

# Partnering With Your Transplant Team

*The Patient's Guide to Transplantation*



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Health Resources and Services Administration



# PARTNERING WITH YOUR TRANSPLANT TEAM

## THE PATIENT'S GUIDE TO TRANSPLANTATION



This booklet was prepared for the Health Resources and Services Administration, Special Programs Bureau, Division of Transplantation by the United Network for Organ Sharing (UNOS).



U.S. Department of Health and Human Services  
Health Resources and Services Administration



## **DEDICATION**

This book is dedicated to organ donors and their families. Their decision to donate has given hundreds of thousands of patients a second chance at life.

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# CONTENTS

	Page
<b>INTRODUCTION</b> .....	1
<b>THE TRANSPLANT EXPERIENCE</b> .....	3
The Transplant Team.....	4
What Are Transplant Centers? .....	8
What Are Organ Procurement Organizations (OPOs)? .....	9
Support Groups and Other Contacts .....	10
The National Waiting List.....	12
Waiting for a Transplant.....	13
When an Organ Becomes Available.....	13
Options.....	18
<b>FINANCING YOUR TRANSPLANT</b> .....	21
The Cost of Transplantation.....	22
Insurance.....	24
Medicare and Medicaid.....	27
TRICARE .....	30
Fundraising .....	30
Prescription Drug Assistance .....	32
The Cost of Care Following Transplantation.....	32
<b>LIFE AFTER A TRANSPLANT</b> .....	38
Transplant Recovery .....	39
Medications — Protecting Your Transplantation.....	39
Post-Transplant Tests .....	45
Rehabilitation — Making Healthy Lifestyle Decisions.....	49
<b>TRANSPLANTATION IN AMERICA</b> .....	52
Transplantation Works! .....	53
Becoming an Organ and Tissue Donation Spokesperson .....	54
A Public Health Partnership.....	56
The U.S. Department of Health and Human Services .....	56
The Organ Procurement and Transplantation Network (OPTN) .....	61
The Patient’s Role in the OPTN.....	62
The United Network for Organ Sharing.....	65
The Scientific Registry of Transplant Recipients .....	65
The University Renal Research and Education Association .....	67

<b>RESOURCES</b> .....	69
Where To Look for Transplant Information.....	70
Contacts.....	72
Legal Framework for Transplantation .....	78
The American Hospital Association’s <i>Patient Care Partnership</i> .....	78
<b>APPENDIXES</b> .....	82
Glossary .....	83
Abbreviations and Acronyms.....	98
List of Contributors.....	102

## INTRODUCTION

### Welcome to the Transplant Community

As a patient, you are part of a large group of people dedicated to making your transplant a success. The nurses, doctors, coordinators and technicians on your transplant team are experts at many things. But to do its best, this medical team needs your help. Only you are an expert on YOU! With the support of family and friends, patients can play a very important part in making a transplant successful. This book will help you learn how to become a “partner” with your transplant team. As a partner, you will take an active role in your health care. Below is a list of ways you can become a partner with your transplant team.

- Be as open as possible with your transplant team.
- Ask a lot of questions so you can make informed decisions.
- Report physical and emotional side effects of drugs or treatments.
- Don't be afraid to discuss fears or concerns.
- Talk to your transplant team about what you hear or read in other places about your illness and your care.
- Be willing to ask for help! Create a strong network of emotional support. Identify the friends and family members to whom you can turn for help and moral support.
- When making choices about your transplant, try to balance your feelings with facts. Information is available to help you with these choices.

### About This Book

This book contains information you can use to help you navigate the transplantation process. It can also serve as a “journal” during visits with your transplant team. Ask the questions listed in the book and use the lined pages to record the answers. All of us have difficulty remembering all of the information given to us by our doctors. Let this book help you through this journey. First you will learn about the members of the transplant team and the transplant hospital. Other chapters will discuss these topics:

- Waiting for a transplant
- How the waiting list and organ matching system work
- How donated organs are distributed around the country
- How to use transplant data to make decisions
- Sources of financial support
- Taking care of yourself after your transplant
- How you can participate in making national transplant policy
- How you can help increase organ and tissue donation
- Resources to help you throughout the transplant process



## THE TRANSPLANT TEAM

Many people will be working to make your transplant as successful as possible. This is your transplant team. It is important that you know the people on your team and what they will be doing to help you through your transplant. You need to feel comfortable talking to them and asking them questions. Each team member is an expert in a different area of transplantation.

As a patient, you are an important part of the team because you know your body best. Before the transplant takes place, you will be called a “transplant candidate.” After the transplant operation, you will be called a “transplant recipient.” Besides you, your transplant team will include all or some of the following health professionals:

- **Transplant Coordinator**

Transplant coordinators fall into two different categories: procurement and clinical.

Procurement transplant coordinators have the responsibility of coordinating the donor’s evaluation, management, recovery, and allocation of organs and/or tissues for transplantation.

Clinical transplant coordinators have the responsibility of the recipient’s evaluation, treatment, and follow-up care.

My transplant coordinator is \_\_\_\_\_  
Phone number: \_\_\_\_\_

- **Transplant Surgeon**

The transplant surgeon is the doctor who performs the transplant surgery. The transplant surgeon has been trained to perform transplants.

My transplant surgeon is \_\_\_\_\_  
Phone number: \_\_\_\_\_

- **Transplant Physician**

The transplant physician is the doctor at the transplant center who manages your medical care, tests and medications. He or she does not perform surgery. The transplant physician works closely with the transplant coordinator to coordinate your care before and after transplant.

My transplant physician is \_\_\_\_\_  
Phone number: \_\_\_\_\_

- **Transplant Unit Staff Nurses**

The transplant unit staff nurses work closely with you while you are in the hospital. They take care of you and help educate you about your tests, medications, follow-up care, etc. Some units will assign you a primary care nurse who will coordinate your care while you are on the unit.

My transplant unit staff nurses \_\_\_\_\_  
Phone numbers: \_\_\_\_\_

- **Financial Coordinator**

A financial coordinator is a professional who has detailed knowledge of financial matters and hospital billing. The financial coordinator works with other members of the transplant team, insurers and administrative personnel to coordinate and clarify the financial aspects of your care before, during and after your transplant. The financial coordinator determines how you can best pay for your transplant.

My financial coordinator is \_\_\_\_\_  
Phone number: \_\_\_\_\_

- **Social Worker**

A social worker is a professional who can help you and your family understand and cope with a variety of problems associated with your illness. The social worker may also perform some of the duties of the financial coordinator.

My social worker is \_\_\_\_\_  
Phone number: \_\_\_\_\_

You have a right to request that the information you share with your social worker or financial coordinator be kept confidential — as long as the information is not vital to your medical care.

- **Family Doctor, Specialist or Primary Care Physician**

Your family doctor, specialist or primary care physician can coordinate medical care with your transplant team, especially if you have to travel a long distance to have your transplant.

My family doctor is \_\_\_\_\_  
Phone number: \_\_\_\_\_

My specialist is \_\_\_\_\_  
Phone number: \_\_\_\_\_

### Questions To Ask Your Transplant Team

Patients usually have many questions as they go through the transplant process. It is important to ask members of your transplant team about your transplant and your health. Below is a list of questions you may want to consider. A space is provided for the answers. There is also a section for notes and other questions you may have.

What are my choices other than transplantation? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What are the benefits and risks of transplantation? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What does the evaluation process include? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How does the evaluation affect whether or not I am put on the waiting list? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How will I know I am definitely on the waiting list? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How long do most patients with my blood type wait at this hospital? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How long has this hospital been doing my type of transplant? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How many of these types of transplants does this hospital or surgeon perform each year compared to others? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What are the organ and patient survival rates for my type of transplant at this hospital and how does that compare to other hospitals? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How does this medical team decide whether or not to accept a particular organ for a patient? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Who are the members of the transplant team and what are their jobs? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How many surgeons at this hospital are available to do my type of transplant? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Who will tell me about the transplant process? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Is there a special nursing unit for transplant patients? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Will I be asked to take part in research studies? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Does the hospital perform living donor transplants? \_\_\_\_\_

Is a living donor transplant a choice in my case? If so, where will the living donor evaluation be done? What is the process for a living donation? \_\_\_\_\_

For a living kidney donor, does this surgeon use laproscopic surgery, and who can explain that procedure to me? What are the advantages and disadvantages? \_\_\_\_\_

Can I tour the transplant center? \_\_\_\_\_

## WHAT ARE TRANSPLANT CENTERS?

A transplant center, also referred to as a transplant hospital, is where transplants are performed. Every transplant hospital in the United States is a member of the *Organ Procurement and Transplantation Network* (OPTN) and must meet specific requirements that promote safe and effective transplants that are carried out by experienced health professionals. For example, there must be a transplant surgeon and a transplant physician with extensive training and experience in transplantation for each type of organ that the hospital staff transplants.

A transplant hospital may have one or more transplant programs. Each program oversees transplantation of one or more different organs. For example, one single transplant hospital may have three transplant programs: a lung program, a heart program, and a kidney program.

As of November 18, 2003, there were 257 transplant centers in the United States. Among these, there were

249	Kidney transplant programs
124	Liver transplant programs
139	Pancreas transplant programs
39	Pancreas islet cell programs
44	Intestine transplant programs
139	Heart transplant programs
71	Heart-lung transplant programs
70	Lung transplant programs
875	Total

## WHAT ARE ORGAN PROCUREMENT ORGANIZATIONS (OPOs)?

Organ procurement organizations are the vital link between the organ donor and the recipient and are responsible for recovering the organ, ensuring the viability of the organ until it is transplanted, and transporting the organ to the recipient's transplant team.

Each OPO provides its services to the transplant programs in its area (this can be a large city, a whole State, or a region.) The OPO's second function is to educate the hospital staff and the general public about the critical need for organ and tissue donation.

When a hospital staff member identifies a patient as a possible organ donor, it is the OPO that is contacted. When the donation is made, the organ recovery coordinator from the OPO accesses the OPTN database to match the donated organs with patients waiting for a transplant. All OPOs allocate donated organs according to established OPTN policy that ensures that the organ goes to the best candidate at the time for that particular organ. See [www.optn.org](http://www.optn.org) for additional information about allocation policies.

There are currently 59 OPOs that provide organ recovery services to hospitals within designated geographical areas of the United States. OPOs are non-profit organizations and, like transplant hospitals, are members of the OPTN. Each has its own board of directors that includes donor families and recipients and a medical director who is usually a transplant surgeon or physician.

Organ recovery coordinators are highly trained professionals employed by OPOs to carry out the organization's mission. Services provided by the OPO include:

- Conducting a thorough medical and social history of the potential donor to help determine the suitability of organs and tissues for transplantation.
- Working with hospital staff to offer the option of donation to the potential donor family or honor an individual's expressed wish to donate.
- Ensuring that the decision to donate is an informed consent.
- Managing the clinical care of the donor once consent for donation is finalized.
- Entering the donor information into the UNOS computer to find a match for the donated organs.
- Coordinating the organ recovery process with the surgical team.
- Providing follow-up information to the donor family and involved hospital staff regarding the outcome of the donations.

These services and the coordinator are available 24/7, whenever an organ becomes available.

OPOs also provide educational activities about the need for organ donation within their communities. This may include volunteer training programs and partnering with other community organizations. In addition to educating the public, OPOs also provide healthcare professionals with services related to donation and transplantation issues that arise in the hospital setting (e.g., directed donation, death record reviews, Joint Commission on Accreditation of

Healthcare Organizations reporting) and educate the healthcare team regarding the actual donation process. To locate the OPO in your area, you can view the list at [www.organdonor.gov](http://www.organdonor.gov), [www.aopo.org](http://www.aopo.org), or call UNOS at 1-888-894-6361.

One aspect of deciding who will receive a particular organ is location. Most OPOs provide organs to their local area first and then look to other areas. One reason is that the organ should be transplanted within a certain amount of time if it is to remain healthy.

Organ Preservation Times	
Heart .....	4 – 6 hours
Liver.....	12 – 24 hours
Kidney.....	48 – 72 hours
Heart-Lung .....	4 – 6 hours
Lung .....	4 – 6 hours
Pancreas .....	12 – 24 hours

## SUPPORT GROUPS AND OTHER CONTACTS

A variety of organizations provide many different types of services for transplant patients and their families. These services include patient education materials, patient advocacy (promoting issues of importance to transplant patients) and charitable support for patients and their families. These services can be found at non-profit voluntary health organizations, for-profit companies and Government agencies.

Charitable support includes limited financial assistance through grants and direct funding. Please note that it is unlikely that one group will cover all of the costs for an individual patient. An organization may have limits on using available funds and may only be able to help with direct transplant costs, food and lodging, or medication costs. Many groups can help you explore other funding sources, ask an insurance company to reconsider a case, or sort out difficulties with Medicare and Medicaid funding.

For a list of transplant-related organizations and their addresses and phone numbers, see the Resources section in the back of this book.

## Why Join a Support Group?

Joining a support group can be of great benefit to you, your family and your friends. Sharing your concerns, fears, struggles, experiences and triumphs with fellow patients and their families can be a comfort to you and your family as well as give you encouragement and confidence. Listening to others in the same situation can provide a feeling of security and assure you that you are “not alone.” Others can help you release pent-up emotions and anxiety. Sometimes there is nothing better than to share your thoughts with someone who has “walked in your shoes” and knows exactly how you feel.

It is also encouraging to see how recipients who have had their transplant for several years, and their families, are coping and how they are enjoying their new life. You’ll meet people who are waiting for their transplant, those who have just had a transplant and others who had transplants years ago. Guest speakers inform you of trends in transplantation, new medications, insurance issues, stress relief, and so on. Groups share helpful information such as how to deal with insurance companies and where to find drug stores with the best service and prices. As you continue your transplant journey and reach out to others, you will gain confidence and enrich your own life. You can make lifelong friends, enjoy social activities and find opportunities to promote the need for organ and tissue donation.

## Types of Support

Support comes in many forms—educational programs, group gatherings, social activities, newsletters, written materials, Internet groups, one-on-one support and talking on the telephone. If one avenue doesn’t fit your needs, try another.

### *Hospital support groups*

These groups are usually run by the hospital social worker, transplant coordinator or another member of the transplant team. They may consist of patients who are immediately pre-or post-transplant or are hospitalized with transplant-related problems. They may meet more frequently than non-hospital groups.

### *Local support groups*

Local support groups are usually run by transplant patients and consist of pre- and post-transplant patients and their families. They allow members who have already had their transplant to help you with the adjustment to a more normal, everyday lifestyle. They usually have monthly meetings and special events.

### *Professional organizations*

Professional organizations provide educational seminars, materials and activities. They also may conduct fundraising to support research, as well as their own activities. They help shape healthcare policy, and some specialize in a particular organ.

### ***Internet support groups (news and chat groups)***

These groups provide information in the comfort of your home and allow you to ask personal questions without asking in front of a group of people. They can provide you with a broad range of experiences from all over the country and around the world. In an Internet support group, you do not have to reveal your real name.

### ***Telephone networking***

Your hospital or support group can introduce you to other patients so you can share experiences by telephone. This telephone networking allows you to get to know other patients in similar situations (same organ, same transplant center, same transplant-related problem). These patients may offer help and knowledge from their own transplant experiences, and telephone networking allows you to meet them without leaving your home.

## **THE NATIONAL WAITING LIST**

Over time, researchers have found ways to make transplants more successful. As a result, more people can be helped by transplantation. However, the number of organ donors has not grown as fast as the number of people who need organs. Therefore, there are not enough organs for everyone.

Patients who need an organ from a deceased donor must wait for a transplant. It is important to remember these points:

- There is no way to know exactly how long you will have to wait for an organ since many factors determine how long an individual patient must wait.
- Your transplant team can talk with you about the waiting period
- HHS, UNOS, OPOs and many other groups are working to increase the number of organs available for patients.

When a person is in need of an organ, their transplant center adds them to the transplant patient waiting list through the computer. The computer, located at United Network of Organ Sharing (UNOS), stores and accesses the information for donor matching. When an organ is donated, a list of potential recipients who match that organ is produced by the computerized database at UNOS (which is in Richmond, VA, but serves all of the United States).

The potential recipients are listed in order of priority based on a certain set of criteria. Through this process, a new list is generated each time an organ becomes available that best matches a patient to a donated organ. Organ Placement Specialists in the UNOS Organ Center assist with matching donor organs with potential recipients 24 hours a day, 7 days a week.

Rules have been made to determine how potential recipients are ranked on the waiting list. These rules, or allocation policies, were developed by patients and transplant professionals and insure

that every patient on the waiting list has a fair and equal chance at receiving the best organ, at the best time for a particular patient's condition.

The criteria used to determine allocation vary depending on the organ. Some of these criteria are medical urgency, tissue typing, time waiting, height and weight of the candidate, and size of the donated organ. Some organs, such as the heart, must be transplanted as quickly as possible, so one of the criteria is location of the donor organ in relation to the location of the recipient.

**Criteria that are *not* used in the computer matching system are gender, religion, celebrity and financial status.**

## **WAITING FOR A TRANSPLANT**

You should try to stay as active as possible while waiting for your transplant. This will aid in your recovery. Even if you become weak or bedridden, you should still try to breathe deeply, tighten and relax different muscles, stretch your arms and lift your legs. You can even try to lift light weights (like a can of soup) to keep your muscles strong. While you are in the hospital after your surgery, you will be gradually increasing your activity. You will soon start sitting up and walking. Walking is one of the most important things you can do on your road to recovery. Once you are home, you should do some type of exercise on a daily basis.

While you are waiting for your transplant and not confined to the hospital, you will be asked to carry a beeper. The transplant team will need to contact you quickly once a suitable organ has been found for you. By carrying a beeper, you will have the freedom to leave your home knowing that you will be contacted no matter where you are. Once you are offered an organ, your transplant center has only one hour to accept the organ or turn it down. If you are not available or are unable to have the transplant at that time, the next potential recipient on the list will be offered the organ.

## **WHEN AN ORGAN BECOMES AVAILABLE**

When your transplant hospital calls you with the good news, you will be asked a series of questions to determine if you have any signs of infection. These signs include a cough, a fever, or a burning sensation when you urinate. If you meet the criteria, you will be asked to go to the hospital to prepare for surgery. Try to stay calm and have someone drive you. If you live far from the hospital, you should already have your transportation planned. Start making your phone calls for transportation, babysitters, petsitters and so on, right away.

### **Tips**

- Always keep your transplant team's phone numbers with you.
- Questions? Don't hesitate to ask your transplant team.

