condition may decline to the point where they are too sick for transplant.
- Abnormal testing may be discovered with pre-op testing that requires further evaluation prior to transplant.
- The program may be busy transplanting organs from deceased donors and your surgery will need to be rescheduled.

The Surgery

The donor is admitted to the hospital on the morning of surgery. You should bring minimal belongings (medications, toiletries and clothing) to the hospital. Leave all jewelry or other valuables at home or give them to your family for safekeeping. You will be prepared for surgery, including having your temperature and blood pressure taken, and having an intravenous (IV) line started. In surgery the donor is given general anesthesia and "put to sleep." An endotracheal tube (breathing tube) is placed to breath for you and a catheter is placed in your bladder to monitor your urine.

A nephrectomy is the surgical removal of a kidney. Laparoscopic nephrectomy is a minimally invasive surgical procedure for obtaining a kidney from a living donor that can make the process easier.

In this procedure, the surgeon makes three small incisions, "ports", around the abdomen. The kidney is removed through a 3-inch central incision below the belly button. Through one of the other openings, a special camera, called a laparoscope, is used to produce an inside view of the abdominal. Surgeons use the laparoscope, which transmits a real-life picture of the internal organs to a video monitor, to guide them through the surgical procedure.

The surgery lasts approximately 3 to 4 hours. During this time, family can wait in the surgery waiting room, located on the 2nd floor of the hospital. It is possible the surgery may be longer or shorter, so do not be alarmed. When the surgery is complete, the physician will speak to your family.

There is a slight possibility that due to problems with the recipient operation, the transplant might not be able to be completed after your kidney was already removed. If such a situation should occur, you will have the following options:

1. The kidney can be transplanted into a suitable recipient from the kidney waiting list.
2. The kidney can be discarded (thrown away).
3. The kidney can be transplanted back into you (autotransplantation). This option may not be feasible or medically advisable and the autotransplant surgery will not be done if the risks to the donor clearly outweigh potential benefit.

These options will be discussed during your pre-operative visit, so your wishes can be made clear.

Risks and Complications

Living donors should fully understand the risks involved in donating a kidney. Even though you are in good health, there is always risk any time someone undergoes surgery. Some of these may include:

- Allergic reaction to anesthesia
- Scaring, pain, fatigue
- Pneumonia and infections of the incision or urinary tract
- Blood clots in the lungs or veins
- Decreased kidney function or kidney failure
- Abdominal or bowel problems such as bloating, obstruction, nausea, vomiting

- Bleeding, requiring the need to return to surgery or blood transfusion
    - Although blood transfusions during this surgery are uncommon, it may be necessary. If you would like to donate your own blood before the surgery, please let the donor coordinator know in advance.
- Death – 0.03% (that is 3 out of every 10,000 surgeries)

After the Surgery

You will go to the recovery room immediately following the surgery. The breathing tube will be removed, and you will be given pain medication. Once stabilized, donors are transferred to the transplant step-down unit on the 11th floor of the hospital (TSU). All rooms on TSU are private and are equipped with a small couch. If a family member would like to stay with you, this is acceptable.

Discharge Planning

The average hospital stay for a donor is 24 hours. As with any operation or treatment, if there are any complications, this may delay your discharge. Every patient has an individualized treatment approach and recovers within different time frames. We encourage talking with other donors, however since everyone's recovery is different, please avoid comparing your circumstances to other patients that you meet.

Your social worker will begin discharge planning during your pre-op visit and in the hospital. This involves assessing your needs during your stay, as well as resources you may need upon discharge from the hospital.

If you live more than two to three hours away from Ochsner you may be asked to stay locally in the New Orleans area for the first 3 to 4 days of your recovery. This will be determined by your transplant surgeon.

Upon discharge from the hospital, you will be provided with a prescription for pain medication. This can be filled at any local pharmacy. **Prescriptions are <u>not</u> covered by the recipient's insurance**. If you have private insurance, this can be used, or you will need to provide payment to the pharmacy.
The Ochsner Outpatient Pharmacy is located on the 1st floor of the hospital. The phone number is (504) 842-3205.

Please let your family/caregiver know you will leave the hospital 24 hours after surgery, so they are aware and prepared.

