



HEARTLAND KIDNEY NETWORK

# **TRANSPLANT BOOKLET**

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COMMUNITY INFORMATION  
& RESOURCES

# TRANSPLANT BOOKLET

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# TRANSPLANT BOOKLET

## PROVISION OF EDUCATIONAL INFORMATION: PATIENTS

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### I. ORGANIZATION AND AUTHORS OF GUIDE

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Organization: Heartland Kidney Network (ESRD Network 12)

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The Heartland Kidney Network makes informational materials available to patients in Iowa, Missouri, Kansas, and Nebraska. The Network informs patients how to contact the Network to obtain these materials on an annual basis.

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### II. TRANSPLANT BACKGROUND INFORMATION

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In the early 1980s, the advent of the immunosuppressant drug cyclosporine made the transplantation of organs other than kidneys feasible. This development led individuals to appeal to the public through the media and their legislators for assistance in finding suitable donor organs. The demand for these organs greatly exceeded the supply.

There was no centralized network to increase the utilization of scarce donated organs nor were there criteria governing how an individual obtained access to transplantation. To further complicate matters there was a growing concern that wealthy citizens of foreign countries were coming to the United States to take advantage of transplant technology to the detriment of terminally ill U.S. citizens also in need of the same technology. These issues resulted in public demand for the implementation of a national system.

Today, United Network for Organ Sharing (UNOS) coordinates the nation's organ transplant system, providing vital services to meet the needs of men, women and children awaiting lifesaving organ transplants. Based in Richmond, Virginia, UNOS is a private, nonprofit membership organization.

UNOS operates the nation's Organ Procurement and Transplant Network (OPTN) facilitating organ recovery and placement under contract with the U.S. Department of Health and Human Services. All clinical transplant centers, organ procurement organizations and tissue typing laboratories in the United States belong to and participate with UNOS. UNOS members have developed membership criteria based on the education, training and experience of medical personnel and monitor compliance with those standards to ensure high quality and consistent patient care. A national waiting list of all patients in the country waiting for solid organ transplantation is maintained on the UNOS computer system. UNOS operates a 24-hour-a-day organ placement center and computer system to ensure efficient and optimal matching of donors and recipients. Policies ensuring access to and allocation of organs are in place and are monitored through the use of a national computer system. To facilitate the development of policy and improve scientific methods, UNOS maintains a Scientific Registry, which contains scientific and demographic data on all organ donors and tracks all organ recipients throughout their lives.

Every patient waiting for an organ transplant in the United States is registered in the UNOS computerized data network. All have equal access to donated organs. The 59 organ recovery organizations across the country are members of UNOS.

The Organ Procurement Organization (OPO) Coordinator contacts UNOS and inputs the organ donor's medical history, physical measurements, and blood type, then prints a computerized list of likely transplant recipients.

The list is printed in order of matching priority, which includes medical criteria, length of time waiting, blood type, body weight, size of recipient diseased organ, and severity of illness.

If the first potential recipient does not match medically with the available organ, the OPO Coordinator maintains the computer search in an assigned region or elsewhere in the nation for a potential recipient who most nearly matches the donor. Likewise, organ recovery organizations throughout the United States will notify each other when an organ becomes available for waiting recipients in their respective areas.

Matching donor organs with recipients is critical. Transplant waiting times may vary from a few months to several years because of matching difficulties.

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### **III. KIDNEY TRANSPLANT PROCESS**

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Transplantation is considered the treatment of choice for most people with ESRD: offering a better quality of life and prolonged survival compared to dialysis. During the past decade, the numbers of kidney transplants performed has steadily increased. According to the 2005 Annual Report of the U.S. Organ Procurement and Transplantation Network (OPTN), the number of kidney transplants performed in the U.S. increased from 10,646 in 1994 to 16,004 in 2004, an increase of 67%.

#### **What is a Kidney Transplant?**

A kidney transplant is a procedure in which people whose own kidneys have failed are replaced with a healthy kidney from another person. The newly placed functioning kidney takes over the work of cleaning blood in your body system. A donated kidney may come from an anonymous donor who has recently died or from someone who is still living, like a family member or living unrelated donor. The blood and tissue of the person donating the kidney must be tested. This is done to see how well they match yours so that your body won't reject the newly transplanted kidney.

#### **How and where do I start?**

Ultimately, you have the right to be evaluated by a transplant program. You also have a right to be referred to the transplant program of your choice. To start, let your nephrologist know that you are interested in a kidney transplant. Your nephrologist will discuss the option and any medical issues and then refer you to a transplant program. If any concern about making the referral arises, make sure you get specific reasons. Remember, not everyone is a transplant candidate.

There are approximately two hundred fifty (250) transplant centers in the U.S. These centers are fully credited and must meet a variety of professional standards. In addition to the patients' relationship with the transplant team, there are many things to be considered when choosing a transplant center.

- ❑ **Access Issues:** travel time and costs associated with travel.
- ❑ **Statistics:** such as average waiting time, success rates.

- ❑ **Cost:** cost of living in that area before and after transplant.
- ❑ **Follow-up Care:** routine checkups, possible emergency care.
- ❑ **Support System:** availability of family and friends for help and moral support.

The time it takes to get a kidney transplant varies. There are not enough deceased donors for every person who needs a transplant. You must be placed on a waiting list to receive a deceased donor kidney. However, if a relative or living unrelated donor gives you a kidney; the transplant operation can be done sooner. Each transplant program has its own evaluation guidelines. Therefore, if one transplant program does not accept you for transplant and you disagree with the decision, you may want to consider applying to another transplant program.

A patient may wish to register at more than one transplant center. However, each center determines who it accepts as candidates and reserves the right to decline patients who are listed at other centers. Patients should inform the centers they contact of their multiple listing plans.

