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MEDICINE of THE HIGHEST ORDER

University of Rochester Medical Center

Living Kidney Donor

Handbook

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Introduction

Thank you for your interest in living kidney donation. This handbook provides an overview of the Living Kidney Donor process at the University of Rochester Medical Center (URMC). We understand this is a life-changing decision. Our transplant team is available to help you make this decision, explain medical tests, review results, and go over the transplant process. This handbook is a supplemental resource to the information provided by the team. It gives an overview of kidney donation options, describes the evaluation process and provides information about the surgical procedure and recovery.

The URMC Living Kidney Donor Program performs a complete evaluation that includes medical testing, surgical screening, social work evaluation, independent living donor advocate evaluation, financial counseling, clinical nutrition counseling, and psychiatric consultation.

The Kidneys

The kidneys are a pair of bean-shaped organs in the back of abdomen that are part of the urinary system. They clean the body of excess water, salt, and waste products, which produces a liquid waste called urine. Urine flows from the kidneys through a pair of thin tubes (ureters) to the bladder, where it is stored until a person urinates. The kidneys also produce important hormones that help regulate blood pressure, form bone, and control red blood cell production in bones. Several diseases and conditions can injure the kidneys and make them stop functioning correctly. When kidneys fail, harmful wastes build up in the body, blood pressure may rise, and the body may retain excess fluid and not make enough red blood cells.

Living Kidney Donation Overview

There are two types of kidney donation. Deceased kidney donation is when the kidney used comes from a deceased person. Living kidney donation is when a living person donates a kidney for transplant into another person. Living donation is the most desirable type of kidney transplantation. It significantly prolongs the life of the transplanted kidney for the recipient when compared with deceased donor kidney transplantation or the alternative option, dialysis. There are several other advantages to living kidney donation over deceased donation. The living donor kidneys usually function immediately upon transplant, donors can be tested for compatibility ahead of time, & the transplant can be scheduled when convenient.

People that receive a kidney transplant have double to triple the life expectancy than if they had remained on dialysis.

There are three types of living donors:

- Living Related Donor—someone who is related by blood, such as a parent, child, sibling, etc. Donors may be genetically similar, which reduces the risk of rejection.
- Living Unrelated Donor—someone who is not related by blood and is emotionally related in some capacity, such as a spouse, friend, co-worker, member of the same house of worship, etc.
- Non-Directed Donor—a stranger who is not related to the recipient. Paired kidney donation is an example of non-directed donation.

Matching: Tissue Typing and Compatibility Testing

Blood type matching:

For most transplants, the donor and the recipient must have compatible blood types. This means that if the donor can give blood for a transfusion to the recipient, their blood type is compatible for a kidney transplant. We often will do this test first.

Donor Blood Type	Can Donate To Recipient Blood type
O	O, A, B, AB
A	A, AB
B	B, AB
AB	AB

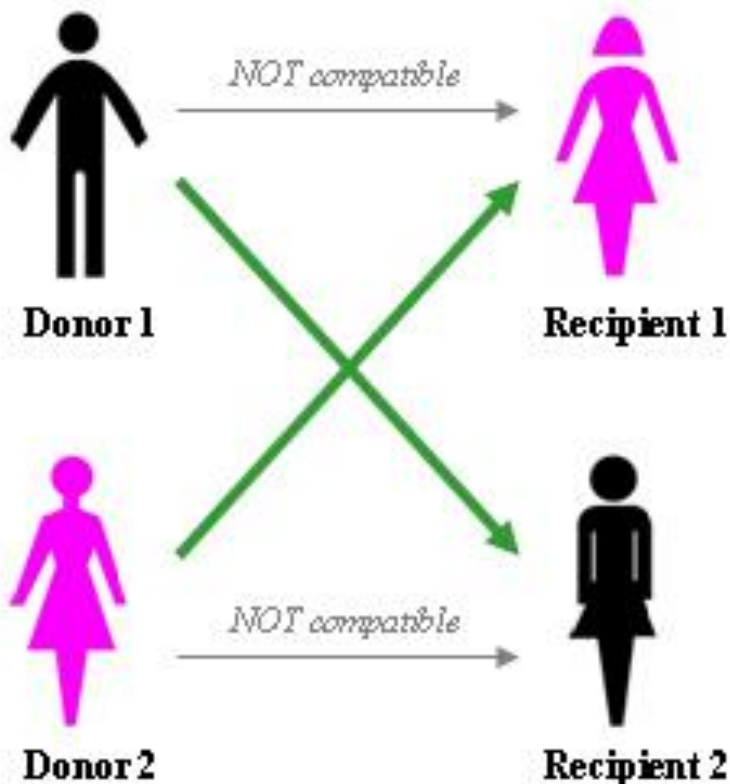
HLA testing & Serum Cross-Matching

HLA testing is genetic testing that identifies how many of the donor & recipient's tissue antigens are the same. The more that match the better. Biological parents & children have at least ½ that match.