After Donation

Recovery

Average length of recovery after kidney donation can take 4 to 6 weeks. You will experience pain and discomfort after the surgery, medication will be prescribed. Over time, the pain will ease and become less severe, but it may linger for several weeks after the surgery. Some people may experience a temporary loss of appetite.

Donors can not lift, carry, push, or pull anything heavier than 10 pounds (a gallon of milk) or engage in physically demanding activities for 4 to 6 weeks. You will not be able to drive for up to 2 weeks. Driving can be resumed when pain medication is no longer required, and you are able to comfortably move as required to drive safely. Your doctor will let you know when you are medically cleared to return to work and resume exercise and heavy lifting.

A donor will need to take off about 2 to 3 weeks from work if you have a desk job, and approximately 4 to 6 weeks if you perform physical labor. If there are disability or leave of absence forms which need to be completed, please let us know as soon as possible.

A lab appointment and physician appointment will be scheduled within 2 weeks and at 4 weeks after surgery to assure laboratory values are acceptable and that you are healing without any problems. At this time, you will be released from our care and can return to your normal activity.

- If you live out of the state, you will be seen within 3 to 4 days after being discharged from the hospital, before you return home. An appointment with your local physician should be scheduled for 4 weeks after your surgery.

Before the surgery, most of the focus is on the living donor. After the surgery, the focus changes to the kidney recipient, helping them recover and making sure the body doesn't reject the new kidney. This shift in attention may be hard for the donor and the donor's family, causing a feeling of abandonment.

It is important to have the proper emotional and physical support to help recover from surgery. A caregiver (family/close friend) for potential donors is required for post donation care. The availability of your support system to you after your donation could not be emphasized more! As with any major surgery or treatment, you will need help. You can not get through this recovery alone. (It is beneficial to have your support system available to you prior to the donation as well.)

What we mean by "SUPPORT" can take on several meanings... needing physical support when you are weak, needing emotional support when you are feeling discouraged, needing spiritual support, or needing assistance with concrete needs (grocery, meals, transportation). It can be anyone who is reliable and will assist you in coping better with your recovery from donation.

One person will need to be identified as your **primary caregiver**. This would be the main person that will be helping you, as well as interacting with the transplant team. Having one primary person provides continuity- they are aware of your needs, problems, medications, etc. Multiple family members and/or friends who would be able to alternate assisting you would also be appropriate.

Follow-up after Donation

Every transplant center is required to report living donor follow-up data at six months, one year, and 2 years after donation.

This information is reported to UNOS (United Network of Organ Sharing) to ensure the health of our donors and the health of future donors. Learning about donor outcomes can help future potential living donors make informed decisions.

It is important to attend all follow-up appointments to make sure that you are recovering appropriately. Information that will be reported includes the following:

- Patient status
- Working for income, and if not working, reason for not working
- Loss of medical (health, life) insurance due to donation
- Admissions to the hospital or need for diagnostic testing
- Kidney complications
- The need for dialysis
- Development of hypertension requiring medication
- Development of Diabetes
- Laboratory Data
    - Serum creatinine (blood)
    - Urine protein

A reminder letter will be sent to you a couple of months before your anniversary date.

This follow-up can be completed by your local physician and information faxed to the transplant coordinator. Lab orders can also be sent to you to obtain lab locally using your own health insurance.

If you do not have health insurance, we are happy to schedule the required testing at our facility, at no cost to you.

Life with One Kidney

There has been little national long-term data collection on the long-term risks associated with living kidney donation. Based upon limited information that is currently available, overall risks are low. Risks differ among donors depending on personal medical and family history.

Possible long-term risks of kidney donation may include:

- High blood pressure (hypertension)
- Reduced kidney function or protein in the urine.
    - On average, donors will have a 25-35% permanent loss of kidney function after donation.
- The risk of developing kidney failure after donation is similar to the general population
- Because kidney disease generally develops in mid-life (40-50 years old) and kidney failure after age 60, the medical evaluation of a young donor cannot predict lifetime risk of kidney disease or kidney failure.
- Donors may be at higher risk for kidney disease if they sustain damage to the remaining kidney.
- The progression to kidney failure may be more rapid with only one kidney.
- Incisional hernia
- Women may have increase risk of pre-eclampsia (elevated blood pressure and protein in the urine) during pregnancy. Donation does not affect your ability to become pregnant and have a normal pregnancy and childbirth.
- Depression or anxiety after the surgery and years after donation, requiring the use of prescription medication and/or mental health counseling due to:
    - Donated kidney may not function or may be lost
    - Medical problems from the surgery in the recipient and/or donor
    - Scarring
    - Feelings of regret, resentment or anger