If a patient would like to change transplant centers, the patient may transfer his or her primary waiting time to the new center upon listing at that center. The patient should then notify his or her original center that he or she needs to be removed from that center's waiting list. Patient should ask the following questions when choosing a transplant center and its staff:

- ❑ Do I have choices besides transplantation?
- ❑ What are the benefits and risks of transplantation?
- ❑ Who are the members of the transplant team and what do they do?
- ❑ What are your criteria for accepting organs for transplant?
- ❑ What does the evaluation and testing process include? How does it affect whether I am put on the list?
- ❑ How many of my type of transplant do you perform each year? How long have you been doing them?
- ❑ What part of the transplant cost is covered by my insurance?
- ❑ What if my insurance does not pay for medications?
- ❑ How much will I have to pay in the end?
- ❑ Will I be asked to take part in research studies?
- ❑ What types of living donor transplants does the center do? Is a living donor transplant a choice in my case? If so, where can the living donor evaluation be done?

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#### **IV. TYPES OF KIDNEY DONORS**

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There are 3 different kinds of kidney donors:

**Deceased Donor**

A deceased donor is one that comes from a person who has just died. The family of this person has given permission for the kidneys, and possible other organs, to be donated for someone who needs a transplant.

**Living Related Donor**

A living related donor kidney comes from a blood relative, like a parent, brother, sister, or an adult child. A kidney from a relative may be a better match. This means that there is less chance of rejection and you may not have to take as much (immunosuppressive) medicines.

There is no waiting time after the evaluation for a living related transplant unless the donor needs to have other medical problems addressed first. You and the transplant team can plan when you will have the transplant surgery. Fewer people need temporary dialysis after a living related transplant than after a deceased donor transplant. The donor will need about 6-8 weeks to recover. The recovery time may be less if a laparoscopic kidney recovery is done.

**Living Unrelated Donor**

A living unrelated donor kidney comes from someone who is not related to the person, like a spouse or a friend. There is no waiting time after the evaluation for a living unrelated transplant unless the donor needs to have other medical problems addressed.

You and the transplant team can plan when you will have the transplant surgery. Fewer people need temporary dialysis after a living unrelated transplant than after a deceased donor transplant. The donor will need about two months or less to recover. If you are thinking about a living donor transplant, there is one basic requirement: The donor must be willing to give you the kidney without pressure from anyone.

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**V. YOUR TRANSPLANT TEAM**

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Maintaining regular contact with your transplant team is very important. Team members will continue to provide medical care, advice, and support for you and your family throughout the transplant process. Team members vary in each transplant center, but usually include:

**You!**

You are the most important member of the transplant team. You should have a good understanding of your medical care and be actively involved in your care through clinic appointments and communicating with members of the team.

**Transplant Surgeon**

Transplant Surgeons are medical doctors who specialize in kidney surgery and transplantation. The surgeons perform the operation and will be involved in your care and medical management as you recover from surgery.

My Transplant Surgeon(s): \_\_\_\_\_ Phone: \_\_\_\_\_

**Nephrologist**

A Nephrologist is a medical doctor who specializes in medical problems of the kidney. Most patients with kidney disease have a Nephrologist who manages their medical care before transplant. Some patients continue care with a Nephrologist after transplant.

My Nephrologist: \_\_\_\_\_ Phone: \_\_\_\_\_

Management varies by transplant center; so you may have follow-up care with a transplant physician, transplant surgeon, or nephrologist. They will be responsible for the management of anti-rejection medications and any medical issues directly related to the transplant. For health problems not related to your kidney transplant, you should continue to contact your local physician or general practitioner. Your transplant coordinator will work with you to plan your follow-up care after you leave the transplant center.

### **Nurse Practitioner (NP) or Physician Assistant (PA)**

A Nurse Practitioner is a registered nurse who has completed advanced education, usually a master's degree, and training in the diagnosis and management of common medical conditions and chronic illnesses. Physician Assistants are non-physician clinicians who are licensed to practice medicine with a physician's supervision. Most PAs also have a master's degree. NPs and PAs provide a broad range of health care services. They provide some of the same care as physicians while working closely with a supervising physician. A Nurse Practitioner or Physician Assistant working at a transplant center might manage your daily medical care when you are in the hospital or may follow your progress in the outpatient clinic.

My NP or PA: \_\_\_\_\_ Phone: \_\_\_\_\_

### **Transplant Coordinator (RN, CCTC)**

Transplant Coordinators are usually licensed registered nurses (RN). They have extensive experience in the care and management of transplant recipients, both before and after transplant. Your coordinator will be involved in preparing you for discharge and will also follow your care after you return home. Your coordinator may refer you to other team members for services that you need and will be available to discuss any questions or concerns you may have as you begin to adapt to life following your transplant. The initials CCTC after your coordinator's name mean that your coordinator has passed a transplant certification examination and is now a Certified Clinical Transplant Coordinator.

My Transplant Coordinator: \_\_\_\_\_ Phone: \_\_\_\_\_

### **Medical Social Worker (MSW)**

A Medical Social Worker in transplantation specializes in helping patients and families cope with the stresses and challenges of the transplant process. Your Social Worker may help you by identifying community support, assisting you with housing while staying in the hospital community, helping with financial issues, providing emotional support, and providing information and referrals for support groups or counseling.

My Social Worker: \_\_\_\_\_ Phone: \_\_\_\_\_

### **Clinical Nurse Specialist (CNS)**

A Clinical Nurse Specialist is a registered nurse with an advanced practice degree in a nursing specialty. The transplant Clinical Nurse Specialist is usually involved in the transplant evaluation as well as post-transplant care and will provide information on all facets of the transplant process, assess any potential problems, provide supportive care, and will help in preparing you for discharge. This advanced practice nurse may be involved with your care while you are in the hospital and after discharge.

My CNS: \_\_\_\_\_ Phone: \_\_\_\_\_

### **Pharmacist**

A Pharmacist is a licensed medical professional who dispenses prescription medications. As part of the transplant team, the transplant pharmacist may help monitor your medications while you are in the hospital

and during clinic visits. The pharmacist may also be involved in your discharge education and will provide information about your medications and instructions on how to take them.