Serum Cross Matching mixes the donor & recipient blood samples together to see how they interact. If the recipient's antibodies react strongly to the donor's cells it indicates that there is a great risk for the recipient to reject the donated kidney. If this occurs, a direct donation cannot occur.

What happens if the Donor & Recipient Don't Match

Sometimes donors can't donate DIRECTLY to their recipient because they are blood type incompatible or are HLA incompatible. There are other reasons such as the size of the kidney or there is a significant difference in age between the donor & recipient. The paired donor exchange program allows the exchange of living donor kidneys between two incompatible donor/recipient pairs to create two compatible pairs. The donor donates to another transplant center in exchange for their recipient to receive a kidney from another donor elsewhere.



The Regulations

Federal and state governments, as well as health care organizations, heavily regulate organ transplantation. Our program policies and guidelines are based upon the applicable Transplant Regulations established by NOTA, UNOS, Organ Procurement and Transplantation Network (OPTN), Center for Medicare and Medicaid Services (CMS) as well as the New York State Department of Health.

The United Network for Organ Sharing (UNOS) is the primary governing agent over organ transplant centers in the United States. In 1984, UNOS was contracted by the Federal government, as a result of the National Organ Transplant Act (NOTA). NOTA is a bill that established rules and regulations for organ procurement and transplantation in the United States. Section 301 of NOTA (42 U.S.C 247e) indicates that the buying and selling of organs is prohibited and punishable with a \$50,000 fine and/or imprisonment for up to 5 years. NOTA also covers “valuable consideration”, which refers to the transfer of monetary or valuable property between the donor, recipient and/or organ agent. It is permissible for the donor to be reimbursed for medical expenses, travel expenses, & lost wages directly due to donation.

The Organ Procurement Organization (OPO) is part of the UNOS network and is responsible for assisting families with making decisions about organ donation, obtaining consent for organ donation, communicating with transplant centers about the condition and availability of donated organs, as well as assisting with the retrieval and transportation of organs to transplant centers. The OPO for the URM Kidney and Pancreas programs is the Finger Lakes Donor Recovery Network (FLDRN).

Confidentiality

To protect the interest of the donor and ensure there is no conflict of interest, the donor and recipient evaluations are completely separate. The donor has a different health care team, as well as an Independent Living Donor Advocate.

The potential recipient is only entitled to know that the evaluation is in progress, the candidate has been cleared to donate, or that the candidate has been excluded from donation. No details about the medical evaluation are released to the potential recipient. If you choose to stop the donor process, the potential recipient will only be told you are excluded from the evaluation and will not be given any other information.

As a donor, you are our highest priority. We will respect your privacy, give you the time and space you need to make the right decision for you, and perform adequate testing to ensure your safety and health. If you are uncomfortable with the questions or discussions you are having with your recipient, we are here to help.

Opting Out

At any time during the evaluation process, you may opt out of donation. You do not need to provide us with any reason for opting out. The only information provided to the potential recipient is that you have been excluded from donation.

If you find yourself wanting to stop or defer your donor evaluation, please call your Donor Coordinator, Social Worker, or the Independent Living Donor Advocate. We can help you with any questions you may have and provide advice on how to speak with your recipient after he/she receives the news that we have excluded you from donating.

People often feel guilty about wanting to opt out, and we do not want anyone to feel that way. Kidney donation is a wonderful gift, but it is also a major surgery. In order to be a donor, you must have a solid support system and be physically, mentally, emotionally, and financially ready. Even with the best of intentions, there are times when these different aspects do not fall into place together.

Surgical Risks & Complications

The operation involves the same level of risk as any other major surgery, even the risk of death (which is estimated to be 0.03% for living kidney donors). The donor team will review all of the risks to you in more detail during your evaluation to make sure you are well informed & comfortable with the potential risks of donation.