Things to Think About

Financial Considerations

The recipient's insurance will cover the evaluation, surgery, hospitalization and post-operative follow-up tests and medical appointments. The recipient's insurance will not cover medical problems which may occur from the donation later in life. **If you receive a bill from Ochsner, for donation related charges, please notify the donor coordinator immediately, so this can be handled.**

The following are expenses to plan for which are not covered by the recipient's insurance:

- Lost wages from time off work
- Travel expenses: gas, airfare, lodging, meals
- Child care costs
- Prescriptions (pain medication after surgery)
- Need for life-long follow-up and potential future health problems
- Negative impact on the ability to obtain future employment

Donors need to make financial arrangements to ensure they have adequate funds to cover expenses. This is especially important if your employer does not offer compensation for time off. You may also want to look into whether your short-term disability covers kidney donation.

Talk to your employer about leave policies before committing to donation. Think carefully about the financial impact on your family, especially if you and/or your caregiver may face lost wages.

If you are a federal employee, there are laws that may assist you with organ donation. Some states have tax breaks which you can investigate prior to surgery.

National Living Donor Assistance Center (NLDAC)
Phone: 703.414.1600
Fax: 703.414.7874
Website: www.livingdonorassistance.org

NLDAC helps people who are considering being a living organ donor with the non-medical expenses associated with the process. NLDAC covers for eligible donors:

1. Travel expenses
2. Lost wages
3. Dependent care expenses

They can help with evaluation, surgery, and follow-up trips, but donors need to apply and be approved before the trip they would like help with. Applications must be approved and funded before the donation surgery.

Eligibility is based on the household income of the **recipient**. Both the donor and recipient must complete an application which is submitted to the transplant center along with income documentation. Priority will be given to those individuals who cannot otherwise afford the expenses. Approval for funding is not guaranteed.

Donors who are approved for help with travel expenses receive a controlled value card, which is like a credit card with restrictions, to pay for their transportation (airfare, gas, rental cars, taxis, etc.), hotel, and meals on trips to the transplant center. Donors can also use this card for the travel expenses of a support person who accompanies them. NLDAC can only cover travel within the U.S. and its territories.

Donors who are approved for help with lost wages also receive a controlled value card, which they can withdraw cash from, or use to make purchases. NLDAC deposits wage reimbursements on these cards around the time of each appointment. Donors can request reimbursement of the wages they lose during:

1. An evaluation trip, up to 3 days
2. Recovery from donation surgery, up to 4 weeks
3. Follow-up trips or rehospitalization, up to 2 weeks

To receive reimbursement of lost wages, donors must be working for pay at the time of their donation surgery or other trip and submit clear documentation of their current wages. NLDAC cannot pay wages to donors who are unemployed or furloughed.

Tax Deduction/Credits for Living Donors
If you live in Louisiana you may take a state tax credit up to $10,000 to cover the costs of the donation, including unreimbursed cost of travel, lodging, and lost wages.

If you live in Mississippi you may receive a state tax deduction up to $10,000 to cover the costs of the donation, including unreimbursed cost of travel, lodging, and lost wages.

Insurance after Living Donation
Obtaining and keeping health, disability or life insurance after donation has been reported. There is a chance your premiums may increase, or coverage denied. It is important to talk to your insurance company before donation to assure your coverage will not be affected afterwards. Consider obtaining any forms of insurance you may need prior to surgery taking place.

Journal
Consider keeping a journal throughout your donation experience. This is a personal and private way to express your feelings about what you are going through, and you will have these written memories forever. In addition, you may wish to share some of these thoughts with your family.

Pastoral Care Services
Ochsner has hospital chaplains that are available to you during your hospital stay to address your spiritual needs. In addition, there are also Eucharistic ministers that will bring Holy Communion to Roman Catholic patients daily. If you would like to see a chaplain, please ask your nurse to contact the Pastoral Care Department.