- Ask your transplant team when you should start carrying a beeper. Change your beeper battery monthly to be sure it is always working.
- To reduce the chances of contracting a cold, flu or any type of infection,
  - try to avoid crowds during cold and flu season,
  - don't share eating utensils or drinking glasses,
  - avoid sick children,
  - ask family and friends not to visit you when they are sick,
  - ask your team about precautions to take while cleaning up after pets,
  - use antibacterial cleaning solutions, and
  - do not share cosmetics or nail files with anyone (including nail salons).
- Have your laboratory tests done as ordered, even if you are feeling well.
- Keep an extra request for your lab tests with you in case you are out of town and need to have them done.
- Pack a suitcase so it is ready when you get "the call." Pack things you will need: robe, slippers, reading glasses, toothbrush, toothpaste, deodorant, razor, shampoo, hairbrush, socks and underwear. Add other items for comfort as needed: your own pillow, loose clothing (sweat suit), CD player and music, extra batteries, books (large print is helpful), magazines, crossword puzzles, jigsaw puzzles, photographs, paper and pen, makeup, watch or small battery-operated clock, addresses and phone numbers of friends and family, long distance calling card number and if it helps you, spiritual materials.
- If your spouse or other family members will be staying away from home, they should have a suitcase packed, too.

Transplant candidates often ask the UNOS staff about their presence and status on the waiting list. Unfortunately, UNOS cannot provide this information. The patient should discuss this with their transplant team. According to UNOS policy,

- The transplant program must notify the patient in writing within 10 business days of placement on the transplant patient waiting list that he or she has been placed on the list or
- The transplant program must notify the patient in writing within 10 business days after completion of the evaluation that he or she will not be placed on the waiting list.
- Once listed, if the patient is removed from the transplant patient waiting list for any reason other than transplantation or death, the transplant program must notify the patient within 10 business days that he or she has been removed from the list.

This policy is intended to improve communication between transplant centers and their patients and to help patients better understand the listing and transplant process.

### The Organ Matching Process

An organ procurement organization (OPO) plays an important role in the organ matching process. When organ donation occurs, the OPO coordinator works with many people to help

the hospital staff keep the donor in optimum medical condition until the organs are recovered, identify appropriate transplant recipients and arrange for the surgery to remove the donor organs.

There are nine steps in the organ matching process:

1. A hospital refers a potential donor to an OPO. Organ donors are usually referred when brain death is imminent.
2. The OPO coordinator evaluates the potential donor.
3. Consent for donation is obtained.
4. Information about the donor is entered into the UNOS computer.
5. A list of potential recipients is generated.
6. The OPO coordinator notifies the potential recipient's hospital of the donor organ.
7. The transplant surgeon considers the organ for the particular patient to whom it is offered.\*
8. The transplant surgeon decides whether or not to transplant the donated organ.
9. If accepted, the candidate is notified that an organ is available.

\* It is not unusual for a transplant surgeon to say "no" to an organ offer. If an organ is turned down for a potential recipient, it is offered to the next person on the waiting list. Every possible effort is made to place the organs. You may ask your transplant surgeon what characteristics of the organ are right for your need.

### What is brain death?

Most organ donors are people who suffer from head injuries that result in brain death. These are people who may have had a stroke, traumatic head injury due to a car accident or fall, or brain tumor that has not metastasized.

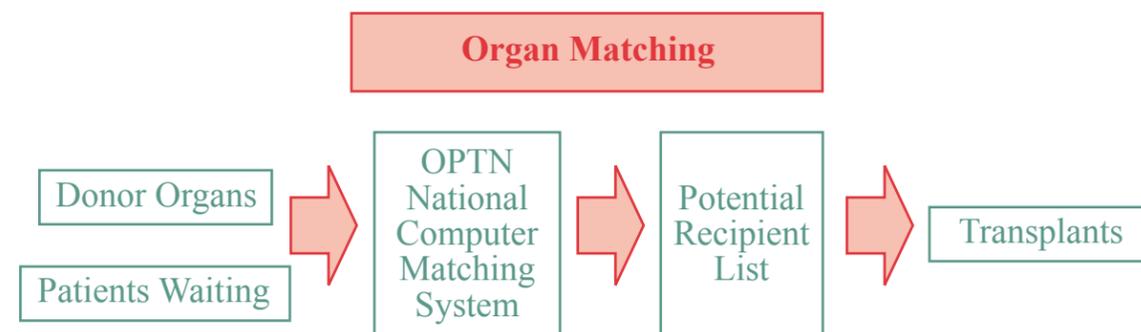
There are two ways to pronounce death. Death may be pronounced when a person's heart stops beating (cardiac death) or when the person's brain stops functioning (brain death). Brain death occurs when blood, and the oxygen it carries, cannot flow to the brain. The person's heart is still beating and providing blood and oxygen to the rest of the body because he or she is on a ventilator (breathing machine). In brain death, the organs and tissue remain viable (healthy) and can be removed for transplantation. The organs and tissue are only removed after brain death has been declared by a physician. This physician is never part of the transplant team.

In certain situations, organs can be recovered for transplantation after the person's breathing and heartbeat have stopped. This is called donation after cardiac death.

Organ donation and transplantation requires the support of many different people:

1. **The deceased organ donor.** This person has been declared brain dead and can now donate an organ for transplantation. Prior to death, this person may have expressed his or her wish to donate either verbally, by signing a donor card or by joining a donor registry; or their next-of-kin consented to donate the organs.
2. **The procurement team.** This is a group of transplant surgeons, perioperative staff and OPO personnel. The surgeons surgically remove the organs, which are then prepared for transport to the organ recipient's medical staff.
3. **The UNOS Organ Placement Specialist (OPS).** The OPS is given information about the donor and the organs, such as blood type, age, size, and hospital at time of death. The information is entered into a computer that "runs a match" with the waiting list. The computer produces a list of potential recipients, in order of priority, who match the new organ. The computer also can be accessed independently by the OPO coordinator to run a match.
4. **The transplant team.** These are the people who care for the patient during and after the transplant. The team might include the transplant coordinator, financial coordinator, social worker, transplant physician and transplant surgeon.
5. **The transplant candidate.** This is an individual who has been identified as medically suited to benefit from an organ transplant and has been placed on the waiting list by his or her transplant program.
6. **The transplant recipient.** This is a transplant candidate who has been ranked by the OPTN computer match program as the person to whom an organ from a specific deceased organ donor is to be offered.

See more detailed descriptions of the participating organizations in the section on Transplantation in America.



## Organ Sharing

When an organ becomes available for transplantation, the donor information is entered into the OPTN database. The database will search thousands of transplant candidates on the national waiting list and locate those matching the donor. Each organ is unique, and characteristics such as size and blood type will affect allocation. The transplant candidate also has specific needs, such as medical urgency, that may affect allocation. Other primary factors that can affect allocation are the length of time a potential recipient has been on the waiting list and the geographic location of the organ in relation to the recipient.

In general, a kidney or pancreas is allocated to a recipient in the local area first, then regionally and then nationally, based on time waiting. However, a kidney or pancreas is offered nationally first if there is a perfect antigen match between the donor and recipient.

Livers are allocated according to the recipient's MELD (Model for End-Stage Liver Disease) or PELD (Pediatric End-Stage Liver Disease) score and his or her geographic location. The scores represent the patient's risk of dying within 3 months. The scores are calculated by objective medical criteria that measure the patient's condition. Your transplant team can answer specific questions about the scoring methods.

Hearts are allocated according to the recipient's degree of medical urgency and geographic location as well, since hearts must be transplanted quickly. The geographic location is defined by concentric circles drawn around the donor hospital. The first choice recipient would be within a 500-mile radius of the donor hospital; if no recipient is available, then the heart would go to a candidate within a 1,000-mile radius from the donor hospital, and then to a candidate more than 1,000 miles from the donor hospital.

## Factors That Affect Waiting Times

Waiting times vary because each patient's situation is unique. Some patients' medical conditions are far more life threatening or are advancing more rapidly than others' conditions. Also, patients receiving medical treatments respond differently, and this may make it easier or more difficult to find matches.

Other factors that affect a transplant candidate's waiting time include the following:

- Blood type
- Tissue type
- Height and weight of the transplant candidate
- Size of the donated organ
- Medical urgency
- Distance between the donor's hospital and the candidate's transplant hospital
- The number of donors in the local area

- The number of families who are offered the opportunity to donate a loved one's organs and whether or not they consent
- The transplant program's criteria for accepting organ offers

To better understand what is influencing your waiting time, talk with your transplant team and the OPO that serves your area.

Depending on the kind of organ you need, some factors play a more important role than others. These factors are described below.

#### ***Kidney, pancreas, and kidney-pancreas combination***

Blood and tissue typing are important when matching organs for these candidates. Another important factor is the panel reactive antibody (PRA) that is measured in a blood test. A candidate with a high PRA will have a greater chance of rejecting a donated organ than one with a low PRA. Candidates with a high PRA usually have to wait longer for an organ in order to find a suitable match. People often have a high PRA if they have received blood transfusions, have had a prior transplant or have been pregnant.

#### ***Liver***

MELD and PELD scores are important factors affecting waiting time. Patients' scores will be updated on a regular basis so that their scores will reflect their current medical condition.

#### ***Heart, heart-lung combination***

Blood type and medical urgency status are important factors when matching for heart and heart-lung combination transplants.

#### ***Intestine***

Blood type and size-compatibility are important factors when matching a donor intestine to the potential recipient.

### **OPTIONS**

As an informed participant in your medical care, it is important to know your treatment options. Based on individual needs, some patients choose to be listed for a transplant at several hospitals in different parts of the country, or they may change hospitals and transfer their waiting time to a different center. Others may choose to receive a transplant from a living donor.

#### **Multiple Listing**

Sometimes patients choose to register for a transplant at more than one transplant hospital. When a patient lists at a transplant hospital, he or she is generally considered for organs from a donor in the local area first. If a patient is put on the list at more than one transplant hospital, he or she will be considered for donor organs that become available in more than one local area. There is

no advantage to being listed at more than one hospital that is served by the same OPO.

National transplant policy allows a patient to register for a transplant at more than one transplant hospital. However, each hospital may have its own rules for allowing its patients to be on the list at another hospital. Patients should ask each hospital whether it allows its patients to list at more than one transplant hospital. Generally, each transplant center will require the patient to go through a separate evaluation, even if the patient is already listed at another hospital.

Being listed at more than one transplant center does not guarantee that an organ will become available sooner for you than for patients registered at only one transplant hospital.

#### **Transferring Waiting Time**

Patients may choose to list at a different transplant hospital and transfer their waiting time to that hospital. Waiting time from the original hospital is added to the time at the new hospital.

For information about transferring waiting time, contact the transplant hospital directly. The transplant teams at the original hospital and the new hospital will be responsible for coordinating the exchange of information and notifying UNOS of the transfer of waiting time. Patients should ask each hospital if they accept transferred waiting time.

#### **Variability Among Transplant Centers**

Hospitals can vary widely in the number of transplants they perform, the characteristics of the donor organs they choose to transplant and the severity of illness among the patients in their care. Organ procurement organizations also can vary widely in the number and types of donations they receive each year.

Large amounts of data are available to help prospective transplant patients. The OPTN and SRTR allow patients to take a look at data from individual transplant centers and OPOs. (See the section on the U. S. Scientific Registry of Transplant Recipients.)

#### **Living Donation**

In addition to deceased donor transplants, patients also may receive organs from living donors. In 2002, more than 6,549 living donor transplants were performed. With more than 83,000 people currently waiting for transplants in the United States, the need for donor organs is far greater than the supply. Living donation offers an alternative for individuals awaiting transplantation.

The first successful living donor transplant was performed between identical twins in 1954. Since that time, hundreds of patients have received successful transplants from living donors. Parents, children, brothers, sisters, and other relatives are eligible to donate organs to family members. Unrelated donors (for example, spouses, close friends or anonymous individuals) may also donate their organs if they are a match for the candidates and the transplant hospital approves.



## THE COST OF TRANSPLANTATION

The cost of transplantation and follow-up care varies across the country and by organ. Even before your transplant, these costs can add up quickly. These costs may include

### Medical costs

- Pre-transplant evaluation and testing
- The hospital stay and surgery
- Additional hospital stays for complications
- Follow-up care and testing
- Anti-rejection and other drugs, which can easily exceed \$8,500 per year
- Fees for surgeons, physicians, radiologist and anesthesiologist
- Fees for the recovery (procurement) of the organ from the donor
- Physical, occupational and vocational rehabilitation
- Insurance deductibles and co-payments

### Nonmedical costs

- Transportation to and from your transplant center, before and after your transplant
- Food, lodging, long distance phone calls for you and your family
- Child care
- Lost wages if your employer does not pay for the time you or a family member spends away from work

If your transplant center is not near your home, you may need to live near the center before and for a while after your transplant. Some centers offer free or low-cost lodging. You may need to make arrangements for air travel to get to your transplant hospital quickly. You should also make back-up plans to get to your transplant hospital in bad weather.

Few patients are able to pay all the costs of transplantation from a single source. For example, you may be able to finance the transplant procedure through insurance coverage and pay for other expenses by drawing on savings accounts and other private funds, or by selling some of your assets. Most likely, you will have to rely on a combination of funding sources. It's a good idea to keep your transplant center social workers and financial coordinators informed of your progress in obtaining funds.

The most common funding sources are

- Insurance
- Extending insurance coverage through COBRA
- Medicare and Medicaid
- TRICARE
- Charitable organizations
- Advocacy organizations
- Fundraising campaigns

- Other sources of insurance

Each of these sources is described in the next several pages.

This information is only a brief summary and is not intended as complete information. New laws and rules are made every year and may change some of the programs discussed here or create new ones. Ask your transplant financial team and your insurance provider or employee benefits officer for the latest information or help. Here are examples of questions you may have:

### Financial Questions

How much of the transplant cost is covered by my insurance, and what specifically is covered? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What financial coverage is accepted by the hospital? Does the hospital have an agreement with my insurance company to accept a lower payment than the normal charge? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How much will I have to pay in addition to my insurance? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What happens if my financial coverage runs out? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Who will pay for my living donor's testing and surgery? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How much are the organ recovery costs if I have a living donor? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## INSURANCE

You and your family may have health insurance coverage through an employer or a personal policy. Many insurance companies offer at least optional coverage for transplant costs. However, the terms and benefits of insurance vary widely. Your insurance company may pay some or all of your transplant costs. This includes the costs before, during and after your transplant. Read your policy and contact your insurance company if you have questions.

### Financial team

The financial team at your transplant center will contact your insurance company to review your benefits. The financial coordinator should be able to explain to you what is covered and what is not, at least for the time you are in the hospital. You may also need to call your insurance company to ask how many of your costs they will pay, including your lab tests, medications and follow-up care.

Unless you have made other arrangements, you are responsible for any costs not paid by your insurance. If you are responsible for paying any or all of your insurance premiums, be sure to pay them on time so you do not lose your insurance.

### Insurance “cap”

Many insurance policies have a lifetime maximum limit, or “cap.” This is the total amount of money they will pay out in your lifetime. After the insurance company pays this “maximum” amount, it does not have to pay any more benefits (in other words, you have no more insurance). The amount of the cap varies greatly, depending on the individual policy. Some policies also put a cap on how much the company will pay for a particular procedure or treatment, such as a transplant, or the total amount of drugs per year. Even after the actual transplant, the ongoing cost of care may exceed the cap. It is important to be familiar with the amount and terms of your insurance cap and how your insurance dollars are spent, so you don’t run out.

### “Experimental” transplants

Some insurers consider certain transplant procedures “experimental” or “investigational” and do not cover these cases. If your transplant center asks you to be involved in any experimental procedures or investigational studies, ask if you (or your insurance company) will be responsible for payment. If you (or your insurance company) must pay, be sure to ask your insurance company if they will cover the costs for the procedure or study. You can refuse to participate in experimental procedures or investigational studies at any time—before or during the study. If you have any doubts, contact your insurance company, your employer’s benefits office, and/or your State insurance commissioner.

### Tips

- Be sure to ask your insurance company if there are any special rules you need to follow, such as pre-certification or using a specific provider. Be sure to follow the rules so that your benefits will not be decreased.

- Keep copies of all medical bills, insurance forms and payments (canceled checks).
- If you speak to anyone in the hospital’s billing office or your insurance company, write down who you talked to, the date and time, and what they said.
- If you have more than one insurance company, make sure your transplant center knows.

### Questions for your insurance company

- Is everything set for my transplant? Is there anything more I need to do?

\_\_\_\_\_

- Do I need authorization (approval) from you before I have a transplant? \_\_\_\_\_
- Do I need a second opinion? If so, who will pay for it? \_\_\_\_\_
- Do I need to notify you when I am admitted to the hospital? How soon after I am admitted? \_\_\_\_\_
- Am I covered for a transplant right now, or do I have to wait a certain period of time (pre-existing exclusion clause)? If I have to wait a certain period of time, how long must I wait? \_\_\_\_\_

\_\_\_\_\_

### Extending insurance coverage through COBRA

COBRA (Consolidated Omnibus Budget Reconciliation Act of 1985) is a Federal law that requires certain employers to allow you and your dependents to temporarily continue your health insurance coverage when you leave their employment. You usually have to pay the premiums yourself, at the same cost as your employer (plus 2 percent).

- You are eligible for COBRA coverage for up to 18 months.
- You may be able to get 11 more months (up to a total of 29) if you have a disability. The premium may be increased to 150 percent of the employer’s cost for the last 11 months of coverage.
- Dependents are eligible for coverage for up to 36 months.
- Your employer must inform you of your right to continue coverage, how much your premiums will be, and where to send your payment.
- You must sign up for COBRA within 60 days or lose all rights to COBRA.

### You are eligible for COBRA if

- Your employer is required by law to offer these benefits; AND
- You lose your benefits because you must leave your job (for reasons other than “gross misconduct”); OR
- Your work hours are reduced, making you no longer eligible for health insurance benefits.

**Coverage may end before the maximum time limit in any of the following cases:**

- You don't pay your premium.
- Your original employer stops offering a group health plan.
- You join another group health plan (unless it limits you for a period of time because of your "pre-existing condition").
- You become eligible for Medicare.
- Your employer goes out of business.

After your COBRA coverage ends, some insurance companies allow you to change to an individual policy. The individual policy may cost you more and the benefits may not be as good.

**To learn more, contact your insurance benefits office at work or call**

- Employee Benefits Security Administration at 202-219-8776.
- The National Association of Insurance Commissioners at 816-842-3600, or visit the State Insurance Departments at [www.hiaa.org/consumer/state\\_insurance.cfm](http://www.hiaa.org/consumer/state_insurance.cfm).
- Each State has its own insurance department to oversee all types of insurance. These offices are responsible for enforcing laws and regulations, and will provide the public with helpful information.