Surgical risks include:

- Blood clots, infections (pneumonia, surgical site, urinary), damage to other organs or nerves, hernia.
- Scars, pain, fatigue
- Abdominal or bowel symptoms, such as bloating, nausea, developing bowel obstruction, constipation
- Transient or permanent surgical risks that include but are not limited to; acute kidney failure and the need for dialysis or kidney transplant for the living donor in the immediate post op period.

Long-Term Medical Risks

Although the risk of End Stage Renal Disease (ESRD) does not exceed that of members of the general population with the same demographic profile, risk of ESRD in living kidney donors may exceed that of healthy non-donors with similar medical characteristics. Some of these conditions cannot be predicted at the time of the kidney donor evaluation. On average, donors will have a 25-35% permanent loss of kidney function at donation.

After donating a kidney, you may have an increased risk of high blood pressure, protein in the urine, and reduced kidney function and still feel fine. Maintaining a healthy lifestyle with a healthy body weight, good diet, & exercise will help decrease your risks of damage to your kidney.

High Blood Pressure: People with one kidney may develop slightly higher blood pressure because only one kidney is doing the work of two kidneys. However, high blood pressure may take years to decades to develop. If it develops it can be treated with medication.

Proteinuria: This occurs when there is excessive protein in the urine and can be a sign of kidney damage. People living with a single kidney for many years may have slightly increased risk of proteinuria.

Reduced Glomerular Filtration Rate (GFR): The glomerular filtration rate (GFR) shows how efficiently your kidneys are removing wastes from your bloodstream. People living with one kidney have a reduced GFR.

For women, the risk of preeclampsia or gestational hypertension is increased in pregnancies after donation. You should be followed by a high risk OB/GYN during your pregnancy.

Potential Psycho-Social Risks

Making the decision to donate a kidney, and the donation itself, can be emotionally taxing. For most people, there is a long-term benefit to being a living kidney donor: the knowledge that you have helped somebody get their life back. This feeling is extremely rewarding. There is, however, the potential to develop depression, Post Traumatic Stress Disorder (PTSD), generalized anxiety, anxiety regarding the dependence on others during recovery, or possible feelings of guilt. There are some situations that can increase the risk of psychosocial concerns. These situations include:

- Impact on your lifestyle as you are evaluated and post-operatively
- Post-operative adjustments with normal activities of daily living
- Body image disturbances
- Recipient rejection and/or need for re-transplantation
- Recurrence of the recipient's disease
- Recipient death

With all transplants, there is some chance that you will benefit from talking to somebody before and after. We have a team ready to help, including a Social Worker, Psychiatrist, and Independent Living Donor Advocate. Please feel free to call your team at any time, even several years after you have donated.

Potential Financial Risk

Charges for a donor evaluation are billed to the Kidney Acquisition Fund at Strong Memorial Hospital. The donor/donor's insurance should not be billed for any tests related to the medical evaluations. The recipient's insurance or Medicare covers the fees associated with the donor surgery. In some cases, the recipient insurance requires a denial from the donor insurance prior to covering these charges. Sometimes the testing lab or the hospital will send you a bill for a test done or hospital stay, please check with our office to see if it should be covered as a donor related expense.

If you need to change health or life insurance, you should be aware that there have been some reports of insurance companies charging higher premiums to kidney donors as some insurers view having one kidney a pre-existing condition.

As a potential donor, you may want to consider the financial impact donation may have on the following:

- Child care costs
- Loss of employment while recovering
- Ability to find future employment
- Ability to obtain or afford health, disability, and life insurance, including the possibility of increased premiums or denial of coverage.
- Other costs, such as travel to the hospital, hospital parking fees, & overnight lodging
- Some health problems after donation may not be covered by the recipient's insurance

There are certain programs available that offer some financial assistance related to donation, which will be discussed further at your evaluation.

Evaluation Process

The process of living donation starts when the person who needs a kidney transplant is referred to the URMH Kidney Transplant Program for an evaluation. As a part of the evaluation, the recipient is asked if he/she knows anyone interested in donating a kidney. If the answer is yes, the recipient is encouraged to have all interested donors contact the office at (585) 275-7753. The recipient cannot call and give your name as a potential donor.