Making the Decision….Be Sure

The decision to become a living donor involves careful consideration. We realize that this can be a very stressful time for you and your family. Some of the information you have received may overwhelm you and provoke questions or concerns which need to be addressed. To help you through the process, consider reaching out to family members, close friends, someone who has gone through this process, or your social worker.

It may also be helpful to ask yourself these questions:

- How do I feel about organ donation?
- Can I afford being a kidney donor?
- What will my insurance cover?
- Do I know enough to make a logical and educated decision?
- Am I being psychologically pressured to be a living donor?
- Is there someone else who could possibly donate?
- Will donation have an impact on my relationship with the recipient?
- What are the medical risks involved?
- How does my religion view organ donation?
- Am I up to it physically? Are there current aspects of my health that I know should keep me from donating?
- Do I have a "support network" to help me through this process?
- How will I feel if I am rejected as a result of the screening process?
- Am I prepared to deal with the possible rejection of the organ?

Our goal is to make your donor experience positive. We hope this packet has provided you with a wealth of information for you and your family.

Please contact your Transplant Team with any questions or concerns.
504-842-3925 or 800-928-6247

Resources

On Donation

One of the quickest and easiest ways to find the answers to your questions about organ donation is by looking on the Internet. The web sites below are excellent resources available to you.

www.transplantliving.org

www.lopa.org
This is the site for Louisiana's Organ Procurement Agency.

www.kidney.org
This is the site for the National Kidney Foundation.

www.livingdonors.org

www.livingdonorassistance.org
This site is for the National Living Donor Assistance Center who provides financial assistance for living kidney donors.

www.ochsner.org

www.srtr.org
Transplant outcomes for all transplant centers

In the Area

If you are not from this area you may need some assistance locating some of the following resources.

Grocery Stores: Winn-Dixie Grocery Store - 3623 Jefferson Highway (831-1840).
Rousse's Grocery Store - 2701 Airline Dr. - corner of Airline Dr. & Labarre Blvd. (828-4101)
Wal-Mart Superstore: Located on Jefferson Highway just past South Clearview Parkway (733-4923)
Legal Services: Your social worker can assist you in obtaining legal services.
Shopping Mall: Lakeside Mall located on Causeway Blvd. and Veterans Memorial Blvd.
Movie Theater: Palace Theater is located at 1200 Elmwood Park Blvd. behind the Elmwood Shopping Center on South Clearview Parkway (734-2020).
Restaurants: multiple restaurants on South Clearview Parkway & Veterans Memorial Blvd.
Laundromat: Your hotel may have laundry machines which require quarters.

LODGING OPTIONS FOR
OCHSNER ORGAN DONOR PATIENTS:

(ask for special rate if available for OCHSNER TANSPLANT patients)

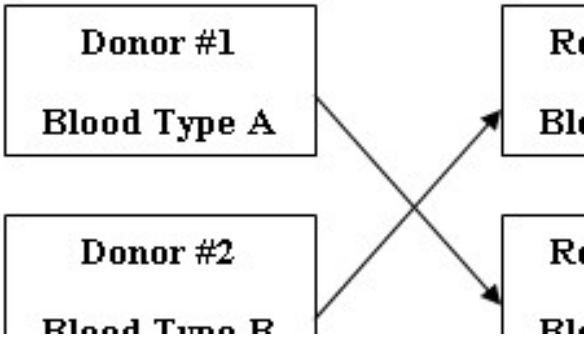
	Housing:
1.	**Brent House Hotel** Ochsner Main Campus 1512 Jefferson Highway New Orleans, LA 70121 (504) 835-5411 (800) 535-3986
2.	**La Quinta Inn** 3100 I-10 Service Road (I-10 & Causeway Blvd) Metairie, LA 70001 (504) 835-8511 (800) 531-5900
3.	**Holiday Inn** 3400 I-10 Service Road (I-10 & Causeway Blvd) Metairie, LA 70001 (504) 833-8201
4.	**Hampton Inn & Suites (2 locations)** -5150 Mounes St. (Off Clearview Pkwy) Harahan, LA 70123; (504) 733-5646 -2730 N. Causeway Blvd. Metairie, LA 70002; (504) 831-7676 -Any location: (800) HAMPTON
5.	**Marriott Residence Inn** 3 Galleria Boulevard Metairie, LA 70001 (504) 832-0888 (800) 331-3131
6.	**Best Western Landmark Hotel** 2601 Severn Ave. Metairie, LA 70002 (504) 888-9500 (800) 277-7575
7.	**Country Inn & Suites** 2713 N. Causeway Blvd Metairie, LA 70002 (504) 835-4141 (800) 228-2828
8.	**Courtyard by Marriott** 2 Galleria Blvd Metairie, LA 70001 (504) 838-3800