My Pharmacist: \_\_\_\_\_ Phone: \_\_\_\_\_

My Pharmacy: \_\_\_\_\_ Phone: \_\_\_\_\_

**Dietitian**

A Dietitian specializes in helping patients maintain good nutrition. Your dietitian will help manage your nutrition before and after transplant. The dietitian may also work with you on any special dietary instructions or diets for medical complications such as diabetes, high blood pressure, high potassium levels, or high cholesterol.

My Dietitian: \_\_\_\_\_ Phone: \_\_\_\_\_

**Other members of my Transplant Team:**

Name/Title	What they do	Contact information

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**VI. GETTING ON THE WAIT LIST**

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For most transplant candidates, the first step in receiving a transplant is to get on the OPTN/UNOS (Organ Procurement and Transplantation Network, United Network of Organ Sharing) national waiting list. The UNOS Organ Center maintains this list. All transplant candidates who do not have the option of a living donor (and even some who do) usually have to wait for some length of time because there are not enough donor organs for all who need them. Your transplant center will place you on the UNOS list, and an official letter will be sent to you confirming you are listed.

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**VII. OTHER HELPFUL INFORMATION TO KNOW**

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**Your Donor:**

In addition to deceased donor transplants, patients may also receive organs from living donors. In 2004 there were 27,038 organ transplant performed in the United States. More than 6,991 of these were living donor transplants. Living donation offers an alternative for individuals waiting transplantation and increases the existing organ supply.(UNOS)

- ❑ The donor will not have to pay for the testing or the surgery. This is paid for through your health insurance.
- ❑ The donor will need to have 4-8 weeks off from work to recover from the surgery. If the donor has been working before the surgery, it may be possible for them to receive state disability payments while they are recovering.
- ❑ The donor will have many tests before the surgery. There will be laboratory tests, x-rays, a physical exam and a visit with the social worker or psychologist. This testing is done to make sure that the donor is healthy. It helps to limit complications for both the donor and for you.
- ❑ The transplant coordinator will arrange for testing of the potential donor.

### **You:**

As soon as your name is added to the transplant waiting list, it would be wise to make a list of things you may want to have with you while in the hospital after surgery. Also consider making a list of people you would like to contact after surgery. Consider packing a bag and leaving it in an easy to find area. Ask a friend or relative to help you remember some last minute items. The excitement of the call can send your mind racing and you could forget some of the items you may want.

If the transplant center is close, consider designating a driver – if possible. If you decide not to designate a driver, remember slow and easy wins the race – the transplant team wants you to arrive at the center uninjured. If the transplant center is farther away, the coordinator can assist you and your family with transportation arrangements. If you choose to make your own arrangements and flight travel is involved, consider calling the airlines in advance to retrieve updates on flights and routes every month. If possible, a direct flight is the best option. It would be wise to have a backup plan in case your flight is delayed. Ask family and friends to stay within driving distance of the transplant center.

Weeks and months may pass while you and the transplant team wait for UNOS to locate the right kidney for you. During your wait you can prepare and take positive steps to deal with the stress of waiting. Waiting for the phone call that a match has been located can possibly send you into a daze of excitement, stress and anxiety. The following are tips to assist you in coping with the stress you may feel:

- ❑ Eat right; take your medications and exercise according to the transplant teams plan.
- ❑ Don't place your life on hold; keep social and work engagements. Relax to the best of your ability.
- ❑ Share your feelings if you begin to feel depressed or have other concerns. The transplant team is willing to assist you and help alleviate your fears. The Social Worker can locate support groups in your area in addition to listening to your concerns.
- ❑ Enjoy a hobby to the fullest. Not only can it be enjoyable, but it can also absorb energy, take your mind off of the waiting, and help you relax.
- ❑ Laughter is the best medicine. Spend time with family and friends – good company can take your mind off the wait.
- ❑ Learn and practice relaxation techniques, such as reading, yoga or music.

### **Other Options**

If you are not a candidate for transplant or are not interested, you have a number of other options. You need to decide what is a good fit for your lifestyle and needs. Each option has its own benefits; however, there is evidence that home options may provide a better quality of life and improved medical outcomes. Not

everyone is a candidate for the home options and not every facility offers every option, so ask your nephrologist and facility for more information. Here is the list of options:

- ❑ **In-center hemodialysis** – usually 3 times a week but some facilities are now offering nocturnal and daily schedules
- ❑ **Continuous ambulatory peritoneal dialysis (CAPD)** – a manual form of peritoneal dialysis, with no machine
- ❑ **Continuous cycling peritoneal dialysis (CCPD)** – a form of peritoneal dialysis using a machine (called a cyclor) at night
- ❑ **Conventional home hemodialysis** – 3 times a week hemodialysis at home
- ❑ **Daily home hemodialysis** – short (2-3 hour) treatments, 5-6 days a week
- ❑ **Nocturnal home hemodialysis** – nightly (6-8 hour) treatments, 3 plus days a week

To learn more about home dialysis options or to locate facilities providing certain options, visit the website [www.homedialysis.org](http://www.homedialysis.org) or contact the Network.

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## **VIII. COMMONLY ASKED QUESTIONS ABOUT TRANSPLANTATION**

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### **How are patients added to the national organ transplant waiting list?**

When a patient's physician determines that an organ transplant may be necessary, the patient is referred to a transplant center for evaluation. The medical team at the transplant center considers the patient's past and present medical condition as well as his or her ability to follow prior medical instructions and the emotional support from the patient's family or friends. If the transplant team determines a patient is a good candidate for transplantation, he or she is then added to the waiting list.

### **How are donated organs matched to patients awaiting transplant?**

When a deceased organ donor is identified, a transplant coordinator from an organ procurement organization (OPO) enters medical information about the donor into the UNOS computer system.

The system then matches the donor's medical characteristics with the medical information of candidates awaiting a transplant. The computer generates a ranked list of patients for each organ recovered from the donor. These "matches" are based on many things that may include the level of illness, medical urgency of the transplant candidate, time spent on the waiting list, biological similarities between the donor and the candidate (such as organ size, blood type and genetic makeup) and the candidate's availability to be transplanted immediately.

Generally, donated organs are also distributed in certain geographic order.

### **Can patients list at more than one transplant center?**

Yes. This is called "multiple listing." It presently permits patients to be considered for organs that become available in other areas. Patients should keep in mind that there is no advantage to listing at more than one transplant center in the same organ procurement organization local area. Each center has its own criteria for who it accepts as a candidate and reserves the right to decline patients who are listed at other centers. Patients who wish to list at more than one center should inform the centers they contact of their plans.

**How long does it take to receive an organ?**

Patients added to the national organ transplant waiting list may receive an organ that day, or they may wait years. Factors affecting waiting time include how well the donor and recipient “match,” how ill the patient is and the availability of donors compared to the number of patients waiting. UNOS publishes waiting time statistics by geographic region, sex, age, blood type and ethnicity.

**Am I a candidate for living donation?**

Living donation is handled by the transplant centers. Living donors have historically been a close relative (spouse, sibling, parent, etc.) or friend of the recipient. Living non-directed (stranger-to-stranger) donation is newer. There are additional types of living donation, such as paired exchange, kidney donor waiting list exchange, positive cross match, and blood type incompatible.

For more information patients should contact their transplant program.

**Does UNOS oversee donation and transplantation around the world?**

No. However, UNOS can provide a list of similar organizations in other countries that may be contacted for transplant information.

**Can a patient from another country receive a transplant in the U.S.?**

Yes. Patients can travel from other countries to the U.S. to receive transplants. Once accepted by a transplant center, international patients receive organs based on the same policies as those that apply to U.S. citizens. These types of transplants are limited in number.

**How can I find out about organ allocation policy changes and legislation that affect organ transplantation and donation?**

Information on policy and legislation is routinely found on [www.unos.org](http://www.unos.org) and [www.optn.org](http://www.optn.org) and in UNOS publications. UNOS also maintains a mailing list of patients and members of the public who wish to receive policy proposals published for public comment.

To request these resources, please contact UNOS.

**How can I access data on organ transplantation and donation?**

Phone toll-free (888) 894-6361 or visit [www.transplantliving.org](http://www.transplantliving.org) or [www.optn.org](http://www.optn.org).

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**IX. PREPARING FOR SURGERY**

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When a donor kidney is available, the transplant coordinator will call you to get ready. The call could come during any part of the day. It is very important that the transplant team can reach you wherever you are. Provide the transplant team with your cell phone number or pager number and always inform them if the numbers change. Provide the transplant team phone numbers of friends and family members so that when your kidney is available they can contact you immediately. When the transplant coordinator calls you, everything may seem like a blur. The coordinator will inform you when to go to the transplant center. Do not delay; there is a time limit once a kidney becomes available.

Once at the Hospital you will be admitted. After admission, you will be examined, have more blood work taken, a chest x-ray, an EKG, dialysis and possibly other tests. Before surgery, you may receive an enema or a laxative to clean out your intestines and prevent constipation after surgery. Hair from the chest and abdomen may be shaved to prevent infection, and an intravenous (IV) line could be inserted in the arm or just under the collarbone to give medication and prevent dehydration. You may also be given a sedative to help you relax and feel sleepy before going to the operating room.

It is important to note that surgery may be postponed in some cases. Sometimes this could be due to certain reasons such as; the donor kidney does not function well or there are signs of damage or If the cross match testing between you and the donor shows a reaction, which means you are not compatible with that donor. If an infection has developed or any other medical problem that could interfere with your surgery and recovery you could be sent back home. If surgery is postponed, this is only a temporary setback. The search for another kidney will continue.

### **IMPORTANT:**

Because transplantation is a major surgical procedure, you may need a transfusion. Today, all blood is screened very carefully; the likelihood of getting a disease is very small. Any concerns that you have regarding the source of the blood can be relayed to the transplant team during the waiting period, before getting to the hospital. Most hospitals offer the option of "auto transfusion" – You may donate your own blood before surgery. Your blood is stored and then used during transplantation. Each facility may vary, some do not offer this option. Please check with the transplant team to see if this is an option at their facility.

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## **X. WHAT TO EXPECT DURING EVALUATION AND BEFORE SURGERY**

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Pre-transplant tests in addition to a health screening are performed to assist the transplant team in discovering potential difficulties thus improving the survival of the transplant for you, the patient. Some of the tests you may expect are:

**Physical Exam** – The doctor can determine the patient's overall condition.

**Chest X-Ray** – Allows the doctor to assess the condition of the patient's lungs and health of the respiratory tract.

**Medical and Surgical History** – allows the doctor to have information on previous diseases and can determine if any additional tests need to be performed.

**Electrocardiogram** (elec-tro-car-dio-gram) – Sometimes called and EKG or ECG. This test evaluates how well the heart functions and can show heart disease that may not have been suspected.

**Ultrasound** – Evaluates the condition of the vessels where the transplanted kidney will be placed.

**Blood Tests** – Similar to the monthly labs run at your dialysis clinic. Additionally, these tests may also evaluate for any immune problems that could lead to rejection down the line.

**Blood Typing** – Your blood type is either A, B, AB or O. This test determines which type. Transplant recipients do not have to have the same blood type, however their types must be compatible.

**Pulmonary Function Tests** – The patient is asked to breathe into a tube and a device measures the amount of oxygen the blood can carry and how well your lungs are working.

**Upper and Lower Gastrointestinal Series (Upper and Lower GI)** – This test is usually done under mild sedation. In an upper GI, a scope is passed down your throat to evaluate the upper intestines, stomach and esophagus. A lower GI evaluates the colon and is also done under mild sedation with a scope that is placed in the rectum. Both tests could be used to make sure you are disease free.

**Renal function studies** – They may request a 24-hour urine to determine current kidney function.

**Tissue Typing** – This is used to find a matching kidney. It looks at the “special markers” – genetic markers on white blood cells – your “tissue type”.

**Panel Reactive Antibody – (PRA)** – A blood test that measures the immune response to foreign tissue, transfusions, pregnancy or previous transplants. Your immune system may be active from illness, transfusions or infections. The optimal on this test would be a 0% activity.

**Viral Testing** – A blood test that evaluates if you have been exposed to viruses like Hepatitis, HIV, Cytomegalovirus (CMV) and Epstein-Barr (EBV).

**Mammogram** – Typically women only, an x-ray of a woman’s breast that can evaluate for possible breast cancer.

**Pap smear** – Women only, cells from your cervix are looked at under a microscope and examined for possible cancer.

**Echocardiogram** (ech-o-car-di-o-gram) – An ultrasound of the heart to look for any abnormalities.

**Dental Evaluations** – All teeth and gums must be healthy before you are added to the transplant list. Any cavities must be filled. You will need to have regular dental check-ups while you await transplantation. If you are on dialysis, check with your dialysis team before any dental appointment. The dialysis team may want you to take antibiotics before the appointment to help prevent any infections.

**Cross match Testing** – When a donor kidney is available, your blood is mixed with the donor’s blood. If there is no reaction, you are compatible with the donor.

**Other Tests** – The transplant doctor may want additional tests, for example, if you are diabetic, they may request additional tests on your heart.

**AIDS / HIV** – You will be tested at one of your clinic appointments.

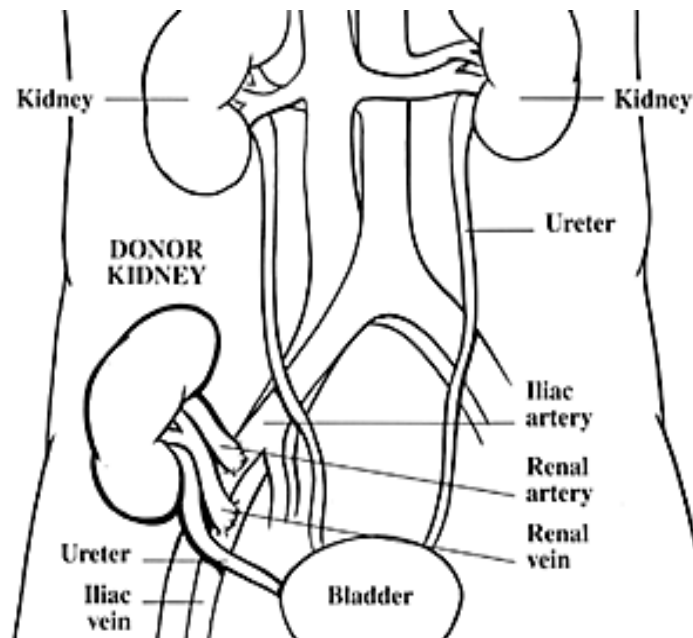
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## XI. UNDERGOING SURGERY

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You will be given general anesthesia during the surgery. Once you are asleep, the transplant surgeon will make an incision on the right or left side of your lower abdomen just above the groin.

The illustration below shows where the transplanted kidney will be placed. Notice that it is usually located in the abdominal area. One reason for this is to make it easier for the physician to feel it and check it after your surgery.



After surgery, you will wake up in the intensive care unit (ICU) or the recovery room after the anesthesia wears off. You can expect to experience some or all of the following:

- ❑ Some pain and discomfort, the pain medication will help relieve this.
- ❑ Someone will ask you to turn, cough and deep breathe periodically. This is done to help keep your lungs clear and prevent pneumonia. If it hurts to cough, ask someone to assist you in supporting your abdomen.
- ❑ You will have an IV line in your arm or neck under your collarbone, which will be used to give fluids and medication for the first few days after your surgery.
- ❑ For several days after surgery, you will have a catheter in your bladder to drain urine. The catheter may feel uncomfortable and you may feel like you need to urinate constantly, this is only temporary. The catheter is usually removed several days after surgery.
- ❑ During surgery, one drain may be placed in or near the incision. This drain will be removed 5 to 10 days after surgery. (This is the Jackson Pratt) The surgical team places the donor kidney into the abdomen and connects the kidney's blood vessels to your iliac artery and vein. The surgeons will

then connect the ureter to the bladder. A small drain, called a Jackson Pratt, may be placed into the abdominal cavity to drain any excess fluid. **Do not open this drain yourself.** The nursing staff at the hospital will drain it and teach you how to drain it, if necessary. Opening this drain without assistance can lead to an infection in your abdomen, new kidney or throughout your body. Not all transplant centers use drains after surgery.

- ❑ You may still need dialysis to help clear excess fluid and toxins in your body until the kidney recovers from the transplant process.
- ❑ The length of a hospital stay will depend on your progress. You are encouraged to talk to someone on your transplant team if you are uneasy or uncomfortable.

After your medical condition has stabilized after surgery, you may be transferred from the ICU to the acute care unit. During your stay on this unit, laboratory studies, medications, nutritional status and exercise tolerance are monitored. As soon as you are able, discharge instructions will begin to prepare you for going home.

Feel free to use this space to list any special discharge questions you want to ask, instructions that you may have been given, information on medications you will now take or questions for follow-up clinic appointments.

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**Clinic Visits:** When you leave the hospital, you will receive a schedule of follow-up clinic visits for lab tests and checkups. Make sure you do not miss these appointments; they are intended to track your progress and detect any complications as soon as possible.

**Follow-up visits:** On the day you go for a follow-up visit, remember to bring your medication list and either this handbook or the one the transplant center provided. You will be given specific instructions for routine lab work or special tests that you may need.

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## XII. FINANCIAL ISSUES

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Financing a transplant raises many questions and concerns for patients and their families. Because the cost of a transplant starts to add up even before your transplant, it is common for patients to rely on several sources to help pay for all medical and non-medical expenses of pre and post transplantation. You do have choices when it comes to hospital care. The most important consideration in any choice is the individual's specific situation. Each patient has different needs, desires and preferences that need to be taken into consideration when selecting an appropriate hospital. All options should be investigated to make sure you make the best decision. To be covered by Medicare; your kidney transplant must be done in a hospital that is approved by Medicare to do kidney transplants. Most private health insurance policies cover many expenses associated with kidney transplants, including medications. In addition, most kidney transplant candidates are eligible for Medicare, which should cover 80 percent of the cost of the transplant surgery.

After transplantation, you should take medications to prevent rejection of your new kidney. Medicare Part B should cover 80 percent of the cost of these anti-rejection medications, but not the cost of other medications you may need. For most patients, this Medicare coverage should stop after 36 months. However, if you are eligible for Medicare coverage based on age or disability, the cost of your anti-rejection medications may be covered for as long as you are on Medicare. Most transplant programs are staffed with social workers that are ready to help you and your family sought out such matters. You will find a list of financial resources in the next section.


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### XIII. RESOURCES FOR TRANSPLANT RECIPIENTS

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- ❑ **Air Lifeline**  
 50 Fullerton Court, Suite 200  
 Sacramento, CA 95825  
 (800) 446-1231  
 [www.airlifeline.org](http://www.airlifeline.org)  
 Transports ambulatory patients up to a distance of 500 to 700 miles using private pilots and their aircraft. Can transport people for transplant and follow-up appointments. Medical and financial need must be documented. Service is free of charge.
- ❑ **Air Care Alliance**  
 4620 Haygood Rd.  
 Virginia Beach, VA 23455  
 (800) 296-1217  
 [www.aircareall.org](http://www.aircareall.org)
- ❑ **American Kidney Fund**  
 6110 Executive Blvd., Ste. 1010  
 Rockville, MD 20852  
 (800) 638-8299  
 [www.akfinc.org](http://www.akfinc.org)
- ❑ **American Liver Foundation**  
 75 Maiden Lane, Suite 603  
 New York, NY 10038-4810  
 (800) 465-4837, (800) GOLIVER  
 [webmail@liverfoundation.org](mailto:webmail@liverfoundation.org)  
 [www.liverfoundation.org](http://www.liverfoundation.org)
- ❑ **Angel Flight**  
 American Medical Support Flight Team  
 3237 Donald Douglas Loop South  
 Santa Monica, CA 90405  
 (888) 426-2643
-  [www.angel-flight.org](http://www.angel-flight.org)  
 Provides free air transportation on private aircraft for needy people with healthcare problems and for healthcare agencies, organ procurement organizations, blood banks and tissue banks. No fees of any kind. Volunteers serving the public since 1983.
- ❑ **Burkhead Foundation**  
 P.O. Box 105723  
 Jefferson City, Missouri 65110  
 [www.burkheadfoundation.org](http://www.burkheadfoundation.org)
- ❑ **Children's Organ Transplant Association**  
 2501 COTA Dr.  
 Bloomington, IN 47403  
 (800) 366-2682
- ❑ **Fujisawa Patient Assistance Program**  
 P.O. Box 221644  
 Chantilly, VA 20153-1644  
 (800) 477-6472  
 Provides help on a one time only basis if the medication is available. For several of the drugs, the program replaces what has already been given to the patient.
- ❑ **Medicare Hotline**  
 (800) 638-6833
- ❑ **National Insurance Consumer Hotline**  
 (800) 942-4242

❑ **National Organization of Social Security Claimants' Representatives**

 (888) 431-2804


 [www.nosscr.org](http://www.nosscr.org)


❑ **National Transplant Assistance Fund**

150 N. Radnor Chester Road

Suite F-120

Radnor, PA 19087

 (610) 535-6105, (800) 642-8399

 (610) 535-6106

 [lsamson@transplantfund.org](mailto:lsamson@transplantfund.org)


 [www.transplantfund.org](http://www.transplantfund.org)

❑ **Nielsen Organ Transplant Foundation**

Provides financial assistance to pre- and post-transplant patients in the NE Florida area.

580 W. 8th St.

Jacksonville, FL 32209

 (904) 244-9823


 [www.notf.org](http://www.notf.org)


❑ **National Foundation for Transplants**

1102 Brookfield, Ste. 200

Memphis, TN 38119

Contact: Janice Hill

 (800) 489-3863, (901) 684-1697

 (901) 684-1128

 [jhill@transplants.org](mailto:jhill@transplants.org)

 [www.transplants.org](http://www.transplants.org)

### **Kidney Transplant Education Resources**

- ❑ United Network for Organ Sharing (UNOS) [www.unos.org](http://www.unos.org)
- ❑ American Organ Transplant Association (AOTA) [www.aotaonline.org](http://www.aotaonline.org)
- ❑ Children's Organ Transplant Association (COTA) [www.cota.org](http://www.cota.org)
- ❑ National Kidney Foundation (NKF) [www.kidney.org](http://www.kidney.org)
- ❑ American Association of Kidney Patients (AAKP) [www.aakp.org](http://www.aakp.org)
- ❑ Transplant Experience [www.TransplantExperience.com](http://www.TransplantExperience.com)
- ❑ International Transplant Nurses Society [www.itns.org](http://www.itns.org)

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## XIV. TERMS TO KNOW - A TRANSPLANT GLOSSARY

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### **Allograft**

An organ or tissue transplanted from one individual to another of the same species i.e., human to human. Example: a transplanted kidney.

### **Antibody**

A protein substance made by the human body in response to a foreign substance, such as a previous transplant, blood transfusion, virus or pregnancy. Because antibodies attack the transplanted organ, transplant patients must take drugs to prevent organ rejection.

### **Antigen**

A foreign substance, such as a transplant, that triggers a response. This response may be the production of antibodies, which try to destroy the antigen (the transplanted organ).

### **Anti-rejection Drugs**

Medicines developed to suppress the immune response so that the body will accept, rather than reject, a transplanted organ or tissue. These medicines are also called immunosuppressants.

### **Brain Death**

When the brain has permanently stopped working, as determined by the physician. Artificial support systems may maintain functions such as heartbeat and respiration for a few days, but not permanently. Donor organs are usually taken from persons declared brain dead.

### **Coalition on Donation**

A non-profit group of health care professionals, transplant patients and voluntary health and transplant organizations. The Coalition works to increase public awareness of the organ shortage and create a greater willingness to donate organs and tissues.

### **Compliance**

The act of following orders, adhering to rules and policies. Example: taking medications as directed.

### **Cross match**

A blood test for patient antibodies against donor antigens. A positive cross match shows that the donor and patient do not match. A negative cross match means there is no reaction between donor and patient and that the transplant may proceed.

### **Durable Medical Power of Attorney**

A document in which individuals may designate someone to make medical decisions for them when they are unable to speak for themselves.

### **End Stage Renal Disease (ESRD)**

End-Stage Renal Disease/chronic kidney failure. A condition in which the kidneys no longer function and for which patients need dialysis or a transplant.

### **Graft**

A transplanted organ or tissue.

## **HLA Antigens**

Markers found on cells in the body that distinguishes each individual as unique. Human leukocyte antigens (HLA) are inherited from one's parents. In donor-recipient matching, HLA determines whether an organ from one individual will be accepted by another.

## **HLA System**

There are three major genetically controlled groups: HLA-A, HLA-B and HLA-DR. In transplantation, the HLA tissue types of the donor and recipient are important in deciding whether the transplant will be accepted or rejected. Genetic matching is generally performed on kidneys and pancreases only.

## **Immune Response**

The body's natural defense against foreign objects or organisms such as bacteria, viruses or transplanted organs or tissue.

## **Immunosuppressant** (im mu·no·sup·pres sant)

A drug used following transplantation to prevent rejection of the transplanted organ by suppressing the body's defense system.

## **Immunosuppression** (im·mu·no·sup·pres·sion)

The artificial suppression of the immune response, usually through drugs, so that the body will not reject a transplanted organ or tissue.

## **Informed Consent**

A process of reaching an agreement based on a full understanding of what will take place. Informed consent has components of information sharing, and the ability to understand and freely make a choice.

## **Lung Allocation Score**

The lung allocation score is a numerical scale, ranging from 0 (less ill) to 100 (gravely ill), that is used for lung candidates age 12 and over. It gives each individual a "score" (number) based on how urgently he or she needs a transplant and the chance of success after a transplant. The number is estimated using lab values, test results and disease diagnosis.

## **NOTA**

The National Organ Transplant Act, passed by Congress in 1984, outlawed began the development of a national system for organ sharing and a scientific registry to collect and report transplant data.

## **Organ Procurement and Transplantation Network (OPTN)**

The purpose of the OPTN is to manage the nation's organ procurement, donation and transplantation system and to increase the availability of and access to donor organs for patients with end-stage organ failure.

## **Organ Preservation**

Donated organs require special methods of preservation to keep them healthy between procurement and transplantation. Without preservation, the organ will die.

The length of time organs and tissues can be kept outside the body vary depending on which organ, the type of preservation and the storage temperature.

## **Organ Preservation Time**

- Kidney 24–48 hours
- Pancreas 12–18 hours
- Liver 12–18 hours
- Heart 4–6 hours
- Lung 2–4 hours
- Heart-Lung 2–4 hours

### **Organ and Tissue Procurement**

Recovery of organs and tissues for transplantation.

### **Organ Procurement Organization (OPO)**

OPOs are the vital link between the donor and recipient and are responsible for the recovery, preservation and transportation of organs for transplantation. As a resource to their communities, OPOs educate the public about the critical need for organ donation. Currently, there are 59 OPOs around the country and all are UNOS members.

### **OPO Local Service Area**

Each OPO provides its services to the transplant programs in its area. An OPO's local service area can include a portion of a city, a portion of a state or an entire state, or more than one state. Presently, when most organs become available, a list of candidates is generated from the OPO's local service area. If a patient match is not made in that local area, a wider, regional list of potential candidates is generated, followed by a national list.

### **PRA**

Panel reactive antibody (PRA) is the percentage of cells from certain donors with which a candidate's blood serum reacts. The more antibodies in the candidate's blood, the higher the PRA. High PRAs lessen the chance of receiving an organ that will not be rejected. Patients with a high PRA have priority on the waiting list.

### **Rejection**

Rejection occurs when the body tries to destroy a transplanted organ or tissue because it is a foreign object. Immunosuppressive (anti-rejection) drugs help prevent rejection.

### **Retransplantation**

Due to organ rejection or transplant failure, some patients' need another transplant and return to the waiting list to be retransplanted. Reducing the number of retransplants is critical when examining ways to maximize a limited supply of donor organs.

### **Required Request**

Hospitals must tell the families of suitable donors that their loved one's organs and tissues can be used for transplant. This law is intended to increase the number of donated organs and tissues for transplantation by giving more people the opportunity to donate.

### **Sensitization** (sen-si-ti-za-tion)

Patients become sensitized when there are antibodies in the blood, usually because of pregnancy, blood transfusions or previous rejection of an organ transplant. Sensitization is measured by panel reactive antibody (PRA). Highly sensitized patients are less likely to match with a suitable donor and more likely to reject an organ than unsensitized patients.

### **Status/Score**

A code or a number used to indicate the degree of medical urgency for patients awaiting heart, liver or lung transplants.

### **Survival Rates**

Survival rates indicate what percentage of patients are alive or organs (grafts) are still functioning after a certain amount of time. Survival rates are used in developing organ allocation policy. Since survival rates

improve with technological and scientific advances, developing policies that reflect and respond to these advances will also improve survival rates.

### **Tissue Typing**

The examination of human leukocyte antigens (HLA) in a patient, tissue typing (genetic matching), is done for all donors and candidates in kidney transplantation to help match the donor to the most suitable recipient.

### **U.S. Scientific Registry of Transplant Recipients**

A database of post-transplant information. Follow-up data on every transplant are used to track transplant center performance, transplant success rates and medical issues impacting transplant recipients.

### **Waiting List**

After evaluation by the transplant team a patient is added to the national waiting list by the transplant center. Lists are specific to organ type: heart, lung, kidney, liver, pancreas, intestine, heart-lung, and kidney-pancreas. Each time a donor organ becomes available, the UNOS computer generates a list of candidates based on factors that include genetic similarity, organ size, medical urgency, proximity of the donor to potential recipients and time on the waiting list. Through this process, a match run list is generated each time an organ becomes available that best “matches” possible patients to a donated organ.

### **Xenograft** (xen·o·graft)

An organ or tissue procured from an animal for transplantation into a human.

### **Xenotransplantation** (xen·o·trans·plan·ta·tion)

Transplantation of an animal organ or tissue into a human. Although xenotransplantation is experimental, many scientists view it as an eventual solution to the shortage of human organs.

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## XV. TRANSPLANT FACILITIES IN OUR NETWORK

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### IOWA

Provider # 16004F  
V.A. Medical Center Dialysis - Iowa City  
Dialysis Unit, 5 South Highway 6  
Iowa City, IA 52246  
Phone: (319) 338-0581  
Fax: (319) 887-4983

Provider # 160082  
Iowa Methodist Medical Center  
1215 Pleasant #506  
Organ Transplant Department  
Des Moines, IA 50309  
Phone: (515) 241-4044  
Fax: (515) 241-4100

Provider # 160058  
University of Iowa Hospital & Clinics Dialysis  
200 Hawkins Drive W336-4AZ  
Iowa City, IA 52242  
Phone: (319) 356-3047  
Fax: (319) 353-7327

Provider # 160083  
Mercy Hospital Medical Center – Transplant  
1111 Sixth Ave  
Des Moines, IA 503143190  
Phone: (515) 247-4261  
Fax: (515) 247-2461

### KANSAS

Provider # 170040  
University of Kansas Medical Center - Dialysis  
4720 Rainbow Blvd #200  
Westwood, KS 66205  
Phone: (913) 588-6968  
Fax: (913) 588-4058

Provider # 170122  
Via Christi Regional Medical Center  
929 N St Francis Transplant Unit  
Wichita, KS 672143882  
Phone: (316) 268-5890  
Fax: (316) 291-7727

### MISSOURI

Provider # 260014  
Barnes Hospital  
One Barnes Hospital Plaza  
Tx- Unit 90-72-398  
Saint Louis, MO 63110  
Phone: (314) 362-5365  
Fax: (314) 362-5470

V. A. Medical Center - Kansas City Dialysis  
4801 Linwood Blvd (MC-111A)  
Kansas City, MO 64128  
Phone: (816) 861-4700  
Fax: (816) 922-4640

Provider # 260020  
Saint Johns Mercy Medical Center Dialysis  
615 S. New Ballas Rd.  
Saint Louis, MO 63141  
Phone: (314) 251-6424  
Fax: (314) 251-4445

Provider # 26009F  
V. A. Medical Center – Saint Louis  
Renal Transplant Unit  
915 N Grand Blvd (111B-JC)  
Saint Louis, MO 631061621  
Phone: (314) 289-6485  
Fax: (314) 289-7012

Provider # 260027  
Research Medical Center Transplant Unit6400  
Prospect Suite 328  
Kansas City, MO 641321199  
Phone: (816) 822-8257  
Fax: (816) 822-8259  
Provider # 26004F

Provider # 260105  
Saint Louis University Hospital - Transplant Unit  
3635 Vista Blvd. P.O. Box 15250  
Saint Louis, MO 631100250  
Phone: (314) 577-8867  
Fax: (314) 268-5133

Provider # 260138  
Saint Lukes Hospital Kidney Transplant Unit  
4401 Wornall  
Kansas City, MO 64111  
Phone: (816) 932-2000  
Fax: (816) 932-3973

Provider # 260141  
University of Missouri Hospital & Clinics  
One Hospital Drive, Transplant Dept  
Columbia, MO 65212  
Phone: (573) 882-8763  
Toll Free: 1-877-895-7400  
Fax: (573) 884-4237

Provider # 263300  
Cardinal Glennon Children's Hospital  
1465 S Grand Blvd  
Transplant Unit 2 North  
Saint Louis, MO 63104  
Phone: (314) 577-5662  
Fax: (314) 268-6422

## **NEBRASKA**

Provider # 280013  
University Hospital Transplant ESRD  
98-7555 Nebraska Medical Ctr  
600 S 42nd St  
OMAHA, NE 68198-7555  
Phone: (402) 552-2440  
Fax : (402) 552-3052

Provider # 263301  
Saint Louis Children's Hospital  
One Children's Place, Renal Transplant Unit  
Saint Louis, MO 631101077  
Phone: (314) 454-6289  
Fax: (314) 454-2762

Provider # 263302  
Children's Mercy Hospital  
2401 Gillham Rd, Renal Transplant Unit  
Kansas City, MO 641089898  
Phone: (816) 234-3100  
Fax: (816) 234-3863

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## XVI. SOURCES

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1. National Kidney Disease Education Program (NKDEP) [www.nkdep.nih.gov/patients/index.htm](http://www.nkdep.nih.gov/patients/index.htm)
2. National Kidney Foundation (NKF) [www.kidney.org/](http://www.kidney.org/)
3. United Network for Organ Sharing (UNOS) [www.unos.org](http://www.unos.org)
4. American Association of Kidney Patients (AAKP) [www.aakp.org](http://www.aakp.org)
5. American Kidney Fund (AKF) [www.akfinc.org](http://www.akfinc.org)
6. American Organ Transplant Association (AOTA) [www.aotaonline.org](http://www.aotaonline.org)
7. Transplant Living [www.transplantliving.org](http://www.transplantliving.org)

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