Donor safety is of the utmost importance, in order to be screened to be a donor the following is criteria must be met:

- The donor must be healthy (no diagnosis of diabetes, recent cancers, liver disease, heart disease, kidney disease, lung disease, etc.)
- The donor must have active health insurance
- The donor must be up to date on screening tests such as PAP smear, Colonoscopy, and Mammograms
- Be within a healthy weight range
- No active drug or alcohol abuse
- Be willing to quit smoking before surgery
- No infections that could be passed to recipient such as, HIV & Hepatitis B or C.

The donor coordinator will conduct a phone interview with more in depth questions about your health history. Based on this interview, if it seems that you might be safe to donate, screening labs will be ordered. The labs include routine lab work that screen for blood type, organ health, & hepatitis testing. You will be required to complete a 24 hour

collection of urine to evaluate how well your kidneys are working. If these results are okay a formal evaluation will be scheduled.

Sometimes multiple donors come forward at the same time. Initial lab testing might be completed on several potential donors, but we only evaluate one donor at a time. If we find the person is not suitable to donate, another donor will be called to schedule a full evaluation.

The Evaluation

The evaluation of a potential donor is comprehensive; we want to make sure that you are physically & emotionally safe to donate. In order to make the donation process as convenient as possible, we try to schedule all of the testing and the evaluation appointments in 2 days. You can choose if you would like them to be consecutive days or have a week or two between the testing and the evaluation appointment. We will work to find a schedule that works best for you. We will send you a detailed letter outlining the dates & times of your appointments & directions on getting to the various locations.

Your evaluation will consist of the following:

- Bloodwork & urine testing, which includes infectious disease testing, including HIV, hepatitis, & syphilis, & tuberculosis. Testing for illicit drugs is also completed.
- Your heart health by doing a stress test & an ECG
- Review of your kidneys and other internal organs by CT scan
- Lung health by doing a chest x-ray.
- The Nurse Practitioner or Physician Assistant will complete a health history & physical exam, the Nephrologist (a kidney specialist) will evaluate your kidney health & counsel you on risks, & the Transplant Surgeon will explain the donor operation & surgical risks involved.
- The Registered Dietitian Nutritionist will evaluate your eating habits & weight, and offer advice as needed.
- The RN Donor Coordinator will complete a teaching session to provide more knowledge on the donation process, surgery, & recovery.
- The Social Worker will complete a psychosocial evaluation, which assesses psychological, emotional, and social stability, as well as motivation to donate. The Social Worker assists with financial & insurance issues.
- The Financial Coordinator will verify your health insurance.
- The Independent Living Donor Advocate will complete an evaluation to ensure that you are fully informed & understand the kidney transplant process & potential risks. The Donor Advocate looks out for your best interests as a donor.
- Sometimes we have the Transplant Psychiatrist see potential donors to assess your motivation to donate & your understanding of the risks & benefits to donation. The Psychiatrist will also assess for psychosocial readiness to donate. It gives you the opportunity to discuss any concerns you may have about donation.

You may need to submit past medical records or have additional medical evaluations completed in order for us to determine your safety to proceed as a donor.

Committees and Surgical Review

The Independent Living Donor Advocate Team (IDAT) will meet and discuss your evaluation. This team includes the Independent Living Donor Advocate, Donor Coordinator, Social Worker, Donor Transplant Nephrologist, Transplant Psychiatrist, and a member of URMIC's Ethics Board. The team will review the information gathered during the evaluation process to ensure that you meet the criteria set by the program and regulatory agents for safe living organ donation, free of coercion. The team will make recommendations regarding any psychosocial and/or ethical considerations that may be appropriate for you & determine if you are safe emotionally & financially to proceed as a donor.

Your evaluation will also be discussed by the Medical Selection Committee. This team consists of a Transplant Nephrologist, Transplant Surgeon, Nursing Coordinators, Social Worker, Independent Living Donor Advocate and Registered Dietitian Nutritionist. It is the Committee's job to look at the results of your evaluation and medical testing and make sure it is physically/medically safe for you to donate. They may recommend additional testing to determine if it is safe for you to donate.

If both committees deem you safe to donate, you will then be able to schedule your surgical date.

Surgery Scheduling

We try to accommodate your schedule as best we can for your donation. Once your surgery is scheduled, we will let you know as soon as possible so that you can make arrangements. We will also schedule your Pre-Anesthesia Testing at the same time.

There are times when a living donor surgery needs to be postponed because of the availability of a deceased donor organ for another patient. Deceased donor organs must be transplanted within a certain window of time in order to have the best chance of successful transplantation. We know this can be frustrating, as you have planned time off of work and/or for help at home. We apologize for any inconveniences the delay may cause, and will try to reschedule your surgery as soon as possible.

Pre-Anesthesia Testing (PRAT)

One to two weeks before the surgery, you will have Pre-Anesthesia Testing (PRAT), where multiple members of the donor team will meet with you. The testing will repeat blood work, chest x-ray, and EKG. This visit will take the majority of the day. You will be mailed the schedule & location of PRAT testing.

These tests are very important to ensure it is safe for you to donate a kidney and undergo the stress of surgery. Occasionally, the team will find something on PRAT testing that may delay or cancel a transplant. This might include a positive pregnancy test, a cold or flu infection. It could also be because you and your recipient are no longer a good blood/tissue match. If this happens, we will call you immediately.

Instructions for preparing for surgery will be provided at the PRAT appointment.

The Surgical Procedure

We will insert IV lines in order to keep you hydrated & administer medications needed during and after surgery. You will undergo general anesthesia, a breathing tube will be placed during surgery to ensure you have a safe airway. A urinary catheter will be placed while you are under general anesthesia.

In living donor kidney transplant, a kidney is removed (nephrectomy) for transplantation into the recipient's body. The surgical procedure can take up to four hours, depending on the type of nephrectomy performed. Kidney donations at UPMC occur by hand assisted laparoscopic, robotic, or open technique. For the hand assisted laparoscopic nephrectomy, the surgeon makes small incisions in the abdomen to insert a videoscope & surgical instruments to remove the kidney. There is another 4 inch to 5 inch incision on the abdomen for the surgeon to use a hand port device to extract the kidney from your body by hand. The robotic technique is similar to the hand assisted laparoscopic technique, but the surgeon is seated in front of a video console that shows your abdominal cavity & directs a robot to complete the procedure. The average stay in the hospital for hand assisted laparoscopic & robotic technique is 2-3 days.

In some cases it is necessary to complete an open nephrectomy. In an open nephrectomy, a 6-12 inch incision is made through several layers of muscle on the side or front of the abdomen. If an open nephrectomy is performed, the hospital stay will be about 4-7 days and you will require a longer recovery at home.

After Surgery

Postoperatively, donors report having pain, bloating, constipation, nausea, and fatigue.

You will experience pain at your incision sites, as well as general abdominal and gas pain. This is normal and most donors underestimate the pain. You will receive pain medications to keep you comfortable. Getting up and walking around soon after surgery will help to dissipate gas pain.

You will take deep breaths and cough to prevent pneumonia. You may have pain with coughing, which can be eased by splinting with a firm pillow against your abdomen when you cough. You may also experience constipation or nausea, which are common after surgical procedures.

You will begin sitting in a chair and walking the day after surgery. Walking is very important to your recovery. Walking as soon as possible after surgery will help prevent complications such as blood clots and pneumonia.

You will have a urinary catheter for approximately 24 hours or until you can get out of bed. You will begin to drink soon after the surgery. If you are not nauseous after sipping water, you will progress to clear fluids and then to a regular diet.

Due to the large volume of fluid you receive in the operating room, you will be quite swollen after surgery. This swelling will decrease over the first few days after surgery.

Leaving the Hospital & Physical Recovery

You will have a prescription for pain medications & stool softeners, instructions for activity, & an appointment for your 1 week follow up visit with the surgeon. The pharmacist will review medications to resume at home. Women on estrogen typically have to wait for 4 weeks after surgery due to the risk of blood clots.

Physical recovery time varies from person to person. Many donors experience fatigue for up to 12 weeks after surgery. You will need to ensure you are getting adequate rest to allow your body to heal.

We advise that you do not drive for at least the first two weeks after surgery. You must be physically and mentally strong, with normal reflexes and without abdominal pain or discomfort before you drive. Pain medications containing narcotics (i.e., oxycodone, dilaudid) can affect your mental alertness. You should not drive if you are taking these types of pain medications.

Your surgical team will review weight lifting restrictions with you at your follow up visits. Although the skin is fully healed at about 4 weeks, the internal healing takes up to 6 months and you can be at risk of hernia during this time. Typical restrictions are no more than 10# the first 8 weeks, no more than 20# until week 12, then no more than 40# until 6 months after surgery. Yoga, rowing, & competitive sports, & core abdominal exercises should wait until 6 months post op.

You will be able to return to work in 4-6 weeks, unless your job requires heavy lifting or physical exertion.

You may resume sexual activity when you feel ready.

Living with One Kidney

While living with one kidney has been shown to have no effect on your lifespan, you will need to take proper care to ensure good health of your remaining kidney.

In order to maintain good kidney function, it is important to start with adequate water intake. This means staying hydrated with about 12 glasses (3 liters) of water a day.

Some prescription medications can be toxic to the kidneys. It is important to remind any prescribing physicians that you have donated a kidney. In addition, always ask the pharmacist if they are safe for you to take before starting any new over-the-counter (OTC) medications, vitamins or supplements. Non-Steroidal Anti-Inflammatory Drugs (NSAIDS) can cause damage to the kidneys and are not recommended.

You should avoid contact sports such as rugby, football, wrestling and certain types of martial arts to reduce the risk of injury to your remaining kidney. Talk with your provider if you have questions about your specific situation.

If you are a female of childbearing age, you should avoid getting pregnant in the first year post-donation, in order to give your body enough time to heal. You should be followed by a high risk OB/GYN as you are at increased risk for preeclampsia or gestational hypertension.

It is important that you maintain a healthy weight in an effort to reduce your risk of diabetes and hypertension, as both of these diseases are very harmful to your kidneys. It is also very important that you seek health care from your primary care provider on a yearly basis. She/he will need to check your weight, blood pressure, urine testing and blood work to monitor you for good kidney function and overall health.

Follow-Up Care

Donors should follow up with the transplant center for the first 24 months after surgery. If you are from out of town, you should have follow up care with your PCP. This is very important to ensure you are healthy post-donation and the kidney is functioning well. It is important that you have your blood pressure, weight, and blood work and urine checked 1-2 weeks after surgery and then 1, 6, 12, and 24 months after donation. At 3 months after donation we will ask you to have blood & urine testing to monitor kidney function. The United Network for Organ Sharing (UNOS) requires that transplant centers report the donors' progress for up to two years after surgery. We understand that you may feel fine, but there are conditions, which can go undetected, without blood work and a provider's exam. It is expected that you will comply with these routine checkups done for the first two years after transplant. We will pay for your lab work and routine health checkups the first two years after your kidney donation. We also strongly recommend that you continue having routine health maintenance exams for the rest of your life to ensure you are healthy.

Frequently Asked Questions

Is the recipient removed from the deceased donor kidney waiting list while I am being evaluated?

No changes are made to the recipient's status on the waiting list if they opted to be listed for a deceased donor kidney.

Will I require a blood transfusion?

Blood transfusion during this surgery is very rare. You may donate your own blood in the event that you need a transfusion. If you do need a transfusion, we can use your own blood so you are not exposed to possible risks of a transfusion from someone else. If you choose to do this, you must donate your blood two to four weeks prior to surgery. There may be shipping charges if you donate blood at your local blood bank. Often, your insurance provider does not cover these costly charges. Should this be the case for you, arrangements can be made for you to donate your blood through Strong Memorial Hospital Blood Bank services.

Who will fill out my disability forms?

A member of the team will complete these forms. Please bring them to your PRAT appointment.

Why is my menstrual cycle different?

The stress of the surgery may cause irregularities during your first menstrual cycle after the surgery. If this persists, please notify your OB/GYN.

Will I require care at home after the surgery?

Although you will be tired and weak, you should not need any professional nursing care at home. You will need a friend or family member to help with household chores, errands, perhaps cook your meals, and take you to and from the transplant surgery clinic for your check-ups.

Will I have staples or sutures that need to be removed?

Usually, the wound is closed with dissolving subcuticular stitches or a medical grade glue. These stitches will be absorbed by the body & the glue will dissolve, so there is no need for them to be removed. Additionally, sometimes small strips of tape (Steristrips) are placed over the external incision and can be removed or will fall off about one week after surgery.

Useful Websites

United Network for Organ Sharing

Organ availability information, education materials, and policies

www.unos.org

Scientific Registry of Transplant Recipients

A national database of statistical information for solid organ transplantation

www.srtr.org

National Kidney Registry

A reference website with plenty of information

www.kidneyregistry.org

Donate Life

An educational website

www.donatelife.net