KIDNEY PAIRED DONATION (KPD)

What is Kidney Paired Donation (KPD)?

KPD may be an option if you are not a match for your family member/friend. This is a computerized system that allows transplant centers to search for other donor/recipient pairs who are compatible with you and your recipient. Reasons for incompatibility could be an incompatible blood type or incompatible tissue type as identified by a positive crossmatch.

KPD results when one donor (Donor #1) is willing to donate to a spouse, friend or relative (Recipient #1), but cannot. The KPD Program (discussed below) helps find another incompatible pair (Donor #2 and Recipient #2) who might wish to exchange donors. If Donor #1 is compatible with Recipient #2, and Donor #2 is compatible with Recipient #1, two transplants can be pursued. Sometimes, more than two compatible pairs can be matched to each other. This results in more than two life-saving transplants.



KPD programs may also include individuals who wish to donate to any individual who is currently waiting for a kidney transplant. These individuals are called non-directed donors and are not linked to a specific potential recipient. An exchange started by a non-directed donor is called a donor chain (see diagram 2). In a donor chain, the non-directed donor donates to a recipient whose intended donor would then donate to another recipient. The donor at the end of the chain will donate to a candidate on the deceased donor waiting list.

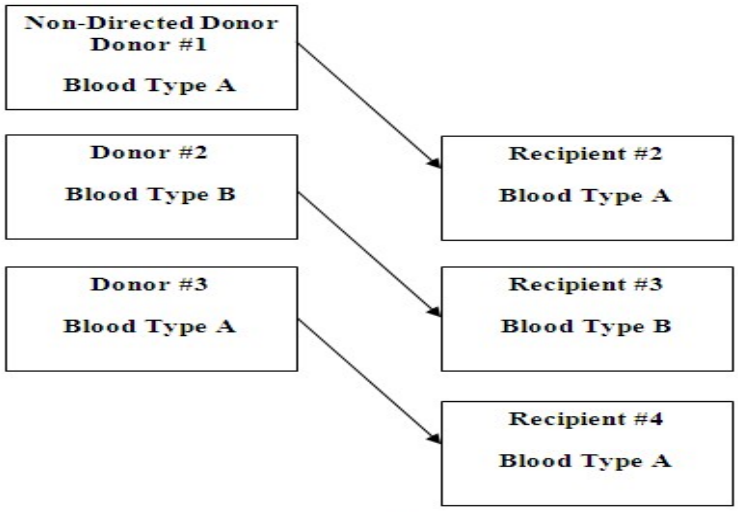


Diagram 2

What will happen if a recipient/donor pair agrees to join the KPD Program?

- Once a potential living donor and a recipient are found to be blood type or tissue type incompatible, their medical data is entered into the KPD database, which is used to track everyone who is registered in the program. This database allows a computerized matching program to run and identify compatible recipient/donor pairs. This exchange match program is routinely run twice a week. If a potential exchange pair is identified, the match will be reviewed by the transplant surgeon, physicians, and transplant center program staff. If the match is favorable, the potential living donor and the recipient may be asked to provide a blood sample for crossmatching (mixing of blood between recipient and donor to establish compatibility). The recipient/donor pair will be notified about whether the crossmatch results indicate that the exchange offers a favorable arrangement for all participants and whether the paired exchange will move forward.

- Once all participants agree to go forward with the exchange, the medical information of both the potential living donor and recipient (as applicable) will be shared with the participating transplant center. Any further evaluation requested by the surgeon or physician to determine the potential living donor's or recipient's eligibility will be completed. After the physicians and surgeons accept the medical eligibility of all the participants, the transplants can be scheduled. In two-way and three-way exchanges, the donation surgeries are scheduled to begin at the same time. Recipient surgeries begin after donor surgeries. In donor chains, surgeries may or may not occur on the same day.
- The recipient/donor pair will remain in the KPD database as long as they are medically acceptable and are willing to participate.