**Health Insurance Portability and Accountability Act of 1996 (HIPAA)**

On August 21, 1996, the HIPAA was enacted. In addition to changing some of the COBRA requirements, HIPAA enables workers to change jobs without a lapse in coverage of pre-existing conditions, in many cases.

When you leave your company's health plan, your former employer must provide proof of how long you were covered on that plan.

**Other Sources of Health Insurance**

**High Risk Pools**

These are for people with pre-existing conditions who have been denied insurance coverage. High risk pools are only offered in some States, and premiums may be 50 to 200 percent higher. Benefits are usually more limited, and coverage for outpatient medication is limited.

Most pools have an average waiting time of 6 to 12 months before coverage begins, but some States allow for first-day coverage, if you pay a premium increase. Some States restrict the number of policies offered each year.

**Guarantee Issue**

Only some States have this law. It requires insurers to offer individual coverage regardless of pre-existing conditions. All individual policies are usually more costly in these States.

**Federal Fallback**

Federal Fallback is available only in some States. It requires the insurance company to offer people whose COBRA benefits are ending a choice of the two most popular insurance plans the insurance company offers. The premium is the same as for everyone else with the same policy.

Call your State Insurance Commissioner at the National Association for Insurance Commissioners at 816-842-3600 to see if these plans are available in your State.

**MEDICARE AND MEDICAID**

**Medicare Services**

Medicare is a health insurance program funded by Federal tax money. It is administered by the Centers for Medicare and Medicaid Services and includes three service branches:

- Center for Medicare Management
- Center for Beneficiary Choices
- Center for Medicaid and State Operations

Please check with the Centers for Medicare and Medicaid Services, toll-free at 1-877-267-2323, to see if these benefits apply to you.

Medicare is available to people who are citizens or permanent residents of the United States and who are

- Age 65 or older, OR
- Disabled (Medicare usually begins after two years of disability), OR
- Have permanent kidney failure (End Stage Renal Disease or ESRD)

It offers two basic plans, Part A and Part B.

**Medicare Hospital Insurance (Part A)**

This insurance is offered free to those who qualify, and covers

- Inpatient hospital services
- Skilled nursing facilities
- Some home health services
- Kidney, kidney-pancreas and pancreas-after-kidney transplants
- Certain heart, lung, liver, heart-lung and intestinal transplants, if you already have Medicare due to age or disability

**Medicare Medical Insurance (Part B)**

You must pay a premium for Part B. This insurance covers

- Physician services
- Outpatient hospital services
- Medical equipment and supplies
- Some other medical services that Part A doesn't cover (like some home health care)
- Part of the cost of anti-rejection drugs for the life of your transplanted organ, effective as

of December 21, 2000, IF your transplant was covered by Medicare AND if you are

- Age 65 or older OR
- Disabled according to Medicare for reasons other than ESRD.

(Please see section on Medicare for people with permanent kidney failure.)

You must continue to pay your Part B premiums. Please check with your local Medicare office to see if these benefits apply to you.

To receive full Medicare benefits for a transplant, you must go to a Medicare-approved facility (one that meets Medicare standards for the number of transplants they perform and the quality of patient outcomes). You may have to meet certain Medicare conditions, such as the medical reason you need a transplant.

If you have both employer group health insurance and Medicare, Medicare would be the secondary payer (your group insurance pays first) for the first 30 months that you are eligible for Medicare coverage. Medicare then becomes the primary payer and your group insurance pays second.

#### **“Medigap” supplemental policy**

Medicare does not always pay 100 percent of your medical expenses. It generally pays according to a set fee, which may be less than the actual cost of a service. You must pay deductibles and various other expenses, such as co-pays. You may also choose to buy a private insurance policy, called a supplemental or “Medigap” policy, to help pay for some of the expenses Medicare does not cover. Check with a local insurance agent for further information.

If you have additional questions, contact your local Social Security office, Medicare at 1-800-633-4227 or your transplant financial coordinator.

#### **Medicare for people with permanent kidney failure (End Stage Renal Disease – ESRD)**

You are eligible for Medicare Part A regardless of your age if you need regular dialysis or have a kidney transplant AND

- You have worked the required amount of time under Social Security, the Railroad Retirement Board or the government, OR
- You are getting or are eligible for Social Security or Railroad Retirement benefits, OR
- You are the spouse or dependent child of a person who has worked the required amount of time to be eligible for Medicare or who is getting Social Security or Railroad Retirement benefits.

Medicare coverage begins

- The fourth month of regular dialysis treatments.
- The first month of dialysis if you participate in a self-dialysis training program in a Medicare-approved facility.
- The month you are admitted to an approved hospital for a kidney transplant or

preliminary procedures, if your transplant takes place in that same month or within the next two months. If your transplant is delayed more than two months after you are admitted, coverage will begin two months before the month of your transplant.

#### **Kidney transplant surgery**

Medicare Hospital Insurance (Part A) also pays for

- Laboratory and other tests to evaluate a potential living donor
- Medical costs for recovering a kidney from a deceased donor
- Full cost of medical care for a living donor (no deductibles or co-payments)

Payments are made directly to the hospital.

Medicare Insurance (Part B) also pays for

- Doctor’s services provided to your living donor
- Part of the cost of anti-rejection drugs for 36 months  
(Your Medicare Part A and B benefits end 36 months after your transplant, IF you are only eligible for Medicare due to ESRD.)
- Part of the cost of anti-rejection drugs for the life of the transplanted organ, IF you remain eligible for Medicare because you are
  - Age 65 or over, OR
  - Disabled according to Medicare for reasons other than ESRD (such as a back problem)

You must continue to pay your Part B premiums.

For more details and the latest information, call Medicare at 1-800-MEDICARE (1-800-633-4227) or your local Medicare office and ask for their book *Medicare Coverage of Dialysis and Kidney Transplant Patients*.

#### **Medicaid Services**

Medicaid is a health insurance program for some patients without health insurance. Individual States decide who is eligible for Medicaid; determine what benefits and services to cover (not all States cover transplants); and set payment rates. It is funded and administered through a State-Federal partnership. Some Medicaid programs will not cover a transplant if you use a transplant center outside of your State (unless there are no centers in your home State that provide your particular type of transplant).

#### **Two Medicaid categories of need**

- Categorically Needy—if you fall below the income and resource level designated as the “poverty line” by your State.
- Medically Needy (Spend Down)—The “spend down” is the process of deducting medical costs from your income until your income reaches a certain level and you become eligible for Medicaid (not in all States).

For more information, call the Social Security office at 1-800-772-1213 or ask your transplant team’s financial coordinator if you qualify.

## TRICARE

Rising healthcare costs and the closure of military bases, along with their hospitals, required that the Federal Government find new ways to provide health care. TRICARE is the Federal Government's new health insurance program for all seven of the uniformed services. "TRICARE Standard" is the new name for CHAMPUS. TRICARE is a cost-sharing program that helps pay for health care when military care is not available.

TRICARE may share the cost of heart, lung, heart-lung, heart-kidney, liver, kidney, liver-kidney, kidney-pancreas and living related liver donor transplants. Patients must receive pre-authorization from the TRICARE medical director and meet TRICARE selection criteria. For more information, contact your nearest military healthcare facility or call the TRICARE Benefits Service Branch at 303-676-3526.

### Veterans Administration (VA)

If you have been honorably discharged from the military, you may be eligible for VA benefits. If you have a service-connected disability, you may be eligible to receive a transplant at a VA Medical Center. Some veterans may also receive medications funded by the VA. The VA covers certain heart, lung, heart-lung, liver, kidney and kidney-pancreas transplants for qualified individuals. For more information, contact your local veterans hospital or VA office or the VA Health Benefits Service Center at 1-877-222-VETS (1-877-222-8387).

## FUNDRAISING

Patients and families often use public fundraising to help cover expenses not paid by medical insurance. It is a good idea to ask for assistance in planning, promoting and carrying out these activities. You may want to contact local newspapers or radio and television stations. Try to enlist the support of local merchants and other sponsors to promote or contribute to your events. Your friends, neighbors, religious groups, local chapters of volunteer or service groups and other community groups may be able to help you plan fundraising activities.

Before you begin, keep in mind that there are many legal and financial laws and guidelines. Check with your city and county governments and with your legal advisor. For example, you must have a place to put the money raised, such as a special bank account or a fundraising organization's account. These funds should be used only for your transplant-related expenses—medical, prescription drugs, and travel. Never mix public donations with personal money. Sometimes donated money is considered income and is taxable. In such cases, a patient could lose Medicaid eligibility.

Before you place any funds with an organization, obtain a written agreement that the funds will be used only for *your* medical expenses. Also, you must have access to the money when you need it. Ask your transplant team, legal advisor, and/or bank about any group that is holding your funds. Most important, have your legal advisor go over any papers you are required to sign.

## Questions to ask any fundraising organization

- Are you a 501(C) (3) (tax-exempt) organization? If yes, can people use the amount of money that they donate to my fund as an income tax deduction? (This can be very important to people who are donating money.) \_\_\_\_\_
- Where are my funds kept? What type of account will be used? \_\_\_\_\_
- Who has access to my funds? \_\_\_\_\_
- How and when can I find out how much money is in my account? \_\_\_\_\_
- Do you take any fees from my funds? How much? \_\_\_\_\_
- If I don't receive a transplant or don't need all the money, what will happen to the money? \_\_\_\_\_
- How many patients and families have you worked with? \_\_\_\_\_
- Can I talk to other patients you have helped? \_\_\_\_\_
- Who should I call if I have questions or problems? \_\_\_\_\_
- How do I pay my bills with these funds? \_\_\_\_\_
- Do I send my medical bills to you? \_\_\_\_\_
- Will you check my bills for accuracy? \_\_\_\_\_
- What other services do you have available? \_\_\_\_\_
- Can you refer me to other sources for financial help? \_\_\_\_\_

### Organizations that support transplant families

Other groups provide limited financial assistance through grants and direct funding. However, it is very unlikely that one group can cover all of the costs for an individual patient. Some organizations have limits on how their funds may be used and may only be able to help you with specific transplant-related costs such as transportation, food and lodging, or medicines. See the Resources section for a list of support organizations.

## PRESCRIPTION DRUG ASSISTANCE

### Pharma Patient Assistance Directory

Many drug companies provide medicines for patients who need financial assistance. The *Pharma Patient Assistance Directory* describes more than 48 programs and the States that are eligible to receive assistance. It also lists which drugs are covered and explains how to receive help. To request the directory, call 1-800-762-4636. It can be viewed and copied from Pharmaceutical Research and Manufacturers of America on the Internet at [www.helpingpatients.org](http://www.helpingpatients.org) or you can check your local library. Ask your transplant team to help you find these programs.

### Questions to ask about prescription drug assistance

- Am I eligible for your program? \_\_\_\_\_
- Do I need to be referred by my transplant team? \_\_\_\_\_
- How long does it take to get set up with your program? \_\_\_\_\_
- How do I receive the drugs? \_\_\_\_\_
- How long am I eligible for your program? \_\_\_\_\_

## THE COST OF CARE FOLLOWING TRANSPLANTATION

There are several programs and initiatives that can help finance your care after transplantation. This section outlines the following:

- Vocational Rehabilitation
- Social Security Coverage for the Disabled
- Americans with Disabilities Act (ADA)
- Federal Rehabilitation Act (FRA)

### Vocational Rehabilitation

If you have a disability that makes it difficult for you to work, you may be a candidate for vocational rehabilitation. The goal of rehabilitation is to prepare people with disabilities to return to work, enter a new line of work, or start working for the first time.

You are eligible if you have a physical or mental condition that makes it difficult for you to work, but you would be able to work after receiving rehabilitation; or you need these services to be able to prepare for, start or maintain gainful employment. You must complete an application and be evaluated for eligibility. You should start rehabilitation as soon as possible after you are discharged from the hospital to protect your disability coverage. Contact your transplant social

worker or the agency for help in applying.

### *Patient services*

Each State provides rehabilitation services through its department of vocational rehabilitation. These agencies are funded by the State and Federal governments.

These services may be provided:

- Evaluation of your eligibility and your physical or mental condition, skills and abilities
- Counseling and guidance to choose an appropriate occupation
- Training (educational or on-the-job) to help you obtain or retain a meaningful job
- Job placement
- Services to help your family adjust to your disability
- Transportation to rehabilitation activities
- Resume development
- Occupational licenses, tools and equipment
- Physical and technological aids and devices (such as custom wheelchairs, a specially modified van)
- Follow-up services after you obtain a job

### *Assessment and rehabilitation plan*

The department of vocational rehabilitation will assess your job skills, abilities and aptitudes. This includes medical, psychological and vocational testing. The agency will then work with you to develop an individualized, written rehabilitation plan to enhance your skills and abilities.

The plan typically includes

- Long-range vocational goals
- Specific services to be provided
- Intermediate objectives to achieve vocational goals
- The process for evaluating your participation and progress
- Rehabilitation equipment or devices
- Client assistance (including financial services)
- Post-employment services

### *Training and assistance*

Depending on your needs, you will receive vocational training and assistance. Basic services may include physical and occupational therapy; use of physical aids or devices such as artificial limbs or wheelchairs; and training for the specific type of work you can perform (classroom instruction, individual tutoring and simulated work).

### *Job seeking and placement*

You will be counseled in job-seeking skills, such as preparing a resume or handling job interviews. Most agencies will place you with an employer. After placement, the agency will follow up with the employer to ensure that the job match is successful. If you encounter difficulties or need additional assistance in your job, you can receive post-employment services.

## Social Security Coverage for the Disabled

If your medical condition prevents you from working, you may qualify for disability benefits. Social Security provides benefits to people who are disabled. Under this program

- You must be unable to perform any work for which you are qualified.
- Your disability must be expected to last at least a year or result in death.
- You must have earned enough work credits when you were able to work (SSDI only).
- You must file a formal application.
- If you are turned down the first time but believe you qualify, you may file an appeal.

If you qualify,

- You may receive benefits until you are able to work again on a regular basis.
- Certain members of your family may also qualify for benefits.
- A number of incentives are available to help you return to work.

### *Social Security Administration disability programs*

- **Social Security Disability Insurance (SSDI)**  
SSDI is for individuals who are working and paying Social Security taxes. You must wait 5 months after disability begins to receive SSDI benefits. You may begin receiving these benefits while you are involved in an approved rehabilitation program.
- **Supplemental Security Income (SSI)**  
SSI makes monthly payments to disabled individuals with few assets and low-incomes. No waiting period is required before receiving SSI benefits.

These programs should not be viewed as permanent or as your only sources of income. They should, in every case possible, be used as a stepping stone to improving your economic condition.

Work incentives are designed to help people with disabilities enter or reenter the workforce by protecting their right to cash payments and/or Medicaid or Medicare protection until they can support themselves. They are intended to give you the support you need to move from dependency on benefits to self-sufficiency.

Contact the Social Security Administration at 1-800-772-1213 or your financial team to apply for these programs.

### *Applying for disability*

Apply for disability as soon as you become disabled. You cannot collect benefits until your sixth full month of disability. You may be able to qualify retroactively (dating back to the disabling event), but you may find it harder to gather complete information later.

The claims process takes 60 to 90 days. During that time, Social Security will be gathering your medical information and assessing your ability to work. Ask your social worker for help in

applying. You may apply by telephone, mail or in person at any Social Security office.

### *Review of your application*

The Social Security office will check your application to see if you meet the initial requirements for disability. It will then send your application to your State's Disability Determination Service for a formal evaluation. Reviewers will gather information from your doctors about your medical condition, history and treatment as well as your ability to perform normal work activities. You may need to take a physical examination for further assessment. If additional testing is required, Social Security will pay for these expenses. You will receive written notice about your claim. Even if another insurer or government agency has ruled that you are disabled, you must still meet Social Security requirements in order to receive Social Security benefits.

### *Review periods and termination of benefits*

Your case will be reviewed periodically to see if you are still disabled. Your benefits will end if

- You work on a regular basis and earn an average of \$800 (\$1330 for people who are blind) or more a month after deducting disability-related work expenses in the year 2003.
- Your medical condition improves and you are no longer considered disabled (unless you are in a vocational rehabilitation program).

You must report any improvements in your condition or change in work status to Social Security. They will tell you what to report.

### *Work incentives*

Most people with disabilities want to work. You may still receive Social Security benefits if you attempt to work. We encourage you to call your Social Security administrator and ask about work incentives and how they affect your benefits. The following is a general discussion.

If you earn more than \$570 in a month, it will be considered a trial month. You may work for up to 9 trial months over a 5-year period. After 9 trial months, Social Security will evaluate your work. Generally, if your earnings average \$800 (\$1300 if you are blind) a month or less, you will continue to receive benefits. If you earn more than \$800 (\$1300 if you are blind) a month on average, you will receive benefits for 3 more months. If you are still defined as disabled, you may receive a monthly benefit for any month that your earnings fall below \$800 (\$1300 if you are blind), for up to 36 months.

You must make Social Security aware of any special expenses you must pay in order to work. These expenses will be subtracted from your earnings to calculate your monthly earnings. These expenses include things like medications, travel costs related to your job and some medical costs.

If you complete a trial work period, but you are still defined as disabled (up to 36 months after the trial period ends), you may receive a monthly benefit for any month that your earnings drop below \$740. You will not have to complete a new application within this time period to qualify. The rules for blind people are different, so please contact your Social Security office.



## LIFE AFTER A TRANSPLANT

### Transplant Recovery

### Medications – Protecting Your Transplant

### Post-Transplant Tests

### Rehabilitation – Making Healthy Lifestyle Decisions

#### *Did you know?*

*In 2002 more than 18,000 patients began new lives thanks to organ donors who had made the decision to donate and had communicated this decision to their families and friends.*

*Talking about donation helps families say yes when the decision about a loved one needs to be made.*

## TRANSPLANT RECOVERY

One of the goals after transplantation is to return to a normal routine of activities, hobbies and work. This goal can be achieved through a positive attitude, a healthy diet, regular sleep habits and daily exercise. However, you are an individual, and your transplant recovery may be very different from someone else's. Some people get well very quickly after surgery. Others take longer to heal. Some people leave the hospital shortly after the transplant. Others have complications and stay much longer. Some people feel well when they go home. Others are able to go home, but are still very ill. It all depends on the type of transplant, the nature of your illness, how ill you were before your transplant and your individual health status.

### Family Medical Leave Act

When you leave the hospital after your transplant, you may need to arrange for family or friends to help you out. You might also need professional healthcare services, such as home visits by a nurse or physical therapist. Your transplant team can help you make these arrangements. A family member may be able to take time off from work under the Family Medical Leave Act, and you and your family may be able to use Family Medical Leave Act benefits to protect your job while you are recovering. The Family Medical Leave Act (FMLA) of 1993 allows eligible employees to take up to 12 weeks of unpaid, job-protected leave for certain family and medical reasons. Not all companies are required by law to offer these benefits.

To be eligible for FMLA, an employee must

- work for a covered employer,
- have worked for a total of 12 months, and
- have worked at least 1,250 hours during the last 12 months.

FMLA benefits can be used to

- care for a spouse, child or parent with a serious health condition,
- take medical leave when the employee can't work due to a serious health condition, or
- take blocks of time or work fewer hours daily or weekly.

Under the FMLA, the employer must

- inform employees of their rights and responsibilities under the FMLA,
- continue insurance coverage while employees are on leave, and
- in most cases, return the employee to the same job or a job with equal pay and benefits.

Employees

- may have to pay insurance premiums while on leave or
- may have to pay insurance premiums for the time off if they did not return to work after the FMLA time off.

## MEDICATIONS – PROTECTING YOUR TRANSPLANT

Your body protects itself against foreign invaders, such as germs, by using its immune system. Special blood cells attack the invader and destroy it before it can cause an infectious disease.

The body may see a transplanted organ as an invader and try to attack (reject) it also. Because of this “immune” response, you will be taking special drugs to suppress the immune system. These drugs are called immunosuppressants or anti-rejection medicines. One of the reasons transplants are so successful today is because of these medicines. While the risk of rejecting your new organ decreases as time goes on, it never goes away. It is important for you to know what happens to you if your body starts to reject the new organ. Ask your transplant team about the signs and symptoms of organ rejection.

### Important points

- Taking all of your medications every day and on time is one of the most important things you can do to make your transplant a success.
- You may be taking these drugs for the rest of your life.
- You may be taking many different drugs every day.
- You may still be taking drugs that you took before your transplant.
- You may also be taking drugs to help with some of the side effects and prevent complications from all these different drugs.
- You should never change your doses on your own.

Sometimes medications cause adverse reactions. Many people experience side effects from their anti-rejection drugs. The following are some of the more common side effects. This list is included so you will be aware that these problems may be caused by your medications. Talk to your transplant team. They can help you manage any side effects.

### Side effects

acne	increased appetite	tingling hands and feet
anxiety	increased blood sugar	tremors (shaking)
diarrhea	mood swings	trouble sleeping
gum overgrowth	nausea	unwanted hair growth
hair loss	sensitivity to the sun	vomiting
headache	swelling of feet, hands, abdomen, or face	weight gain
high blood pressure		

### Remember—

*Keep all medicines out of the reach of children. Some of these medicines are very dangerous and children often mistake medicines for candy or snacks—especially if the medicines are not in their original containers.*

### Questions to ask the transplant team

What is each of my medicines for? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What are the side effects of the medicines I will be taking? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Which side effects should I call about? Who should I call? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What should I do if I miss a dose of medicine? \_\_\_\_\_  
\_\_\_\_\_

Who should I call when I need a new prescription? \_\_\_\_\_  
\_\_\_\_\_

Are generic drugs OK? \_\_\_\_\_  
\_\_\_\_\_

Which drugs should I take with food? \_\_\_\_\_  
\_\_\_\_\_

Which drugs should I take on an empty stomach? How soon can I eat after taking them? \_\_\_\_\_

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When should I take each of my medications? (Some drugs should be taken 12 hours apart.)

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Does it matter what time of day I take my once-a-day medications? \_\_\_\_\_

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Should I take antibiotics before and after dental visits? For any other procedures? \_\_\_\_\_

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Which over-the-counter medicines should I avoid (such as ibuprofen, Motrin)? \_\_\_\_\_

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What vaccines should I get every year (flu, hepatitis, tetanus, etc.)? \_\_\_\_\_

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Can I take aspirin, calcium, vitamins and mineral supplements? How much? \_\_\_\_\_

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Should I avoid children who have had a vaccine? Which vaccines? For how long? \_\_\_\_\_

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Is it OK for me to have an alcoholic beverage? If so, what kind? How much? How often?

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### Questions for your pharmacist

Is someone available 24 hours a day if I have questions or need to reorder my drugs? \_\_\_\_\_

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Will you waive my co-pay? \_\_\_\_\_

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Do you offer a discount if I pay with a credit card or check? What if I have no insurance coverage? \_\_\_\_\_

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Do you charge for delivery? \_\_\_\_\_

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How soon after I call in my prescription will my medications be available? \_\_\_\_\_

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Do you always keep my medications in stock? \_\_\_\_\_

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Do you have any educational materials you can send me? \_\_\_\_\_

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### Tips about your medicines

- Learn everything you can about your medicines. Your physician, transplant coordinator, pharmacist, support group and educational seminars can help.
- Capsules and time release tablets should be swallowed whole and never crushed, chewed or opened—otherwise, a large dose can be absorbed too quickly.
- Some medications should never be taken with grapefruit juice. Ask your pharmacist if this is the case for your medication.
- All medicines should be kept in their original labeled containers, in containers made for medicines (with labels affixed to the containers) or in foil wrap until used. Follow the directions carefully to ensure the potency (effectiveness) of your medicines.
- Some medications need to be refrigerated, especially liquid antibiotics. Check the directions on the bottle.
- Always check with your transplant team before taking any new medicines, even the ones you buy over the counter, including vitamins and herbal remedies.

- Wear a Medic Alert (or similar brand) bracelet or necklace that states you are a transplant recipient and you take steroids (if you do), in case you are ever in an accident and someone finds you unconscious.
- If any medicine changes odor or color, if it gets wet, or if it is soft, sticky, hard or cracked (and it shouldn't be), it could have lost its effectiveness and should be replaced. Talk to your pharmacist about any changes in your medicines.
- When taking a new drug, ask your pharmacist to fill just a few days' worth of the prescription. If you cannot take the medication for any reason, you will not have wasted money on something that cannot be returned.
- If your insurance company does not require you to use a particular pharmacy, shop around. Prices can vary dramatically.
- Let your insurance company and transplant team know if you are having trouble paying for your medicines.
- Carry a list of your medicines and their doses in your wallet or purse. Share this list with your other doctors.
- Try to buy all your medicines from the same pharmacy. Many pharmacies keep a profile on their customers so that they can track whether or not a new drug will cause problems if taken with the patient's other medications.
- Unwanted hair growth, caused by some medications, can be removed with shaving, waxing, or hair removal (depilatory) products.
- Limit your sun exposure and use a sunscreen.
- Do not take all your medicines at one time because it is more convenient. The doses are spread out to maintain the proper drug level in your body.

### Tips about organizing your medications

To prevent your medicine regimen from interrupting your daily routine, plan ahead, organize your time and consider the following tips:

- Use tools to help organize your medicines, such as a pillbox that has individual compartments labeled with the days of the week.
- If there are no children or grandchildren in the house, clear plastic Ziploc bags labeled with days of the week and times of the day can help, but they must be kept in a safe place—away from children and pets who may think the contents are snacks.
- Use an alarm clock, watch or charts to remind you of the times for medicines.
- Ask your transplant team to help set up your medicine times to fit your schedule.
- Set up a time each week to organize your medicines for the whole next week.
- Get into a routine. Take your medications at the same time each day.
- Keep track of how much medicine you have left. Don't ever run out, even one dose.
- Mark your calendar so you remember to reorder your medications ahead of time.
- At first, you may want to have a family member or friend help you sort out and reorder your pills.
- Keep your medication in a cool dry place, out of the sun and extreme heat.

### Tips on traveling

- Always keep extra doses of your medicine with you when you travel in case you are delayed or miss a plane, train or bus.
- Keep your pharmacy's phone number with you.
- Never pack your medications in your luggage; always carry them with you or they may get lost or be exposed to temperatures that are too cold or too hot.
- Mail-order pharmacies can ship your medicines if you are away from home for an extended period of time.
- Carry a letter (or prescription) from your doctor about your medicines in case you have any problems with customs when traveling overseas. You may be able to fill your prescription in a pharmacy at your travel destination.
- Prevent infection. Wash your hands often and thoroughly, especially before eating. This is even more important the first few months after your transplant, when you are taking higher doses of anti-rejection medication.

### POST-TRANSPLANT TESTS

#### Lab Tests

Throughout the transplant process, you will undergo many tests to determine your health status. It is very important to understand how these tests work and what your normal test values are.

The chart gives a description of tests you may require, depending on the type of transplant you have. Your transplant team can tell you what your normal values are. There is a space on the chart to write this information. You might also want to buy a small notebook to record your results and take these with you on your office or clinic visits.

It is important that you follow your team's instructions about having blood drawn because test results can indicate problems before they are too serious. Also, treatments can be started early. Depending on the test, here are a few questions to ask:

Are you permitted to eat or drink before your blood is drawn? \_\_\_\_\_

If not, how many hours before the test should you stop eating or drinking? \_\_\_\_\_

After you take a particular medicine, how much time must pass before you have blood drawn to measure the level of that drug? \_\_\_\_\_

The lab tests listed alphabetically below are blood tests, except for one urine test and the last four, which use biopsy or radiology to enable the physician to look at how an organ is functioning.

Lab Test	Description of Test	My Normal Value
ALT: alanine aminotransferase Also called SGPT	Monitors liver function	
Alkaline Phosphatase	Monitors liver function	
Bicarbonate	Monitors acid/base balance in blood	
Bilirubin	Monitors liver function	
Blood urea nitrogen (BUN)	Monitors kidney function	
Carbon dioxide (CO <sub>2</sub> )	A measure of respiratory and kidney function	
Cholesterol	Monitors liver function	
Complete Blood Count (CBC)	Hematocrit - monitors anemia Hemoglobin - blood oxygen level Platelets - monitors bleeding tendencies White blood cells - infection/rejection	
Creatinine	Monitors kidney function	
GGTP: gamma glutamyl transpeptidase	Monitors liver function	
Glucose (blood sugar)	Monitors pancreas function	
Immunosuppressant blood level	Monitors level of immunosuppressant drugs in your body	
Magnesium	Monitors kidney function and diabetes	
Phosphorus	Monitors kidney function	
Potassium	Monitors kidney function	
Prothrombin time (PT)	Monitors liver function	
SGOT (or AST)	Monitors liver function	
Serum amylase	Monitors pancreas function	
Sodium	A measure of kidney function	
Urine amylase	Monitors pancreas function	
Biopsy (small amount of tissue from the transplanted organ removed)	Used to assess condition of organ (function, rejection, damage)	
Bronchoscopy	Visualizes airway healing and diagnoses lung infection or rejection	
Cholangiogram	Visualizes bile duct function	
Endoscopic retrograde cholangiopancreatography (ERCP)	Visualizes bile and pancreatic duct function	

### Other Tests

You will need to perform several tests yourself on a regular basis. Your transplant team will show you how to perform these tests and answer your questions. They will also tell you what your results should be. Below is a table of the tests and a place to record your normal values. If your test results are above or below a certain range of numbers, your transplant coordinator may want to be notified. Use the table below to record this value.

Test	Your Normal Value	Call Your Coordinator If Your Results Are (Higher/Lower)
<b>Weight</b>		
<b>Temperature</b>		
<b>Blood Pressure</b>		
<b>Pulse</b>		
<b>Blood Sugar</b>		
<b>Home Spirometry</b>		





## TRANSPLANTATION IN AMERICA

### Transplantation Works!

#### Becoming an Organ and Tissue Donation Spokesperson

#### A Public Health Partnership

The U.S. Department of Health and Human Services

The Organ Procurement and Transplantation Network (OPTN)

The Patient's Role in the OPTN

The United Network for Organ Sharing

The Scientific Registry of Transplant Recipients

The University Renal Research and Education Association

#### *Did you know?*

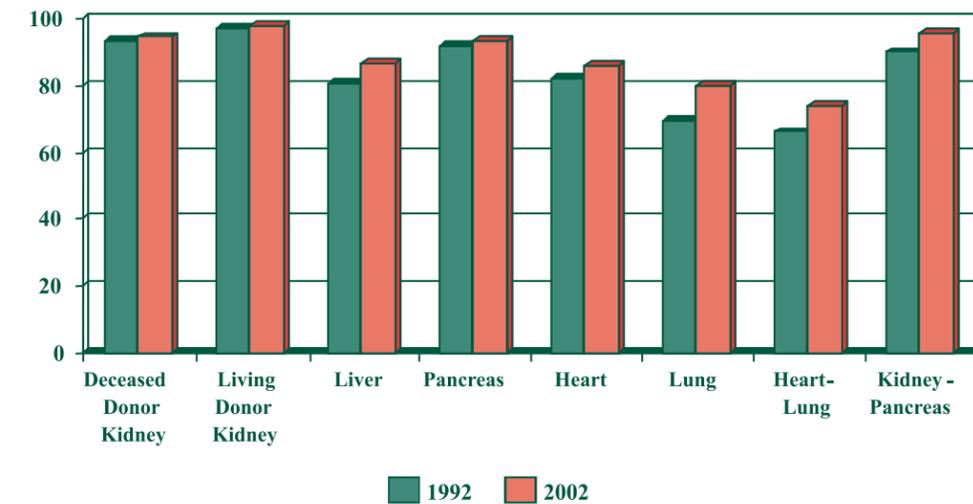
*Organs that can be donated while donors are alive include the kidney, bone marrow, parts of the liver, lung, pancreas and intestine.*

## TRANSPLANTATION WORKS!

Data show that more and more people receive transplants every year and that more people with transplants are living longer after they receive their organ(s).

As scientists learn more about transplantation, new ways are developed to help patients and their new organs survive longer. Patient survival rates at one year after transplantation continue to improve, as demonstrated by the following graph. The green bars show survival rates for various organs in 1992 and the red bars show the rates 10 years later.

One-Year Patient Survival Rates



The second pair of columns shows the survival rates for kidney transplants from living donors, a donor source that is increasing every year. Living donors are able to give one of their kidneys or parts of other organs (such as the liver) and bone marrow. These types of donation are often made between relatives or friends. It is possible to join the Bone Marrow Registry and become a potential bone marrow donor. This matching program finds suitable donors and recipients for bone marrow when the patient is unable to find a match within his or her family.

## BECOMING AN ORGAN AND TISSUE DONATION SPOKESPERSON

Once you have had a transplant and have regained your health, perhaps you would like to be an advocate for organ and tissue donation so that others may have the same opportunity for life-saving and/or life-enhancing transplantations.

As you know, the organ shortage is the reason why patients must wait so long for transplants. Although you may occasionally feel helpless, you can do a lot to help promote awareness of the organ shortage and to increase organ donation.

Many transplant patients, recipients and their families are very active in the community, spreading the word about the vital importance of becoming an organ donor. You can help create donor awareness by visiting youth groups and civic organizations, speaking at schools and churches, writing letters to local newspapers and magazines and even discussing organ donation and transplantation in social situations.

You can also volunteer with various local groups and chapters of organizations, including the Coalition on Donation, OPOs, the National Kidney Foundation, the Transplant Recipients International Organization (TRIO), or the Minority Organ and Tissue Transplant Education Program (MOTTEP). Information on all of these groups is provided in the Resources section of this guide.

### **Share Your Life. Share Your Decision.®**

Two simple steps make a lifesaving difference.

#### Step One - Share Your Life

Make the decision to become an organ and tissue donor.

#### Step Two - Share Your Decision

Sharing your decision to be an organ and tissue donor is as important as making the decision itself. At the time of your death, your family may be asked about donation. Sharing your decision with your family now will prevent confusion or uncertainty about your wishes later.

Carrying out your wish to save other lives can bring your family members great comfort in their time of grief.

## Questions and Answers About Organ Donation

Part of being a responsible advocate for donation is becoming familiar with information about the donation process. Here are some basic facts that may assist you in educating your family, friends and community.

### **Who can become a donor?**

Everyone should consider being a potential organ and tissue donor. Your medical condition at the time of death will determine what organs and tissues can be donated.

### **What organs and tissues can be donated?**

Organs that can be donated include the heart, kidneys, pancreas, lungs, liver and intestines. Tissues include corneas, skin, heart valves, connective tissue (bones, tendons, cartilage, ligaments,) bone marrow, blood vessels and blood.

### **Will my decision to donate affect the quality of my medical care?**

No. Organ and tissue donation takes place only after all efforts to save your life have been exhausted and death has been declared by the physician on the medical team. These doctors, working to save your life, are entirely separate from the transplant team.

### **Will donation disfigure my body?**

No. Donation neither disfigures the body nor changes the way it looks in a casket. Removal of the organs is conducted in an operating room and under sterile conditions like any other surgical procedure.

### **Does it cost anything to donate organs and tissues?**

No. Donation costs nothing to the donor's family or estate.

### **Is there an age limit for donating organs?**

No set age limit exists for organ donation. At the time of death, the potential donor's organs are evaluated to determine their suitability for donation. Therefore, people of any age wishing to become organ and tissue donors should complete a donor card and inform their family that they wish to donate.

### **What medical conditions exclude a person from donating organs?**

HIV and recently diagnosed cancer normally exclude people from donating organs. Otherwise, organs will be evaluated for donation suitability at the time of death. Therefore, those with medical conditions (other than HIV or recently diagnosed cancer) who wish to donate should complete a donor card and share their decision with their family.

### **Does my religion approve of donation?**

All major religions in this country approve of organ donation and consider it a gift—an act of charity. If you have any questions, contact your religious advisor.

### What will happen to my donated organs and tissues?

The Organ Procurement and Transplantation Network administered by UNOS, under contract to the U.S. Department of Health and Human Services, ensures the fair distribution of organs in the United States. The patients who receive your organs and tissues will be identified based upon such factors as blood type, length of time on the waiting list, severity of illness and other medical criteria. Factors such as ethnicity, gender, age, income and/or celebrity status are not considered when determining who receives an organ. Buying and selling organs is against the law.

### A PUBLIC HEALTH PARTNERSHIP

The following section describes, defines, and discusses how transplantation in America works as a public health partnership between the healthcare community and the Federal, State, and local governments.

### THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

The U.S. Department of Health and Human Services (HHS) is one of the largest Cabinet-level departments of the Federal Government. It was established with the charge to protect the health of every American and to provide vital human services, especially for those most vulnerable. HHS consists of 12 different agencies with over 300 programs. Some of these include

#### Agencies within HHS

- Centers for Medicare and Medicaid Services (CMS)
- Health Resources and Services Administration (HRSA)
- National Institutes of Health (NIH)
- Agency for Healthcare Research and Quality (AHRQ)

#### Programs within HHS agencies

- Medicare and Medicaid, overseen by CMS
- Donation and transplantation, overseen by HRSA
- Medical and social science research, overseen by NIH
- Social and behavioral research related to health policy, overseen by AHRQ

For more information, access the HHS Web site at [www.hhs.gov](http://www.hhs.gov).

### Office of the Secretary (OS) of HHS

The Secretary of HHS advises the President regarding the health and welfare of the country and administers these functions through the OS and the agencies within HHS. The Secretary also ensures that the programs operate in the public interest. Through the National Organ Transplant Act (NOTA) of 1984, the OS was charged with overseeing the Organ Procurement and Transplantation Network (OPTN) and establishing a Scientific Registry of Transplant Recipients (SRTR). Some of the duties of the OPTN are to develop transplantation policies,

maintain a computer system that matches donor organs with recipients, and collect data on all donors and transplant recipients. These duties are carried out with direction from the donation and transplantation community as well as the general public. Some of the duties of the SRTR are to provide ongoing research to evaluate information about donors, transplant candidates and recipients, as well as about patient and graft survival rates. The SRTR also tracks all transplant patients from the time of transplant through hospital discharge, and then annually for up to 3 years or until graft failure or death.

In 1999, the OPTN Final Rule was implemented. As part of the Final Rule, the Secretary established an Advisory Committee on Organ Transplantation. This Committee advises the Secretary on organ donation, allocation and transplantation issues, e.g., organ allocation policies and the collection and release of OPTN data.

On his first day as HHS Secretary, Tommy G. Thompson vowed to implement within his first 100 days a national campaign to increase organ and tissue donation and create a “donation-friendly America.” His resulting *Gift of Life Donation Initiative* was launched 2 months later. This initiative includes

- The **Workplace Partnership for Life:** Workplace campaigns that encourage organ and tissue donation are being developed. For example, corporations and organizations of all types and sizes are encouraged to sign up as partners and educate their employees or members about the urgent need for donors. As of December 2003, approximately 8,000 partners have joined the *Workplace Partnership for Life*.
- The **Model Donor Card:** This card provides options for designating whether all organs and tissues will be donated, as well as space for two witnesses’ signatures.

Organ/Tissue Donor Card

I wish to donate my organs and tissues

any needed organs and tissues  only the following organs and tissues:

Donor Signature \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_

Witness \_\_\_\_\_

- **Donor Registries:** *Guidelines for Registry Development*, a national forum on the potential of donor registries to minimize the donor shortage, was held November 29-30, 2001. A full report of the conference is available on [www.organdonor.gov/nfdrguidelines.html](http://www.organdonor.gov/nfdrguidelines.html).
- **National Gift of Life Donor Medal:** The Secretary supports the creation of a Congressional or Departmental medal to honor donors who have saved and enhanced the lives of others.

- **Driver's Education Curriculum:** A curriculum for driver's education or other high school classes has been created, and an Internet program for middle and high school students, called *Sandrine's Gift of Life*, is available to classrooms worldwide.
- **Organ Donation Breakthrough Collaborative:** Secretary Thompson launched this collaborative to dramatically increase access to transplantable organs. Fourteen of the largest hospitals in the United States have donation rates of 75 percent or greater and these high rates are no accident. Through a series of intensive *Collaborative Learning Sessions and Action Periods*, OPOs and their chosen large hospitals will learn to replicate the "best practices" found in the 14 larger hospitals. By replicating these "best practices" in the Nation's 300 largest hospitals, thousands of lives could be saved or enhanced through organ and tissue transplantation every year.

### Centers for Medicare and Medicaid Services (CMS)

CMS was created to oversee Medicare and the Federal portion of Medicaid under one HHS agency. Presently, CMS serves millions of disabled, poor and elderly Americans through these two programs. As one of its services, Medicare provides health insurance coverage for people in need of dialysis or kidney transplants for treatment of end-stage renal disease.

In the mid-1980s there was an attempt to link donation efforts and hospital Medicare reimbursement. Known as "required request," this legislation required that hospitals have policies to identify potential donors and offer families the option to donate.

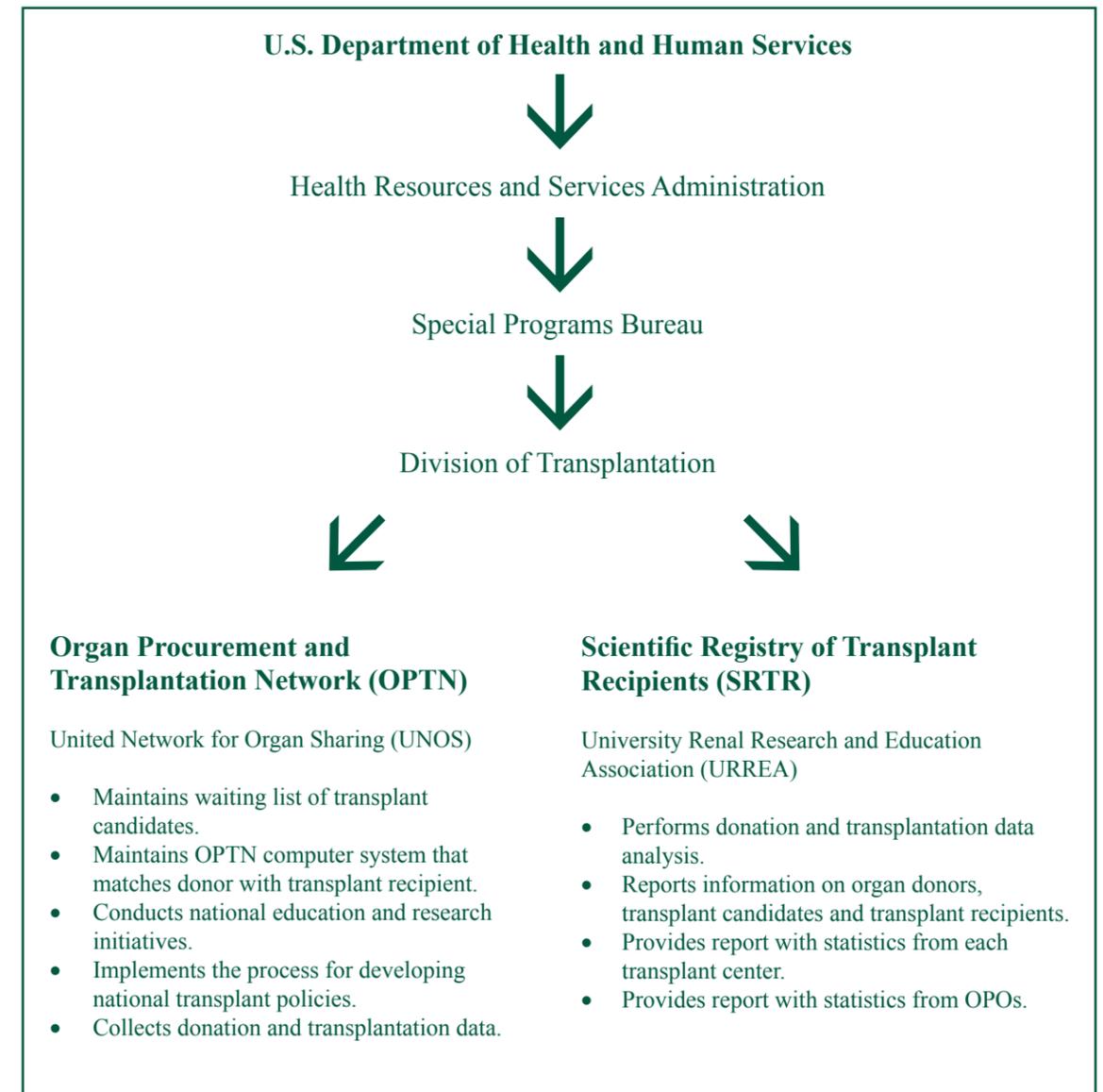
In 1998, a Federal regulation, the "Hospital Conditions of Participation (CoP) for Organ, Tissue and Eye Donation" was issued. It stipulates that in order to receive Medicare and Medicaid reimbursement, hospitals must notify organ recovery agencies of all patient deaths and allow only properly trained persons to speak with the families regarding donation options.

### Health Resources and Services Administration (HRSA)

HRSA is the primary healthcare service agency of the Federal Government that deals with health access issues. Its role is to make essential primary care service available to the poor, uninsured and geographically isolated.

Historically, HRSA has provided funding for and maintained oversight of the two Federal Government contracts that make the OPTN and SRTR possible. Both of these donation- and transplantation-related contracts are administered by HRSA's Special Programs Bureau, Division of Transplantation (DoT). HRSA encourages donation of organs, tissues and bone marrow for transplantation through many of its programs.

## The OPTN and SRTR Organizational Structure



## Division of Transplantation (DoT)

Under its Operations and Analysis Branch, the DoT administers contracts with UNOS for the operation of the OPTN and with URREA for the operation of the SRTR. The DoT also provides technical assistance to organ procurement organizations (OPOs).

### **Grants programs**

The Public and Professional Education Branch of DoT is responsible for helping to initiate programs that will increase awareness about donation and the critical need for organs and tissue. This includes administering a grant program to explore ***Social and Behavioral Interventions To Increase Organ and Tissue Donation***. Projects involving the use of health information about preventing the need for transplantation and projects that propose interventions to change attitudes and behaviors towards donation are of interest. For example, The North Shore Island Jewish Health System evaluated the impact of family communication about organ donation on the rates of consent to donate given by family members in five Long Island hospitals.

The Operations and Analysis Branch of DoT has initiated a grants program to support ***Clinical Interventions To Increase Organ Procurement***. The goal is to assist eligible transplant centers, institutions and organizations in implementing, evaluating and disseminating information and practices (clinical interventions) that will increase the number of potential heart-beating and non-heart-beating donors. These model interventions will also search for ways to increase the number of viable organs that are recovered from such donors.

### **The National Institutes of Health (NIH) The Agency for Healthcare Research and Quality (AHRQ)**

A responsibility of both of these Federal agencies is to fund medical and social research projects nationwide for the purpose of improving healthcare quality. NIH provides millions of dollars for research to improve the clinical practice of transplantation and to increase organ donation.

A project supported by the NIH was the development of State organ donor registries. The National Institute of Allergy and Infectious Diseases within NIH supported the development, implementation and evaluation of a statewide donor registry in Louisiana. Coupled with extensive school-, community- and media-based educational programs, this registry aims to improve the rate of donation, especially among the African-American population.

The NIH Office of Research on Minority Health, with the support of the National Institute of Diabetes and Digestive and Kidney Diseases, also sponsored the National Minority Organ and Tissue Transplant Education Program (MOTTEP) to educate minority communities nationwide on issues concerning organ donation and transplantation. One of the projects funded through the AHRQ was a study of donor and non-donor families to explore factors associated with the decision to donate among families of potential solid organ donors.

## THE ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK (OPTN)

In the 1980s, drugs were developed that greatly increased the likelihood and longevity of post-transplant survival, and increasing numbers of people were placed on the waiting list to receive an organ. Because there were not enough organs for all who needed them, a system had to be developed for fairly and appropriately allocating the donor organs that were available. At that time, the United Network for Organ Sharing (UNOS) assisted in creating such a system to help transplant hospitals across the Nation distribute donated organs to the most suitable patients.

The OPTN was established in 1984, when the U.S. Congress passed the National Organ Transplant Act. The Act said that organ matching and the rules for organ sharing should be made by a network of all transplant centers, laboratories and organ procurement organizations, as well as certain voluntary health organizations and any patient groups and interested volunteers. The law also prohibited the sale of human organs. This system allowed, and continues to allow, transplants and helps assure the best use of each organ. Unfortunately, the organs donated are still not enough to meet the demand.

### ***Did you know?***

***Since 1986, the OPTN has matched organs for more than 224,000 patients.***

***The OPTN is the model for transplant systems around the world, including the United Kingdom, Germany, Spain, Japan, South America, Mexico and Canada.***

### **Who belongs to the OPTN?**

- Patients waiting for transplants
- Transplant recipients
- Friends and family of organ donors
- Living organ donors
- Friends and family of transplant candidates and recipients
- Nurses, surgeons, physicians and technicians who specialize in transplantation
- Healthcare volunteers
- Members of the general public

Many groups of people work together to make transplants possible. Each group has a different job. It's important to know who these groups are and what they do for transplant patients.

All of the members of the OPTN have a voice in developing policies for distributing organs to the people on the waiting list. The policies consider a patient's medical condition and availability for transplant. Once the OPTN develops a policy, it must be approved by the U.S. Secretary of Health and Human Services before it can be put into effect. The OPTN, therefore, forwards its policies to the Federal Government. The HHS Secretary's Advisory Committee on Transplantation (ACOT) reviews them and makes recommendations to the Secretary, who can then approve or reject the policies. The OPTN works hard to make sure that everyone who needs an organ will have an equal chance at getting a transplant. A patient's chance to receive an organ is not affected by age, gender, ethnicity, religion, lifestyle, financial status or social status.

### THE PATIENT'S ROLE IN THE OPTN

Patients play an important role in the OPTN. They are encouraged to

- Provide input on organ-sharing policies and other rules.
- Provide their opinion on how well the OPTN and UNOS are meeting patients' needs.
- Participate in OPTN committees and working groups.
- Help increase organ and tissue donation.

As any transplant candidate knows, the biggest problem facing the field of transplantation today is the organ shortage. You can help by promoting organ and tissue donation in your community. Many patients are already involved. To join the effort in your local area, contact the national office of the Coalition on Donation at 804-782-4920 or visit its Web site at [www.donatelife.net](http://www.donatelife.net) for the phone number of your local chapter. You can also contact your local OPO, the National Kidney Foundation (NKF) at 1-800-622-9010, or a Transplant Recipients International Organization (TRIO) chapter at [www.trioweb.org](http://www.trioweb.org) to find out about volunteer opportunities.

OPTN members work very hard to make transplant policies as fair as possible. To ensure fairness, they encourage input from everyone in the transplant community. Getting involved in the development of transplantation policy may seem overwhelming, but remember that anyone who wants to can bring an issue to the attention of the appropriate OPTN committee.

There are several ways patients can bring concerns, ideas or solutions to the United Network for Organ Sharing (UNOS):

1. Call UNOS and ask for the UNOS Regional Administrator who serves your area.
2. Contact UNOS for the name and address of the chairperson or representatives of the OPTN committee that deals with issues like yours. Write your letter to that person or people. There are 16 standing committees within the OPTN system:

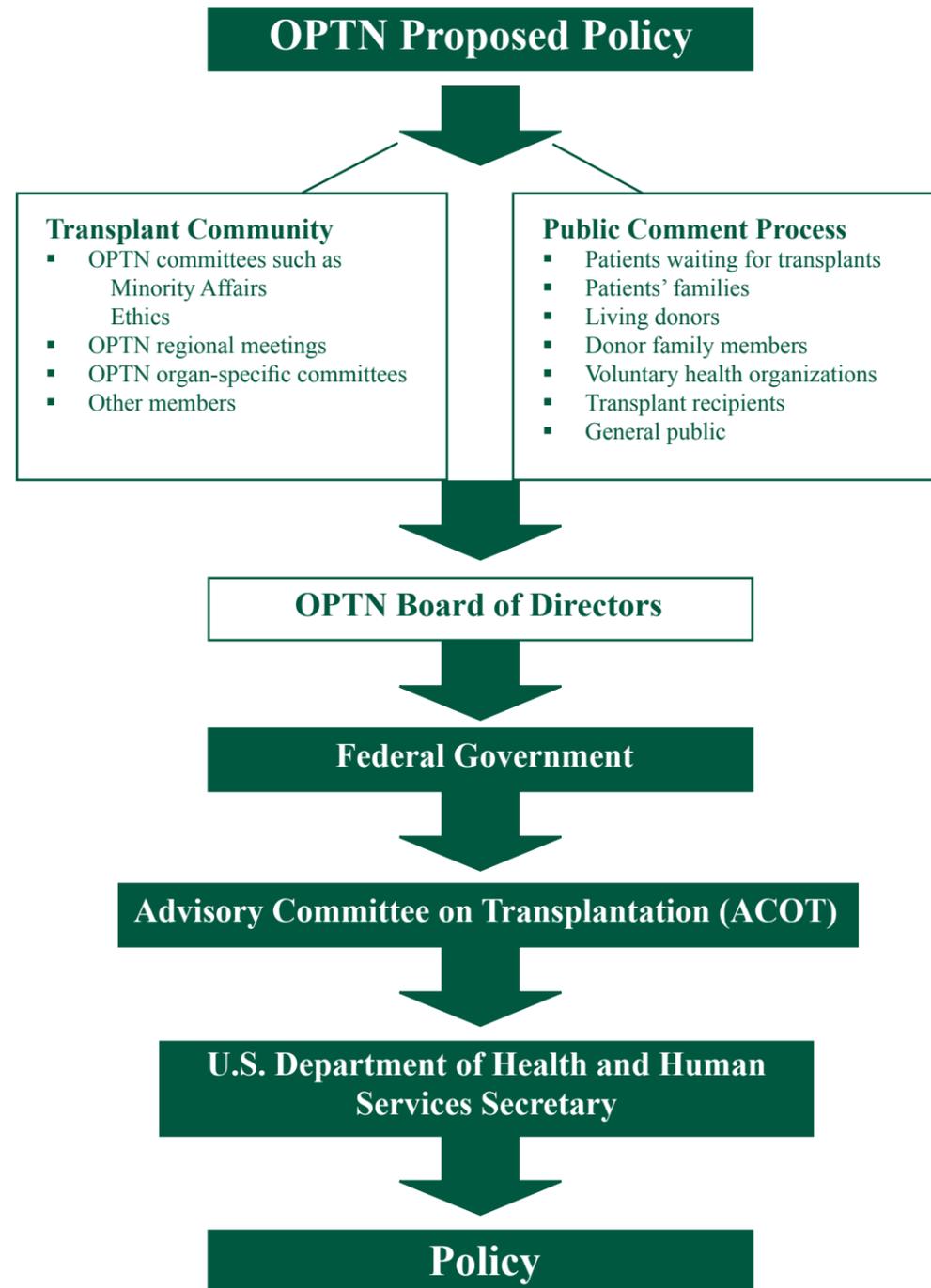
Communications Committee  
Data Advisory Committee

Ethics Committee  
Executive Committee  
Finance Committee  
Histocompatibility Committee  
Kidney/Pancreas Transplantation Committee  
Liver/Intestinal Transplantation Committee  
Membership and Professional Standards Committee  
Minority Affairs Committee  
Organ Availability Committee  
Organ Procurement Organization Committee  
Patient Affairs Committee  
Pediatric Transplantation Committee  
Thoracic Organ Transplant Committee  
Transplant Administrators Committee

3. Call UNOS and request that you be added to the mailing list to receive public comment documents. People on this list are mailed all policy proposals being considered. You can read about the proposed policy and send your comments back to UNOS. This is perhaps the most important way you can participate in the policymaking process. Your voice will be heard!
4. Visit the OPTN or UNOS Web sites and read and respond to issues that are available for public comment. These can be found at [www.optn.org](http://www.optn.org) → Policies and Bylaws → Public Comment, and at [www.unos.org](http://www.unos.org) → What We Do → Policy Management → Public Comment.
5. Contact the Division of Transplantation within HHS at 301-443-7577, or send postal mail to the Division of Transplantation, Room 16C-17, Parklawn Building, 5600 Fishers Lane, Rockville, MD 20857.

## How OPTN Policies Are Made

Transplant patients and the experts face very important problems and try to find solutions to difficult questions. Some of these solutions can be turned into OPTN policies by the following method:



## THE UNITED NETWORK FOR ORGAN SHARING (UNOS)

UNOS is a private, non-profit organization. UNOS is not part of the Federal Government, but manages and supports the OPTN under contract to the Federal Government to make sure the national transplant system provides the greatest benefit to the most patients.

### Mission Statement

*UNOS advances organ availability and transplantation by uniting and supporting its communities for the benefit of patients through education, technology and policy development.*

UNOS membership is made up of all transplant centers, organ procurement organizations, histocompatibility laboratories, patients, donor families, ethicists, transplant recipients, the general public and health organizations.

UNOS, as the OPTN contractor, matches donor organs with waiting transplant candidates and coordinates the development of allocation policy. UNOS works to increase the number of donated organs for transplantation through education and provides patients with information about transplantation.

UNOS operates the OPTN in order to

- Make policies for sharing donated organs.
- Collect all of the information for the U.S. Scientific Registry of Transplant Recipients to help make transplants more successful.
- Promote organ donation.
- Provide information to patients about organ transplantation.

## THE SCIENTIFIC REGISTRY OF TRANSPLANT RECIPIENTS (SRTR)

For improvements in transplantation to continue, researchers must study every aspect of the organ recipient's health and health care before, during and after transplant surgery. All transplant hospitals keep detailed records of organ recipients and some of these data are collected by UNOS in its OPTN role. UNOS collects and provides the data to the University Renal Research and Education Association (URREA), which operates the U.S. Scientific Registry of Transplant Recipients (SRTR). The SRTR is the world's largest transplant database. Analysis and reports of these data provide patients, health professionals and scientists with information they can use to improve health care. Patients can use the information to make informed decisions about their transplants. (All individual patient records are confidential and the data that is collected is not connected to a patient's name.)

The SRTR reports that are available to patients include

- *Annual Report of the OPTN and the United States Scientific Registry of Transplant Recipients*. This report presents information (such as age, gender and ethnicity) about organ donors, patients who are waiting for a transplant, and transplant recipients. It can





## WHERE TO LOOK FOR TRANSPLANT INFORMATION

Today, there is more information for transplant patients than ever before. This information can be found at libraries, hospitals, patient support groups, non-profit agencies and other organizations interested in health care. Technology has made it easier for people to find data and other important information at various organ donation and transplantation Web sites.

### The Internet

One of the quickest and easiest ways to find the answers to your questions about organ transplantation and donation is by looking on the Internet. You can access the Internet at many public libraries. You can also ask your transplant team if you can access the Internet from the hospital.

If you have never been on the Internet or any computer, you may feel a little uncomfortable. Just remember that everyone who uses the Internet today was a newcomer at one time. The number of people going online for transplant information is increasing. The Web sites below are examples of patient education resources available on the Internet.

#### The UNOS Patient Web Site — [www.transplantliving.org](http://www.transplantliving.org)

This site can help patients through the transplant process. It includes information about the waiting list, OPTN policies, the matching process, patient and professional profiles and resources for information.

#### The Scientific Registry of Transplant Recipients (SRTR) University Renal Research and Education Association (URREA) Web Site — [www.ustransplant.org](http://www.ustransplant.org)

This site contains information about the organization, what it does, transplant statistics and research resources.

#### The OPTN Web Site — [www.optn.org](http://www.optn.org)

This site has been created to educate, inform and clarify some of the complexities of the organ transplant process for all those affected by and/or interested in organ donation and transplantation.

#### The Federal Government Organ Donation Web Site — [www.organdonor.gov](http://www.organdonor.gov)

This site was created by the Health Resources and Services Administration of the U.S. Department of Health and Human Services. Patients can find answers to frequently asked questions, public affairs and legislative updates, links to other Web sites, and a glossary. There is also a section addressing myths about organ donation and information about various educational events and grant programs. You can download organ donation cards and brochures and order organ donation pins and bumper stickers to use as handouts for community activities to promote organ and tissue donation.

#### Division of Transplantation (DoT) Web Site — [www.hrsa.gov/osp/dot](http://www.hrsa.gov/osp/dot)

The DoT's Web site presents an overview of DoT's functions and staff, legislation and regulations, public education activities and OPTN and SRTR responsibilities. In addition, this site discusses DoT's responsibilities in bone marrow donation and transplantation.

#### Other Web Sites

See the list of transplant-related organizations in the Contacts section. Where possible, the Web site address is given for each organization.

#### Libraries

Your local library may be a good source of information about specific diseases and medical treatments. Some colleges and universities also have medical libraries with the latest literature about transplantation.

#### Health Organizations

Many organizations help patients with specific illnesses and diseases. You can contact these groups for patient education materials and other services. Some help with patient rights, hold meetings for members and/or provide education for professionals in the field. Health organizations are listed in the Contacts section that follows.

## CONTACTS

### Patient Education and Advocacy

The following organizations may be able to provide patient education and advocacy services for patients. This is a sample listing and should not be interpreted as a comprehensive list or an endorsement.

#### **American Association of Kidney Patients**

3505 East Frontage Road, Suite 315  
Tampa, FL 33607  
Phone: 1-800-749-2257  
E-mail: [info@aakp.org](mailto:info@aakp.org)  
Web address: [www.aakp.org](http://www.aakp.org)

#### **American Diabetes Association**

Customer Service  
1701 North Beauregard Street  
Alexandria, VA 22311  
Phone: 1-800-342-2383  
E-mail: [customerservice@diabetes.org](mailto:customerservice@diabetes.org)  
Web address: [www.diabetes.org](http://www.diabetes.org)

#### **American Heart Association**

7272 Greenville Avenue  
Dallas, TX 75231-4596  
Phone: 1-800-242-8721  
Web address: [www.americanheart.org](http://www.americanheart.org)

#### **American Liver Foundation**

75 Maiden Lane, Suite 603  
New York, NY 10038-4810  
Phone: 1-800-465-4837  
E-mail: [info@liverfoundation.org](mailto:info@liverfoundation.org)  
Web address: [www.liverfoundation.org](http://www.liverfoundation.org)

#### **American Lung Association**

61 Broadway, 6<sup>th</sup> Floor  
New York, NY 10006  
Phone: 212-315-8700  
E-mail: [info@lungusa.org](mailto:info@lungusa.org)  
Web address: [www.lungusa.org](http://www.lungusa.org)

#### **American Medical Association**

515 North State Street  
Chicago, IL 60610  
Phone: 312-464-5000  
Web address: [www.ama-assn.org](http://www.ama-assn.org)

#### **American Organ Transplant Association**

P.O. Box 41766  
Houston, TX 77244  
Phone: 281-493-2047  
E-mail: [info@a-o-t-a.org](mailto:info@a-o-t-a.org)  
Web address: [www.a-o-t-a.org](http://www.a-o-t-a.org)

#### **American Society of Minority Health and Transplant Professionals**

4208 22<sup>nd</sup> Street, NE  
Washington, DC 20018

#### **Association of Organ Procurement Organizations**

1364 Beverly Road, Suite 100  
McLean, VA 22101  
Phone: 703-573-2676  
E-mail: [organdonation@aopo.org](mailto:organdonation@aopo.org)  
Web address: [www.aopo.org](http://www.aopo.org)

#### **Children's Liver Association for Support Services**

27023 McBean Parkway #126  
Valencia, CA 91355  
Phone: 1-877-679-8256  
E-mail: [info@classkids.org](mailto:info@classkids.org)  
Web address: [www.classkids.org](http://www.classkids.org)

#### **Children's Organ Transplant Association**

2501 COTA Drive  
Bloomington, IN 47403  
Phone: 1-800-366-2682  
E-mail: [jennifer@cota.org](mailto:jennifer@cota.org)  
Web address: [www.cota.org](http://www.cota.org)

#### **Coalition on Donation**

700 North 4<sup>th</sup> Street  
Richmond, VA 23219  
Phone: 804-782-4920  
E-mail: [coalition@shareyourlife.org](mailto:coalition@shareyourlife.org)  
Web address: [www.donatelife.net](http://www.donatelife.net)

#### **Forum of ESRD Networks**

1527 Huguenot Road  
Midlothian, VA 23113  
Phone: 804-794-2586  
E-mail: [forum@forum.esrd.net](mailto:forum@forum.esrd.net)  
Web address: [www.esrdnetworks.org](http://www.esrdnetworks.org)

#### **Hepatitis Foundation International**

504 Blick Drive  
Silver Spring, MD 20904-2901  
Phone: 1-800-891-0707  
E-mail: [hfi@comcast.net](mailto:hfi@comcast.net)  
Web address: [www.hepfi.org](http://www.hepfi.org)

**Immune Tolerance Network**

University of California San Francisco  
3333 California Street, Suite 430  
San Francisco, CA 94118  
Phone: 415-514-2530  
E-mail: [sthompson@immunetolerance.org](mailto:sthompson@immunetolerance.org)  
Web address: [www.immunetolerance.org](http://www.immunetolerance.org)

**Insulin-Free World Foundation**

677 Craig Road, Suite 105  
St. Louis, MO 63141-7115  
Phone: 1-888-746-4439  
E-mail: [diabetesportal@sbcglobal.net](mailto:diabetesportal@sbcglobal.net)  
Web address: [www.insulin-free.org](http://www.insulin-free.org)

**International Transplant Nurses Society**

1739 East Carson Street, Box 351  
Pittsburgh, PA 15203-1700  
Phone: 412-488-0240  
E-mail: [itns@msn.com](mailto:itns@msn.com)  
Web address: [www.itns.org](http://www.itns.org)

**Juvenile Diabetes Research Foundation International**

120 Wall Street, 19<sup>th</sup> Floor  
New York, NY 10005  
Phone: 1-800-533-2873  
E-mail: [info@jdrf.org](mailto:info@jdrf.org)  
Web address: [www.jdrf.org](http://www.jdrf.org)

**Living Bank**

P.O. Box 6725  
Houston, TX 77265-6725  
Phone: 1-800-528-2971 or 1-713-528-2971  
E-mail: [info@livingbank.org](mailto:info@livingbank.org)  
Web address: [www.livingbank.org](http://www.livingbank.org)

**Latino Organization for Liver Awareness**

1560 Mayflower Avenue  
Bronx, NY 10461  
Phone: 1-888-367-5652  
E-mail: [mdlola@aol.com](mailto:mdlola@aol.com)  
Web address: [www.lola-national.org](http://www.lola-national.org)

**National Minority Organ and Tissue Transplant Education Program**

Ambulatory Care Center  
2041 Georgia Avenue, NW, Suite 3100  
Washington, DC 20060  
Phone: 1-800-393-2839  
Web address: [www.nationalmottep.org](http://www.nationalmottep.org)

**National Kidney and Urologic Diseases Information Clearinghouse**

Office of Communications and Public Liaison  
NIDDK, National Institutes of Health  
Building 31, Room 9A04  
Center Drive MSC 2560  
Bethesda, MD 20892-3580  
Phone: 1-800-891-5390 or 301-654-4415  
E-mail: [nkudic@info.niddk.nih.gov](mailto:nkudic@info.niddk.nih.gov)  
Web address: [www.niddk.nih.gov](http://www.niddk.nih.gov)

**National Kidney Foundation**

30 East 33rd Street, Suite 1100  
New York, NY 10016  
Phone: 1-800-622-9010  
E-mail: [info@kidney.org](mailto:info@kidney.org)  
Web address: [www.kidney.org](http://www.kidney.org)

**National Organization for Rare Disorders**

55 Kenosia Avenue  
P.O. Box 1968  
Danbury, CT 06813-1968  
Phone: 1-800-999-6673 or 203-744-0100  
E-mail: [orphan@rarediseases.org](mailto:orphan@rarediseases.org)  
Web address: [www.rarediseases.org](http://www.rarediseases.org)

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

United Network for Organ Sharing (UNOS)  
700 North 4<sup>th</sup> Street  
Richmond, VA 23219  
Phone: 804-782-4800  
Web address: [www.unos.org](http://www.unos.org)

**Scientific Registry of Transplant Recipients (SRTR)**

University Renal Research and Education Association (URREA)  
315 West Huron, Suite 260  
Ann Arbor, MI 48103  
Phone: 734-665-4108  
E-mail: [mail@ustransplant.org](mailto:mail@ustransplant.org)  
Web address: [www.ustransplant.org](http://www.ustransplant.org)

**Second Wind Lung Transplant Association**

300 South Duncan Avenue, Suite 227  
Clearwater, FL 33755-6457  
Phone: 1-888-855-9463  
E-mail: [heering@2ndwind.org](mailto:heering@2ndwind.org)  
Web address: [www.2ndwind.org](http://www.2ndwind.org)

**TransWeb: All About Transplantation and Donation**

The Northern Brewery  
1327 Jones Drive, Suite 105  
Ann Arbor, MI 48105  
Phone: 734-998-7314  
E-mail: [transweb@umich.edu](mailto:transweb@umich.edu)  
Web address: [www.transweb.org](http://www.transweb.org)

**U. S. Department of Health and Human Services**

Health Resources and Services Administration  
Special Programs Bureau  
Division of Transplantation  
5600 Fishers Lane, Room 16C-17  
Rockville, MD 20857  
Phone: 301-443-7577  
E-mail: [rlaeng@hrsa.gov](mailto:rlaeng@hrsa.gov)  
Web address: [www.organdonor.gov](http://www.organdonor.gov)

**Financial Assistance**

The following organizations may be able to provide financial assistance for patients. This is a sample listing and should not be interpreted as a comprehensive list or an endorsement.

**Air Care Alliance**

1515 East 71<sup>st</sup> Street, Suite 312  
Tulsa, OK 74136-1064  
Phone: 1-888-260-9707  
E-mail: [mail@aircareall.org](mailto:mail@aircareall.org)  
Web address: [www.aircareall.org](http://www.aircareall.org)

**Angel Flight**

4620 Haygood Road, Suite 1  
Virginia Beach, VA 23455  
Phone: 1-800-296-3797  
E-mail: [angelflight@erols.com](mailto:angelflight@erols.com)  
Web address: [www.angel-flight.org](http://www.angel-flight.org)

**American Kidney Fund**

6110 Executive Blvd., Suite 1010  
Rockville, MD 20852  
Phone: 1-800-638-8299  
E-mail: [helpline@akfinc.org](mailto:helpline@akfinc.org)  
Web address: [www.akfinc.org](http://www.akfinc.org)

**American Liver Foundation**

75 Maiden Lane, Suite 603  
New York, NY 10038-4810  
Phone: 1-800-465-4837  
E-mail: [info@liverfoundation.org](mailto:info@liverfoundation.org)  
Web address: [www.liverfoundation.org](http://www.liverfoundation.org)

**American Organ Transplant Association**

P.O. Box 441766  
Houston, TX 77244  
Phone: 281-493-2047  
E-mail: [info@a-o-t-a.org](mailto:info@a-o-t-a.org)  
Web address: [www.a-o-t-a.org](http://www.a-o-t-a.org)

**Children's Organ Transplant Association**

2501 COTA Drive  
Bloomington, IN 47403  
Phone: 1-800-366-2682  
E-mail: [jennifer@cota.org](mailto:jennifer@cota.org)  
Web address: [www.cota.org](http://www.cota.org)

**Medicare Hotline**

Phone: 1-800-633-4227  
Web address: [www.medicare.gov](http://www.medicare.gov)

**National Foundation for Transplants**

1102 Brookfield, Suite 200  
Memphis, TN 38119  
Phone: 1-800-489-3863  
E-mail: [jhill@transplants.org](mailto:jhill@transplants.org)  
Web address: [www.transplants.org](http://www.transplants.org)

**National Insurance Consumer Hotline**

Phone: 1-800-942-4242

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

6 Prospect Street  
Midland Park, NJ 07432-1691  
Phone: 1-888-431-2804  
E-mail: [webmaster@nosscr.org](mailto:webmaster@nosscr.org)  
Web address: [www.nosscr.org](http://www.nosscr.org)

**National Transplant Assistance Fund**

3475 West Chester Pike, Suite 230  
Newton Square, PA 19073  
Phone: 1-800-642-8399  
E-mail: [NTAF@transplantfund.org](mailto:NTAF@transplantfund.org)  
Web address: [www.transplantfund.org](http://www.transplantfund.org)

**Pharmaceutical Research and Manufacturers of America**

1100 15<sup>th</sup> Street, NW  
Washington, DC 20005  
Phone: 1-800-762-4636 or 202-835-3400  
Web address: [www.helpingpatients.org](http://www.helpingpatients.org)

## LEGAL FRAMEWORK FOR TRANSPLANTATION

Many changes in national and State laws helped form the U.S. transplant system. Following is a list of laws and their impact on transplantation in America:

Law	Impact
1968 Uniform Anatomical Gift Act (UAGA)	<ul style="list-style-type: none"> <li>Established legality of the organ and tissue donor card</li> </ul>
1987 UAGA revised	<ul style="list-style-type: none"> <li>Provided for legality of organ and tissue donation</li> </ul>
1978 Uniform Brain Death Act	<ul style="list-style-type: none"> <li>Expanded traditional definition of death (cardiopulmonary) to include brain death</li> </ul>
1980 Uniform Determination of Death Act	<ul style="list-style-type: none"> <li>Confirmed legality of brain death</li> </ul>
1984 National Organ Transplant Act	<ul style="list-style-type: none"> <li>Established a national Organ Procurement and Transplantation Network (OPTN)</li> <li>Prohibited sale of human organs</li> </ul>
1986 Omnibus Budget Reconciliation Act (OBRA)	<ul style="list-style-type: none"> <li>Established hospital procedures that require a designated person to approach family members about donation at the time of a patient's death (routine request).</li> </ul>
1987 OBRA revised	<ul style="list-style-type: none"> <li>Organ procurement organizations to be notified by hospitals regarding potential donors.</li> </ul>

Source: UNOS Donation and Transplantation Nursing Curriculum.

### THE AMERICAN HOSPITAL ASSOCIATION'S *PATIENT CARE PARTNERSHIP*

In 1973, the American Hospital Association's Commission on Healthcare for the Disadvantaged developed the *Patient's Bill of Rights*. The following is the Association's updated version. It is provided by most hospitals to patients at the time of admission and describes the hospital's responsibilities to patients. It also discusses your rights and responsibilities as a partner on the healthcare team.

#### THE PATIENT CARE PARTNERSHIP:

#### UNDERSTANDING EXPECTATIONS, RIGHTS AND RESPONSIBILITIES

When you need hospital care, your doctor and the nurses and other professionals at our hospital are committed to working with you and your family to meet your health care needs.

Our dedicated doctors and staff serve the community in all its ethnic, religious and economic diversity. Our goal is for you and your family to have the same care and attention we would want for our families and ourselves.

The following sections explain some of the basics about how you can expect to be treated during your hospital stay. They also cover what we will need from you to care for you better. If you have questions at any time, please ask them. Unasked or unanswered questions can add to the stress of being in the hospital. Your comfort and confidence in your care are very important to us.

#### What To Expect During Your Hospital Stay

- High quality hospital care.** Our first priority is to provide you the care you need, when you need it, with skill, compassion, and respect. Tell your caregivers if you have concerns about your care or if you have pain. You have the right to know the identity of doctors, nurses and others involved in your care, and you have the right to know when they are students, residents or other trainees.
- A clean and safe environment.** Our hospital works hard to keep you safe. We use special policies and procedures to avoid mistakes in your care and keep you free from abuse or neglect. If anything unexpected and significant happens during your hospital stay, you will be told what happened, and any resulting changes in your care will be discussed with you.
- Involvement in your care.** You and your doctor often make decisions about your care before you go to the hospital. Other times, especially in emergencies, those decisions are made during your hospital stay. When decision making takes place, it should include

*Discussing your medical condition and information about medically appropriate treatment choices.* To make informed decisions with your doctor, you need to understand

- The benefits and risks of each treatment.
  - Whether your treatment is experimental or part of a research study.
  - What you can reasonably expect from your treatment and any long-term effects it might have on your quality of life.
  - What you and your family will need to do after you leave the hospital.
  - The financial consequences of using uncovered services or out-of-network providers.
- Please tell your caregivers if you need more information about treatment choices.

*Discussing your treatment plan.* When you enter the hospital, you sign a general consent to treatment. In some cases, such as surgery or experimental treatment, you may be asked to confirm in writing that you understand what is planned and agree to it. This process protects your right to consent to or refuse a treatment. Your doctor will explain the medical consequences of refusing recommended treatment. It also protects your right to decide if you want to participate in a research study.

*Getting information from you.* Your caregivers need complete and correct information about your health and coverage so that they can make good decisions about your care.

That includes

- Past illnesses, surgeries or hospital stays.
- Past allergic reactions.
- Any medicines or dietary supplements (such as vitamins and herbs) that you are taking.
- Any network or admission requirements under your health plan.

*Understanding your health care goals and values.* You may have health care goals and values or spiritual beliefs that are important to your well-being. They will be taken into account as much as possible throughout your hospital stay. Make sure your doctor, your family and your care team knows your wishes.

*Understanding who should make decisions when you cannot.* If you have signed a health care power of attorney stating who should speak for you if you become unable to make health care decisions for yourself, or a “living will” or “advance directive” that states your wishes about end-of-life care, give copies to your doctor, your family and your care team. If you or your family need help making difficult decisions, counselors, chaplains and others are available to help.

- **Protection of your privacy.** We respect the confidentiality of your relationship with your doctor and other caregivers, and the sensitive information about your health and health care that are part of that relationship. State and Federal laws and hospital operating policies protect the privacy of your medical information. You will receive a Notice of Privacy Practices that describes the ways that we use, disclose and safeguard patient information and that explains how you can obtain a copy of information from our records about your care.
- **Preparing you and your family for when you leave the hospital.** Your doctor works with hospital staff and professionals in your community. You and your family also play an important role in your care. The success of your treatment often depends on your efforts to follow medication, diet and therapy plans. Your family may need to help care for you at home.

You can expect us to help you identify sources of follow-up care and to let you know if our hospital has a financial interest in any referrals. As long as you agree that we can share information about your care with them, we will coordinate our activities with your caregivers outside the hospital. You can also expect to receive information and, where possible, training about the self-care you will need when you go home.

- **Help with your bill and filing insurance claims.** Our staff will file claims for you with health care insurers or other programs such as Medicare and Medicaid. They also will

help your doctor with needed documentation. Hospital bills and insurance coverage are often confusing. If you have questions about your bill, contact our business office. If you need help understanding your insurance coverage or health plan, start with your insurance company or health benefits manager. If you do not have health coverage, we will try to help you and your family find financial help or make other arrangements. We need your help with collecting needed information and other requirements to obtain coverage or assistance.

While you are here, you will receive more detailed notices about some of the rights you have as a hospital patient and how to exercise them. We are always interested in improving. If you have questions, comments, or concerns, please contact \_\_\_\_\_.

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## APPENDIXES

### Glossary

### Abbreviations and Acronyms

### List of Contributors

#### *Did you know?*

*In 2002, approximately 2,000 living organ donations were made between unrelated donors and recipients.*

*Kidney donation is the most common living organ donation.*

## GLOSSARY

**acute rejection** - The body's attempt to destroy the transplanted organ. Acute rejection usually occurs in the first year after transplant.

**ADA** - Americans with Disabilities Act of 1990.

**administrative fee** - An amount of money charged by an organization that is handling your fundraising money.

**adverse reaction** - An unintended side effect from a drug.

**advocacy organization** - A group that helps someone get what they need or want, promotes a certain point of view, or pleads the case of another.

**allocation** - The process of determining how organs are distributed. Allocation includes the system of policies and guidelines that are followed to ensure that organs and tissues are distributed fairly to those waiting for them.

**allograft** - An organ or tissue that is transplanted from one creature to another of the same species, such as human to human. An example would be a transplanted kidney.

**antibody** - A protein substance made by the body's immune system to attack a foreign substance, for example, a transplanted organ, blood transfusion, virus or pregnancy. Because antibodies attack transplanted organs, transplant patients must take powerful drugs. (See **anti-rejection drugs**.)

**antigen** - A foreign substance, such as a transplanted organ, that triggers the body to try to destroy (reject) it.

**anti-rejection drugs (immunosuppressive drugs)** - Drugs that reduce the body's ability to reject the transplanted organ.

**arteriogram** - An x ray of an artery after a dye has been injected.

**ascites** - A buildup of fluid in the abdomen usually associated with liver disease.

**beneficiary** - The person who receives the benefits of an insurance policy.

**benefits** - Services that are paid for by an insurance policy.

**biopsy** - A tiny piece of tissue removed from the body (usually with a needle) and examined under a microscope. This test is performed to diagnose rejection of a transplanted organ.

**blood vessels** - The veins, arteries, and capillaries through which blood flows. Blood vessels can be donated and transplanted.

**brain death** - When the brain has permanently stopped working, as determined by the physician. Machines may maintain functions such as heartbeat and breathing for a few days, but not permanently.

**cadaver** - A dead body.

**cadaveric** - Refers to things about or relating to a dead body.

**cardiac** - Having to do with the heart.

**Center of Excellence** - An insurance term for a medical center that will negotiate a discounted price for the transplant even if that center is not part of the insurance company's PPO network.

**charitable organization** - A group that does not charge a fee for its services.

**chronic** - A condition that develops slowly and lasts for a long time, even the rest of the patient's life, for example, kidney failure.

**chronic rejection** - Slow failure of the transplanted organ.

**cirrhosis** - A disease of the liver in which normal, healthy tissue is replaced with nonfunctioning tissue, and healthy, functioning liver cells are lost. Cirrhosis usually occurs when there is a lack of adequate nutrition, infection is present or damage has been caused by alcohol abuse.

**Coalition on Donation** - A non-profit alliance of health and science professionals, transplant patients and voluntary health and transplant organizations. The Coalition works to increase public awareness of the critical organ shortage and create a greater willingness and commitment to organ and tissue donation.

**co-insurance** - A percentage of money you must pay toward a service your insurance will cover. A typical amount is 20 percent—you pay 20 percent of the doctor's bill and your insurance company pays the other 80 percent.

**cold ischemia time** - The time an organ is without blood circulation—from the time of removal of the organ from the donor to the time the organ is transplanted into the recipient.

**co-payment (co-pay)** - A flat fee that a person pays for healthcare services in addition to what the insurance company pays, for example, a \$10 "co-payment" each time you visit your doctor.

**corticosteroid** - A hormone produced by the body but given as a synthetic (manufactured) medicine to suppress your body's normal reaction (immune response) to infection and foreign tissue, such as a transplanted organ. Prednisone is an example of a synthetic hormone.

**coverage date** - The day your insurance benefits begin.

**covered benefit** - A service that an insurance company will provide payment toward.

**covered service** - See **covered benefit**.

**criteria (medical criteria)** - A set of standards or conditions that must be met.

**critical care unit** - See **intensive care unit**.

**crossmatching** - A blood test performed before the transplant to see if the potential recipient will react poorly to the donor organ. If the crossmatch is "positive," then the donor and patient are incompatible. If the crossmatch is "negative," then the transplant may proceed. Crossmatching is routinely performed before kidney and pancreas transplants.

**cyclosporine** - A drug used to prevent rejection of the transplanted organ by suppressing, or shutting down, the body's defense system (immune response).

**deceased donor** - A person who has been declared dead and whose family has offered one or more organs or tissues to be used for transplantation. The deceased donor contrasts with the living donor, someone who has agreed to donate a kidney or part of an organ while still alive.

**deductible** - A fixed amount of money you must pay for covered healthcare expenses before the insurance company starts to pay. This is usually a yearly amount of \$250, \$500, \$1000 or more.

**delayed function** - A condition in which the transplanted organ does not work well right after the transplant. Many kidneys have a delay before they begin to function well. Kidneys can sometimes take as long as three weeks to "wake up." Sometimes a kidney recipient needs dialysis until the kidney starts to work.

**Department of Health and Human Services (HHS)** - The department of the Federal Government responsible for health-related programs and issues, including overseeing the OPTN and SRTR contracts and developing organ, tissue and bone marrow donation programs.

**dependents** - Those persons who also receive insurance benefits on your policy, for example, a spouse and children.

**depilatory** - A cream or spray put on the skin to dissolve and remove excess hair.

**dialysis** - The use of a machine to correct the balance of fluids and chemicals in your body and to remove wastes from your body when your kidneys are failing. (See **hemodialysis**.)

**diastolic blood pressure** - The bottom number in your blood pressure (80 in a blood pressure of 120/80), which indicates the pressure in the arteries when the heart is at rest.

**disability (disabled)** - A considerable limitation in major life activity that cannot be helped with the use of a corrective device or medication. A disabled person is someone who is unable to perform the necessary functions of a job with or without a reasonable modification.

**Disability Determination Service** - A State agency that reviews your eligibility for vocational rehabilitation.

**disability insurance** - A type of insurance that provides you with an income if illness or injury prevents you from being able to work for an extended period of time.

**Division of Transplantation (DoT)** - The office of the U.S. Department of Health and Human Services whose principal responsibilities include oversight of the contracts for the national Organ Procurement and Transplantation Network (OPTN), the U.S. Scientific Registry of Transplant Recipients (SRTR) and the National Marrow Donor Program (NMDP). The DoT also provides professional and public education to increase organ and tissue donation and technical assistance to organ procurement organizations (OPOs).

**donor** - Someone from whom an organ or tissue is removed for transplantation.

**donor card** - A document that indicates your wish to be an organ donor.

**donor pool** - A group of people eligible to donate an organ.

**durable power of attorney** - A legal document in which you name someone to make medical decisions for you when you are unable to speak for yourself.

**edema** - Swelling caused when the body retains too much fluid, also called “water weight.”

**end-stage organ disease** - A disease that leads to permanent failure of an organ.

**end-stage renal disease (ESRD)/chronic kidney failure** - A condition in which the kidneys no longer function. Patients then require dialysis or a transplant.

**End-Stage Renal Disease (ESRD) Program** - The part of Medicare that helps pay for dialysis or transplantation for people with end-stage kidney disease, or renal failure.

**ethnicity (formerly race)** - For OPTN data purposes, the use of categories such as White; Black

or African American; Hispanic; Asian or Native Hawaiian; or Other, which includes American Indian, Alaska Native, Mid-East or Arabian, or Indian subcontinent.

**evidence of insurability** - Proof that you are healthy enough for a particular insurance company to insure you.

**exclusion** - Medical services that are not paid for by an insurance policy.

**experimental** - New treatments, procedures or drugs that are being tested. Insurance companies usually do not pay for anything considered experimental.

**federally mandated** - Required by Federal law.

**foreign body** - An entity that enters the body that is not supposed to be there, such as a germ, a piece of glass, a splinter, or a transplanted organ or tissue. Your body normally attacks or tries to reject a foreign body to prevent further injury.

**foundation** - An institution that provides funds for causes, issues, groups, people, etc. A foundation often has a particular interest or interests and solicits donations from those who support these interests. Some foundations help patients and their families with medical expenses.

**fulminant** - Happening very quickly and with intensity, for example, fulminant liver failure or fulminant infection.

**fungal disease** - An infection that usually occurs in patients during treatment with steroids or immunosuppressants. Examples of fungal infections include candida, aspergillus, and histoplasmosis, which tend to be systemic infections.

**gender** - The particular sex of an individual; male or female.

**genetic** - Referring to heredity, birth or origin.

**genetic matching** - See **tissue typing**.

**gingival hypertrophy** - Enlargement of the gums. It can be controlled by good oral hygiene and regular dental checkups.

**glomerular filtration rate (GFR)** - A measurement of kidney function used to determine the severity of kidney disease.

**graft** - A transplanted organ or tissue.

**graft survival rate** - The percentage of patients who have functioning transplanted organs (grafts) at a certain point in time. The data are usually measured in 1-, 3- and 5-year time periods.

**grant** - An amount of money given as a gift, usually for a specific use.

**group health plan** - See **group insurance**.

**group insurance** - Typically offered through employers, although unions, professional associations and other organizations also offer group insurance. Most, if not all, of the premium is paid by the employer.

**health maintenance organization (HMO)** - An insurance plan where you or your employer pay a fixed monthly fee for services, regardless of the level of care. You must usually see your primary care physician and then be referred to a specialist.

**hemodialysis** - A treatment for kidney failure whereby the patient's blood is passed through a machine to remove excess fluid and wastes. The procedure usually takes about 3 or 4 hours per session and is usually done about three times per week.

**hemorrhage** - A rapid loss of a large amount of blood; excessive bleeding.

**hepatic** - Having to do with, or referring to, the liver.

**hepatitis** - An inflammation of the liver that can lead to liver failure.

**high blood pressure (hypertension)** - High blood pressure occurs when the force of the blood pushing against the walls of the blood vessels is higher than normal because the blood vessels have either become less able to stretch or have gotten smaller. High blood pressure causes the heart to pump harder to move blood through the body. High blood pressure can cause kidney failure and heart disease if not treated.

**hirsutism** - An excessive increase in hair growth. It is a common side effect of some drugs and can be controlled with waxing, hair removal creams or shaving.

**histocompatibility (HLA system)** - The examination of human leukocyte antigens (HLA) in a patient, often referred to as "tissue typing" or "genetic matching." Tissue typing is routinely performed for all donors and recipients in kidney and pancreas transplantation to help match the donor with the most suitable recipients to help decrease the likelihood of rejection of the transplanted organ.

**human immunodeficiency virus (HIV)** - A virus that destroys cells in the immune system, resulting in the eventual inability of the body to fight off infections, toxins, poisons or diseases. HIV causes AIDS (acquired immunodeficiency syndrome), a late stage of the HIV infection that can include serious infections, blindness, some types of cancer and neurological conditions such as senility.

**human leukocyte antigens (HLA)** - Molecules found on cells in the body that characterize each person as unique. These antigens are inherited from your parents. In donor-recipient matching, HLA determines whether or not someone will accept an organ from a donor.

**hypertension** - See **high blood pressure**.

**immune response** - The body's natural defense against foreign objects or organisms, such as bacteria, viruses, or transplanted organs or tissues.

**immune system** - The organs, tissues, cells and cell products in your body that work to find and destroy foreign substances, such as bacteria, viruses and transplanted organs.

**immunosuppression** - The artificial suppression of the immune response, usually through drugs, so that the body will not reject a transplanted organ or tissue. Drugs commonly used to suppress the immune system after transplant include Prednisone, azathioprine (Imuran), cyclosporine (Sandimmune, Neoral), OKT3 and ALG, mycophenolate mofetil (CellCept) and tacrolimus (Prograf, FK506).

**immunosuppressive** - Relating to the weakening or reducing of your immune system's responses to foreign material. Immunosuppressive drugs reduce your immune system's ability to reject a transplanted organ.

**infection** - A condition that occurs when a foreign substance enters your body, causing your immune system to fight the intruder. Transplant recipients can get infections more easily because their immune systems are suppressed. It is more difficult for them to recover from infection, such as urinary tract infection, colds and the flu.

**inflammation** - The swelling, heat and redness your body produces when it has an injury or infection.

**informed consent** - The process of reaching an agreement based on a full disclosure and full understanding of what will take place. Informed consent has components of disclosure, comprehension, competence and voluntary response. Informed consent often refers to the process by which one makes decisions regarding medical procedures, including the decision to donate the organs of a loved one.

**inpatient treatment** - Treatment in the hospital involving at least one overnight stay.

**insurance benefits** - Services paid for by an insurance company.

**intensive care unit (ICU)** - A unit in the hospital that has highly technical and sophisticated monitoring devices and equipment for seriously ill patients. The staff is specially trained to take care of these patients who are often critically ill or recovering from surgery.

**intravenous (IV)** - Within a vein or veins; usually refers to medication or fluids that are infused into a vein through a plastic catheter (narrow tube) or “line” inserted into the vein.

**investigational** - A drug or procedure that is in a research phase and has not yet been approved for patient use by the Federal Drug Administration (FDA). Insurance companies normally do not pay for investigational drugs or procedures.

**kidneys** - A pair of organs that remove wastes from your body through the production of urine. The blood in your body passes through the kidneys about 20 times every hour. Kidneys can be donated from living or deceased donors and transplanted into patients with kidney failure.

**legislation** - A law or group of laws proposed or enacted that have the force or authority of a government or other organization.

**leukocyte** - A white blood cell.

**lifetime cap** - See **lifetime maximum**.

**lifetime maximum** - The total amount of money your insurance company will pay out for your covered expenses during your lifetime. Typical amounts are \$150,000, up to \$5,000,000. Once you have reached your lifetime maximum, you will no longer have insurance benefits. It is very important for you to know how your insurance dollars are being spent.

**liver** - Made up of a spongy mass of wedge-shaped lobes, the liver secretes bile, which aids in digestion, helps process proteins, carbohydrates and fats, and stores substances like vitamins. The liver also removes wastes from the blood. The liver can be donated and transplanted. Living donors can give part of their liver.

**living related donor (LRD)** - A family member who donates a kidney or part of a lung, liver or pancreas to another family member, such as a brother to a sister, or a parent to a child.

**living unrelated donor** - A person who is not related by blood who donates a kidney or part of a lung, liver or pancreas to another person, such as a husband who donates to a wife.

**mail-order pharmacy** - A pharmacy that provides medicines and medical supplies via the mail, often at reduced costs when compared to regular pharmacies.

**managed care** - A term used to describe insurance programs that try to control health costs by limiting unnecessary treatment. Health maintenance organizations (HMOs), preferred provider organizations (PPOs) and point-of-service (POS) plans and utilization review are all forms of managed care.

**match** - The degree of compatibility, or likeness, between the donor and the recipient.

**Medicaid** - A partnership between the Federal Government and the individual States to share the cost of providing medical coverage for welfare recipients and to allow States to provide the same coverage to low-income workers not eligible for welfare. Programs vary greatly from State to State.

**medically necessary** - A specific healthcare service or supply that your insurance company has determined is required for your medical treatment and is also the most efficient and economical way to provide that service. Examples would be having a minor surgical procedure performed in the doctor’s office instead of staying overnight in a hospital, or renting rather than buying a piece of medical equipment.

**Medicare** - The Federal Government program that provides hospital and medical insurance through Social Security taxes to people age 65 and over, those who have permanent kidney failure, and certain people with disabilities.

**Medicare-approved facility** - A facility that meets Medicare standards for the number of transplants they do and the quality of patient outcomes.

**Medigap policy (MedSupp, Medicare supplementary)** - Private insurance that helps cover some of the gaps in Medicare coverage.

**mortality** - Death (mortality rate = death rate).

**multiple listing** - Being on the organ transplant waiting list at more than one transplant center.

**National Organ Transplant Act (NOTA)** - Passed by Congress in 1984, NOTA initiated the development of a national system for organ sharing and a scientific registry to collect and report transplant data. It also outlawed the sale of human organs.

**noncompliance** - Failure to follow the instructions of the medical team, such as not taking medicines properly or not attending clinic appointments. Noncompliance can lead to the failure of a transplanted organ.

**nonfunction** - A condition in which a transplanted organ fails to “wake up” (work) after being transplanted into a recipient. In the case of a kidney transplant, the recipient will return to dialysis and/or undergo another transplant.

**OPO service area** - Each OPO provides organ procurement services for transplant centers throughout the United States. An OPO service area can include a portion of a city, a portion of a State or an entire State. OPOs distribute organs according to established allocation policy.

**organ** - A part of the body, made up of various types of tissues, that performs a particular function. Transplantable organs are the heart, liver, lungs, kidneys, pancreas and intestines.

**organ donation** - To give an organ, such as your kidney, to someone in need of that organ, or to have your organs removed for transplantation after your death.

**organ preservation** - Donated organs require special methods of preservation to keep them viable between removal and transplantation. Without preservation, the organs will deteriorate. The length of time organs and tissues can be kept outside the body vary depending on the organ, the preservation solution and the preservation method (pump or cold storage). Common preservation times vary from 2 to 4 hours for lungs to 48 hours for kidneys.

**organ procurement or organ recovery** - The act of surgically removing an organ from a donor for transplantation.

**Organ Procurement and Transplantation Network (OPTN)** - In 1987, Congress passed the National Organ Transplant Act that mandated the establishment of the OPTN and Scientific Registry of Transplant Recipients. The purpose of the OPTN is to improve the effectiveness of the Nation's organ procurement, donation and transplantation system by increasing the availability of and access to donor organs for patients with end-stage organ failure. Members of the OPTN include transplant centers, OPOs, histocompatibility laboratories, voluntary healthcare organizations and the general public. UNOS operates the OPTN under contract with the Federal Government.

**organ procurement organization (OPO)** - OPOs serve as the vital link between the donor and recipient and are responsible for the identification of donors and the removal, preservation and transportation of organs for transplantation. OPOs also collect data on deceased donors for the Scientific Registry. As a resource to the community, OPOs engage in public and professional education on the critical need for organ donation. Currently, there are 59 OPOs around the country. All are OPTN members.

**out-of-pocket expenses** - The portion of health costs that must be paid by the insured person per year, including deductibles, co-payments and co-insurance. After these are paid, the insurance company pays benefits at 100 percent.

**outpatient care (ambulatory care)** - Medical testing or treatment done without an overnight hospital stay, performed in a hospital setting or at a doctor's office.

**pancreas** - A long, irregularly shaped gland that lies behind the stomach and secretes enzymes into the small intestines to aid in the digestion of proteins, carbohydrates and fats. Islet cells within the pancreas consist of four types. The alpha cells secrete glucagons, which raise blood sugar levels. The beta cells secrete insulin, which lowers blood sugar levels. If the beta cells fail, the individual becomes diabetic and may need to take insulin. The pancreas and the islet cells can be donated and transplanted.

**panel reactive antibody (PRA)** - This is a blood test used to find out how a potential organ recipient will react to a donor organ. A patient with a PRA of 80 percent will likely reject 80 percent of donor kidneys. Patients with a high PRA have priority on the waiting list. The more antibodies in the recipient's blood, the more likely the recipient will react against the donor organ. For example, patients who have received multiple blood transfusions are likely to have more antibodies in their blood and a higher PRA.

**pool** - A group of people or objects with a similar characteristic or function.

**potential transplant recipient** - A transplant candidate who has been ranked by the OPTN computer match program as the person to whom an organ from a specific deceased organ donor is to be offered.

**pre-authorization (pre-certification)** - The process of notifying and getting approval from your insurance company before you proceed with an elective (non-emergency) medical procedure. If your insurance plan requires pre-certification and you do not obtain it, your share of the cost will be higher.

**pre-existing condition** - Any disease, illness, sickness or condition that was diagnosed or treated by a provider (insurance company) in the 12 months before the start date of your insurance coverage; also, anything that caused symptoms in those 12 months that would cause you to seek medical care.

**preferred provider organization (PPO)** - A group of hospitals or physicians who have signed a contract with a particular insurance company to provide care to their members, usually at a discount. If you have a PPO insurance plan, your share of the cost is usually lower if you use one of the designated providers.

**premium** - Amount paid to an insurance company for providing medical or disability coverage under a contract.

**private health plan** - An insurance policy obtained by an individual, not through an employer.

**procurement** - The surgical procedure of removing a donated organ or tissue.

**pulmonary** - Having to do with, or referring to, the lungs.

**race** - See **ethnicity**.

**recipient** - A person who has received a transplant.

**recovery or retrieval** - The surgical procedure of removing an organ or tissue from a donor.

**rejection** - When the body tries to attack a transplanted organ or tissue because it reacts to the organ or tissue as a foreign object. Anti-rejection (immunosuppressive) drugs help prevent rejection.

**renal** - Having to do with, or referring to, the kidneys.

**retransplantation** - Due to rejection or failure of a transplanted organ, some patients receive another transplant after having returned to the waiting list.

**risk pools** - High-risk health insurance plans, called risk pools, have become an important safety net for individuals who are denied health insurance because of a medical condition. About 30 States operate risk pools to provide health coverage for individuals who, because of their physical condition, are unable to purchase health insurance at any price.

**routine referral** - Hospitals are required on or before each death to call the OPO in order to determine suitability for organ, eye and tissue donation. The OPO, in consultation with the patient's attending physician or his or her designee, will determine the suitability for donation.

**Scientific Registry of Transplant Recipients (SRTR)** - In 1987, Congress passed the National Organ Transplant Act that mandated the establishment of the Organ Procurement and Transplantation Network and SRTR. The purpose of the SRTR is to provide ongoing research to evaluate information about donors, transplant candidates and recipients, as well as patient and graft survival rates. The SRTR contains historical data from October 1, 1987 to the present. The registry tracks all transplant patients from the time of transplant through hospital discharge, and then annually for up to 3 years or until graft failure or death. URREA, University Renal Research and Education Association, operates the SRTR under contract with the Federal Government.

**second opinion** - A medical opinion provided by a second physician or medical expert after one physician has provided a diagnosis or recommended treatment to an individual.

**sensitized** - Having antibodies in the blood, which means a potential recipient will react against a greater number of potential organ offers. Sensitization usually occurs because of pregnancy, blood transfusions or previous rejection of an organ transplant. Sensitization is measured by panel reactive antibody (PRA). A highly sensitized patient is more likely to react against an organ and, therefore, has a smaller pool of potential organs that he/she may receive.

**side effect** - An unintended reaction to a drug.

**Social Security Administration** - A Federal Government program best known for its retirement benefits. The Social Security Administration also administers disability benefits. Your salary and the number of years you have been covered under this program determine the amount of your monthly benefit.

**spend down** - For disabled people who have higher incomes but cannot pay their medical bills. Under this program, a person pays part of his or her monthly medical expenses (the spend down), then Medicaid steps in and pays the rest. Eligibility is determined on a case-by-case basis.

**status** - A code number used to indicate the degree of medical urgency for patients awaiting heart or liver transplants, such as Status 1, Status 2 or Status 3.

**steroids** - Naturally occurring substances, such as hormones, found in your body that help control important functions. Synthetic or manmade steroids can be used to suppress your immune system.

**supplemental policy (Medigap policy)** - An insurance policy offered by private insurance companies, not the Government, designed to pay for some of the costs that Medicare does not cover. These policies have limited coverage for medicines.

**survival rates** - Survival rates indicate what percentage of patients are still living or grafts (organs) still functioning after a certain amount of time. Survival rates are used in developing organ allocation policy. Because survival rates improve with technological and scientific advances, policies that reflect and respond to these advances are expected to improve survival rates.

**systemic blood pressure** - The top number in your blood pressure (the 120 in a blood pressure of 120/80). It measures the maximum pressure exerted when the heart contracts.

**termination of benefits** - Health insurance benefits stop when an individual has reached the lifetime maximum amount or when an individual is no longer eligible for the plan due to nonpayment of premiums or leaving his or her job.

**thoracic** - Referring to the heart, lungs or chest.

**tissue** - An organization of similar cells that perform a special function. Examples of tissues that can be transplanted are blood, bones, corneas, heart valves, ligaments, veins and tendons.

**tissue typing** - A blood test that helps evaluate how closely the tissues of the potential donor match those of the recipient.

**transplant, transplantation** - To transfer a section of tissue or complete organ from its original position to a new position, for example, to transfer a healthy organ from one person's body to the body of a person in need of a new organ.

**transplant candidate** - An individual who has been identified as medically suited to benefit from an organ transplant and has been placed on the waiting list by the transplant program.

**transplant physician** - A physician who provides nonsurgical care and treatment to transplant patients before and after transplant.

**transplant program** - A component within a transplant hospital which provides transplantation of a particular type of organ.

**transplant recipient** - A person who has received an organ transplant.

**transplant surgeon** - A physician who provides surgical care to transplant recipients.

**United Network for Organ Sharing (UNOS)** – A nationwide umbrella for the transplant community; a non-profit organization that administers and maintains the Nation’s organ transplant waiting list under contract with the Health Resources and Services Administration of the U.S. Department of Health and Human Services. Located in Richmond, Virginia, UNOS also brings together medical professionals, transplant recipients and donor families to develop organ transplantation policy.

**University Renal Research and Education Association (URREA)** - A non-profit organization established for the purpose of conducting clinical and economic studies. It administers the Scientific Registry of Transplant Recipients (SRTR) under contract with the Health Resources and Services Administration of the U.S. Department of Health and Human Services. Located in Ann Arbor, Michigan, URREA is made up of researchers, biostatisticians, programmer analysts and research assistants who have experience in studying health-related issues.

**usual and customary (U&C) fee** - The fee that providers of similar training and experience charge for a service in a particular geographical area. If your provider charges more than the U&C fee, your insurance might only pay up to the U&C amount and you might be responsible for the rest of the fee.

**varices (esophageal)** - Swollen veins at the bottom of the esophagus, near the stomach—a common condition caused by increased pressure in the liver. Varices can ulcerate and bleed.

**vascular** - Referring to blood vessels and circulation.

**ventilator** - A machine that forces air into the patient’s respiratory system when the patient is not able to breathe properly.

**virus** - A group of tiny infectious organisms that can only grow and reproduce themselves while living within cells of the body. After reproduction, the new viruses look for new cells to enter.

**waiting list (waiting pool)** - After evaluation at the transplant center, a patient is added to the national waiting list by the transplant center or organ procurement organization. Lists are specific to each organ type: heart, lung, kidney, liver, pancreas, intestine. Each time a donor organ becomes available, the UNOS computer generates a list of potential recipients based on factors that include genetic similarity, blood type, organ size, medical urgency and time on the waiting list. Through this process, a new list is generated each time an organ becomes available that best

matches a patient to a donated organ.

**waiting period** - A period of time when you are not covered by insurance for a particular problem, such as a pre-existing condition.

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

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

## ABBREVIATIONS AND ACRONYMS

Your transplant team may use these abbreviations when discussing your care. Always clarify what these terms mean, especially when you are receiving instructions about your home care or medicines. Keep a copy of this list with you so you can ask your physician any questions you may have about your diagnosis, treatment, medicines, etc.

**ac** - before meals  
**ad lib** - to the amount desired or as frequently as desired  
**ADA** - Americans with Disabilities Act of 1990 or American Diabetes Association  
**AIDS** - Acquired Immune Deficiency Syndrome  
**apmt, appt** - appointment  
**bid** - 2 times per day  
**BM** - bowel movement  
**BP** - blood pressure  
**BR** - bathroom or bed rest  
**BS** - blood sugar  
**BUN** - blood urea nitrogen  
**C&S** - culture and sensitivity  
**CAT** - computerized axial tomography (CAT scan)  
**CBC** - complete blood count  
**CCU** - Coronary or Cardiac Care Unit  
**CHAMPUS** - Civilian Health and Medical Program of the Uniformed Services, now known as **TRICARE**  
**cm** - centimeter  
**CMS** - Centers for Medicare and Medicaid Services (previously known as the Health Care Financing Administration or HCFA)  
**COBRA** - Consolidated Omnibus Budget Reconciliation Act of 1985  
**CPR** - cardiopulmonary resuscitation  
**Cr** - creatinine  
**CT** - computed tomography (CAT scan)  
**Ctr** - center (Medical Center)  
**DC, D/C** - discharge, discontinue  
**DDS** - doctor of dental surgery  
**DO** - Doctor of Osteopathy  
**DoT** - Division of Transplantation  
**Dx** - diagnosis  
**ECG, EKG** - electrocardiogram  
**ED** - Emergency Department  
**EEG** - electroencephalogram  
**EEOC** - Equal Employment Opportunity Commission  
**ENT** - ears, nose, throat  
**ER** - Emergency Room

**ESRD** – end-stage renal disease  
**Ex** - examination or exercise  
**FDA** – U.S. Food and Drug Administration  
**FUO** - fever of unknown origin  
**GI** – Gastro-intestinal  
**GFR** - glomerular filtration rate  
**gm** - gram  
**GP** - general practitioner  
**gtt, gtts** - drop, drops  
**HCFA** - See **CMS**  
**hct** - hematocrit  
**hgb** - hemoglobin  
**HHS** - U.S. Department of Health and Human Services  
**HIPAA** - Health Insurance Portability and Accountability Act  
**HIV** - human immunodeficiency virus  
**HLA** - human leukocyte antigens  
**HMO** - health maintenance organization  
**hr** - hour  
**HRSA** - Health Resources and Services Administration  
**hs** - hour of sleep  
**ICU** - Intensive Care Unit  
**IM** - intramuscular (injection)  
**IV** - intravenous  
**IVP** - intravenous pyelogram (x ray of urinary structures with dye)  
**K** - potassium  
**kg** - kilogram (1 kg = 2.2 lbs)  
**L** - liter  
**lb** - pound  
**LPN** - licensed practical nurse  
**LRD** – living related donor  
**mcg** - microgram  
**MD** - medical doctor  
**Mg** - magnesium  
**mg** - milligram  
**MI** - myocardial infarction (heart attack)  
**min** - minute  
**MRI** - magnetic resonance imaging  
**ms** - morphine sulfate  
**Na** - sodium  
**NG** - nasogastric  
**NGT** - nasogastric tube  
**NOTA** - National Organ Transplant Act  
**NPO** - nothing by mouth (no food or fluids)

**NSAID** - nonsteroidal anti-inflammatory drug  
**O<sub>2</sub>** - oxygen  
**OD** - doctor of optometry, right eye  
**od** - every day, daily  
**OPO** - organ procurement organization  
**OPTN** - Organ Procurement and Transplantation Network  
**OR** - Operating Room  
**OS** - left eye  
**OT** - occupational therapy  
**OTC** - over the counter (medications)  
**OU** - each eye  
**oz** - ounce  
**PAC** - OPTN Patient Affairs Committee  
**PAKTX** - pancreas after kidney transplant  
**pc** - after meals  
**PCA** - patient controlled analgesia  
**PharmD** - doctor of pharmacy  
**PhD** - doctor of philosophy  
**po** - orally, by mouth  
**PPO** - preferred provider organization  
**PRA** - panel reactive antibody  
**prn** - as needed  
**PT** - physical therapy  
**q** - every  
**qd** - every day  
**qid** - four times per day  
**qod** - every other day  
**R&B** - (hospital) room and board  
**RBC** - red blood cell  
**RN** - registered nurse  
**ROM** - range of motion (as in exercise)  
**RPT** - registered physical therapist  
**RR** - recovery room  
**RST** - registered speech therapist  
**Rx** - prescription  
**SC, sc** - subcutaneous (injection)  
**soln** - solution  
**SPKTX** - simultaneous pancreas and kidney transplant  
**SSA** - Social Security Administration  
**SSDI** - Social Security Disability Insurance  
**SSI** - Social Security Income  
**ST** - speech therapy  
**subcu, subq** - subcutaneous (injection)

**SW** - social worker  
**Sx** - symptoms  
**syr** - syrup or syringe  
**tid** - three times per day  
**TPR** - temperature, pulse and respiration  
**TX** - transplantation  
**Tx** - treatment  
**u** - unit  
**U&C Fee** - usual and customary fee  
**UNOS** - United Network for Organ Sharing  
**URI** - upper respiratory infection  
**URREA** - University Renal Research and Education Association  
**VS** - vital signs (temperature, blood pressure, pulse, respiration)  
**WBC** - white blood cell  
**wk** - week  
**wt** - weight  
**yr** - year  
/ - per  
< - less than  
> - greater than  
≤ - less than or equal to  
≥ - greater than or equal to  
≈ - approximately equal to

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