- Recipient/donor pairs should discuss when they will be contacted about potential matches and other information with Ochsner multi-organ transplant center.

What are Bridge Donors?

A Kidney Paired Donation (KPD) donor who does not have a match identified during the same match run as the donor's paired candidate and continues a chain in a future match run is a *bridge donor*.

Each paired donor, at the discretion of the donor hospital, can be given the option of bridge donation at the time they enter KPD. Before agreeing to bridge donation, the donor must be informed of when a chain will end with a bridge donor.

In the KPD, a chain will end with a bridge donor if the following conditions are met:

- The chain begins with a Non-Directed Donor (NDD) or has been extended with another bridge donor.
- The hospital who entered the NDD choses to extend the chain with a bridge donor.
- The paired donor agrees to be a bridge donor.
- The paired donor hospital agrees for the paired donor to be a bridge donor.

If one or more of these conditions are not met, the last donor in the chain will be offered to the deceased donor waiting list at the hospital that entered the NDD.

The amount of time a bridge donor waits before a match is found and undergoes surgery is primarily based on the ease or difficulty in matching the bridge donor's blood type and antigens with candidates in the pool.

Generally speaking:

- Blood type O donors match immediately
- Blood type A and AB donors may take several months or longer to match.
- Blood type B donors are somewhere in between.

Either the bridge donor, donor hospital or NDD hospital can request that the bridge donor stop attempts at bringing and donate to the waitlist at any time. Bridge donors have the option to revise the amount of time they are willing to be a bridge donor.

Bridge donors may be waiting for a match long enough that their medical evaluation expires per transplant hospital policy. In this case, they would require additional evaluation prior to donor nephrectomy.

Many matches are terminated prior to donation and transplantation. Bridge donors may need to supply multiple blood samples on multiple occasions to crossmatch against candidates in different matches.

What personal information is needed in order to run the match program?

The KPD database requires the recipient's and potential living donor's name, date of birth, blood type, prior living donor status, genetic tissue type, and any tissue markers (antigens) that need to be avoided in the donor in order for a compatible match to be made. The database allows for potential recipients and donors to indicate where a potential donor is willing to travel to donate.

How will personal information be used?

The personal information entered into the database will be used to identify other potential recipient/donor pairs. Potential living donor data will be shared with the surgeons, physicians, and transplant team at the potential recipient's transplant center. Data will be stored indefinitely in a password protected system. Only designated staff at Ochsner multi-organ transplant center and UNOS staff can access the data in the system.

How will medical information be kept confidential?

Prior to locating a possible match, a potential living donor's or recipient's information will not be shared with anyone outside of the KPD Program or the participating transplant centers without the participant's clear permission. Access to the database will be through a secure, password protected system. After a potential match is identified, the matched recipient's health insurance may provide the matched recipient with the name of the actual matched donor on an Estimate of Benefits form that is sent to the recipient before surgery. This means that recipients may learn of their actual matched donor's identity. Otherwise, the participants' medical information will remain confidential to the extent required by law. Potential living donors and recipients should discuss the confidentiality rules at the hospital with Ochsner multi-organ transplant center staff.

What are the risks of participating in the KPD Program?

There is a risk of the loss of confidentiality of medical information if the steps outlined above are not followed. If an exchange pair is identified and the recipient/donor pairs agree to proceed with the surgery, they should understand that, as with any transplant and donor surgery, there are unexpected events that may occur with a paired donation transplant.

- An event may occur in the operating room that makes it necessary to stop a donor procedure. In this case, one recipient would not receive a kidney. If a donor or recipient surgery has begun, this surgery will continue even if another surgery in the match must stop.

- If it is necessary to stop a recipient surgery, a kidney would be available. This kidney would be given to a recipient on the deceased donor waiting list according to OPTN policies.

Possible risks for recipients and donors include (not limited to):

- Surgery is major and requires anesthesia; thus, there are possible medical complications including injury and death.
- The organ may not function after being transplanted into or may be rejected by recipient.
- Scars, pain, fatigue
- Negative psychological symptoms (such as anxiety, depression, etc.) are possible after donation.
- Possible impact on lifestyle
- Potential financial effects

Potential living donors and recipients may decide to withdraw from participating in the KPD Program at any point without penalty.

What are the risks of participating in a kidney paired donation when the kidney is shipped to the recipient transplant center?

The living donor kidney will be shipped via ground and/or air transportation to the recipient transplant center. This form of transportation has the risk of courier delay, flight cancellation, or flight delay which would extend the cold ischemic time of the kidney. Cold ischemic time is the amount of time an organ spends being preserved after recovery from the donor. Too much cold ischemic time can affect the quality of the organ for transplant. With clear-cut, organized plans, this risk is decreased. There is the risk of problems outside of the transplant center's control such as a plane crash, terrorist activity, and natural disaster. There is risk of damage to the kidney during transport which would be discovered at the time of inspection of the kidney at the recipient's transplant center.

What are the benefits of participating in the KPD Program?

There is no guarantee that a potential living donor or recipient will receive any benefit from participating in the KPD Program. Recipients may receive the benefit of a compatible living donor kidney transplant by participating in the program.

The risks and benefits of the donation surgery and the transplant surgery will be discussed with the potential living donor and recipient in detail by Ochsner multi-organ transplant center if and when they consent to move forward with a kidney paired donation.

It is not known if or when any given recipient/donor pair might be identified as part of a possible matched pair. The more participants in the program, the more likely it is that any given recipient/donor will be part of a pair identified for a possible donor-recipient exchange.

What are the alternatives if a recipient or a potential living donor decide not to participate in the KPD Program?

Potential living donors and recipients have the right to change their minds and end the process at any time. There is no penalty for doing so and the decision remains confidential; an explanation of the donor's decision not to continue with the donation is only disclosed if the donor agrees.

Potential recipients should discuss the alternatives with their transplant center staff (such as receiving a deceased donor kidney through the national waiting list maintained by the OPTN).

One option for potential living donors who decide not to participate in the KPD Program would be to donate a kidney to someone else waiting for a kidney transplant.

What is the Remedy for Failed Exchanges for potential recipients?

- A KPD candidate who does not receive a kidney transplant from the matched donor *for any reason* after the candidate's paired donor has donated is considered an *orphan candidate*.
- A candidate will be eligible for orphan candidate priority *only* if the candidate qualified for orphan status through participation in the OPTN KPD program.
- An orphan candidate will receive 1,000,000 priority points, even if the candidate has another willing living donor. The orphan candidate will retain this priority until the orphan candidate receives a kidney transplant. The orphan candidate can always refuse a match offer and retain orphan candidate priority.
- This priority will ensure the orphan candidate receives a match offer *if* the candidate matches to either a non-directed donor or bridge donor in the system but does not guarantee that the candidate will match any donor.
- There is no additional priority on the deceased donor waiting list for any candidate involved in a failed exchange in any KPD program.

What costs or payments are involved?

There is no cost for registering and there will be no payments or compensation of any kind for participating. Potential donors need to discuss the financial risks of participating in the KPD Program and the resources that may be available with the transplant center. There are national and local resources available, such as the National Living Donor Assistance Center, that may be able to assist those who qualify. All local resources are not the same, depending on the area. In certain cases, for example, qualifying donors may be reimbursed for limited travel and subsistence expenses. Ask your transplant center about the resources in your area and nationally that may be able to assist living donors.

Communication between KPD Donors and Candidates

KPD pairs are kept anonymous **prior** to transplant.

Transplant centers can facilitate communication such as meetings or other correspondence between KPD donors and their matched candidates only if all the following conditions are met:

- Any Communication between the KPD donor and matched candidate may be arranged 30 days after transplant performed.

- Both the KPD donor and matched candidate must agree to a correspondence or a meeting. Any such communication will not be arranged if either the KPD donor or the matched candidate chooses to remain anonymous.

Both the KPD donor and matched recipient must agree to share contact information. The living donor coordinator will assist in the facilitation of communication and/or a meeting should both parties request

Whom should recipients and potential living donors contact if they have questions?

If you have questions, please call **Living Donor Coordinator, Tel : 504-842-3925**

NOTES: