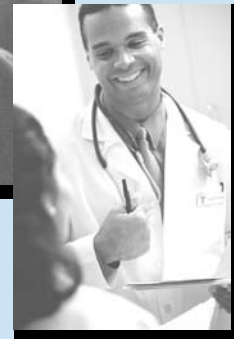

Partnering With Your Transplant Team

The Patient's Guide to Transplantation



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

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

PARTNERING WITH YOUR TRANSPLANT TEAM

THE PATIENT'S GUIDE TO TRANSPLANTATION



U.S. Department of Health and Human Services
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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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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 social workers on your transplant team are experts at many things. But to do their 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 and take an active role in your health care. Below are some tips for becoming a partner with your transplant team.

- Be as open as possible with your transplant team.
- Ask a lot of questions and gather as much information as possible 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 friends and family members you can turn to for help and moral support.
- When making decisions about your transplant, try to balance your feelings with facts. Information is available to help you with these decisions.

About This Book

This book contains information to help you throughout the transplant 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 the following topics:

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

THE TRANSPLANT EXPERIENCE

The Transplant Team

Transplant Centers

Organ Procurement Organizations (OPOs)

Support Groups and Other Contacts

The National Waiting List

Waiting for a Transplant

When an Organ Becomes Available

Options

Did you know?

The organs that can be transplanted include the heart, intestine, kidney, liver, lung and pancreas.

Transplantable tissues include the skin, corneas, heart valves, islet cells, blood stem cells, blood, blood vessels, bone marrow, and connective tissues (bone, tendons, cartilage and ligaments).

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**

There are two different types of transplant coordinators: procurement and clinical.

Procurement coordinators are responsible for the management and evaluation of the deceased donor, as well as the recovery and allocation of the donor’s organs and/or tissues for transplantation.

Clinical coordinators are responsible for the recipient’s evaluation, treatment, and follow-up care.

My clinical transplant coordinator is _____
Phone number: _____

- **Transplant Surgeon**

Transplant surgeons are the doctors who perform transplant surgeries. They have received special training to perform transplants.

My transplant surgeon is _____
Phone number: _____

- **Transplant Physician**

Transplant physicians are the doctors at the transplant center who manage your medical care, tests and medications. They do not perform surgery. Transplant physicians work closely with the clinical coordinator to coordinate your care before and after transplant.

My transplant physician is _____
Phone number: _____

- **Transplant Unit Staff Nurses**

Transplant unit staff nurses work closely with you while you are in the hospital. They take care of you and explain 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 are _____

Phone numbers: _____

- **Financial Coordinator**

A financial coordinator is a professional who helps you with financial matters and hospital billing related to your transplant. The financial coordinator works with other members of the transplant team, insurers and administrative personnel to coordinate the financial aspects of your care before, during and after your transplant. He/she helps you determine 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 handle 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 important 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 a transplant? _____

What are the benefits and risks of a transplant? _____

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? _____

Can I register on the waiting list at more than one center? _____

How long do most patients with my blood and organ type wait at this hospital for a transplant? _____

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? _____

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 an organ for a patient? _____

How many surgeons at this hospital perform my type of transplant? Will they always be available when an organ is offered to me? _____

Who will tell me about the transplant process? _____

Is there a special nursing unit for transplant patients? _____

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 living donation process? _____

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? _____

Can I meet other transplant recipients? _____

How long will I have to stay in the hospital after the transplant? _____

What sort of appointments or tests will I have after the transplant? _____

Will I be asked to take part in research studies? _____

WHAT ARE TRANSPLANT CENTERS?

A transplant center, also called 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 to 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, such as a lung program, a heart program, and a kidney program.

As of May 30 2008, there were 254 transplant centers in the United States. Among these, there were:

245	Kidney transplant programs
127	Liver transplant programs
146	Pancreas transplant programs
29	Pancreas islet cell programs
45	Intestine transplant programs
130	Heart transplant programs
52	Heart-lung transplant programs
65	Lung transplant programs
839	Total number of transplant programs

WHAT ARE ORGAN PROCUREMENT ORGANIZATIONS (OPOs)?

Organ procurement organizations (OPOs) are the link between the deceased organ donor and the transplant recipient. OPOs are responsible for recovering the organ, keeping the organ viable until it is transplanted, and getting the organ to the recipient's transplant team.

Currently, 58 OPOs provide organ recovery services to hospitals within their designated service areas (which can be a large city, a whole state, or a larger area). 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, recipients, and a medical director who is usually a transplant surgeon or physician.

When a hospital staff member identifies a patient as a possible organ donor, the OPO is contacted. When a donation is made, the OPO organ procurement coordinator uses the OPTN database to match the donated organs with patients waiting for a transplant. All OPOs allocate donated organs according to OPTN policies, which make sure each organ goes to the best candidate at that time for that particular organ. See www.optn.org for information about allocation policies.

Organ procurement coordinators are highly trained professionals who carry out the OPO mission and services. OPO services include:

- Completing a thorough medical and social history of the potential donor to help determine if organs and tissues can be transplanted.
- Working with hospital staff to offer the option of donation to the potential donor family or honor the deceased's expressed wish to donate.
- Making sure informed consent for the donation is obtained.
- Managing the medical care of the donor until organ recovery.
- Entering the donor information into the OPTN computer system to find a match for the donated organs.
- Coordinating the organ recovery process with the surgical team(s).
- Providing follow-up information to the donor family and hospital staff about the outcome of the donation.

The above OPO services are available 24 hours a day, 7 days a week, whenever an organ becomes available.

OPOs also educate hospital staff and the general public about the need for organ and tissue donation. Educational activities may include training programs for volunteers and partnerships with other community organizations. OPOs also educate the healthcare team about the donation process and provide these professionals with services related to donation and transplant issues in the hospital setting (e.g. directed donation, death record reviews, Joint Commission reporting: www.jointcommission.org). To locate the OPO in your area, you can view the list of OPOs at www.organdonor.gov, www.aopo.org, or call UNOS at 1-888-894-6361 for assistance.

An important part of making the decision about who will receive an organ is location. Most OPOs provide organs to transplant candidates in 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.

The following chart shows how long each organ type can typically be preserved (or kept viable) once removed from the body.

Organ Preservation Times	
Heart	4 – 6 hours
Liver.....	12 – 18 hours
Kidney.....	24 – 48 hours
Heart-Lung	2 – 4 hours
Lung	2 – 4 hours
Pancreas	12 – 18 hours

SUPPORT GROUPS AND OTHER CONTACTS

A variety of organizations provide different types of services for transplant patients and their families. These organizations can include non-profit voluntary health organizations, for-profit companies, and Government agencies. Such services include educational materials, patient advocacy (promoting issues that are important to transplant patients) and financial support.

Please note that it is unlikely that one agency will cover all of the costs for a patient. Since many organizations have limited funds, they may only be able to help with direct transplant costs, food and lodging, or medication costs. Many groups can help you look for other funding sources, ask insurance companies to reconsider your 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 booklet.

Why Join a Support Group?

Joining a support group can be helpful to you, as well as your family and friends. Talking about your concerns, fears, difficulties, experiences and successes with other patients and their families can be a comfort to you and your family. This process can also give you encouragement and confidence. Listening to others in the same situation can provide a feeling of security and remind you that you are “not alone.” Others may help you release difficult emotions and anxiety. Sometimes there is nothing better than to share your thoughts with someone who has “walked in your shoes” and knows how you feel.

It can be encouraging to see how recipients who have had their transplant for several years, and their families, are coping and 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. Support group guest speakers talk about transplant trends and data, new medications, insurance issues, stress relief, and other important topics. Members discuss 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 ways to promote 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 type of support doesn’t fit your needs, try another. A list of some support groups in each State can be found at www.transplantliving.org (Choose Community> Support Groups) or you can call the UNOS patient services line at 1-888-894-6361 for this information.

Hospital support groups

These groups are usually run by the hospital social worker, transplant coordinator or another member of the transplant team. They may include patients who are immediately pre- or post-transplant or those who 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. Members who have already had their transplant can 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 raise funds to support research, as well as their own activities. They can help shape healthcare policy. Some focus on a particular organ.

Internet support groups (news and chat groups)

These groups provide information in the comfort of your home. You can ask personal questions without being 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 give 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 and the factors that affect waiting time.
- 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, a transplant center adds him or her to the transplant patient waiting list through the computer. The OPTN computer, located at the United Network of Organ Sharing (UNOS), stores and accesses the information for donor matching. When an organ is donated, a list of transplant candidates who match that organ is provided by the computerized database at UNOS (which is in Richmond, VA, but serves all of the United States).

Transplant candidates are listed in order of priority based on a certain set of criteria (according to OPTN/UNOS policies). Through this process, a new list is generated to identify the best matched candidate with the donated organ each time an organ becomes available. Organ placement specialists in the OPTN/UNOS Organ Center run matches between donor organs and transplant candidates 24 hours a day, 7 days a week.

Rules have been made to determine how transplant candidates are ranked on the waiting list for each type of organ. These rules, or allocation policies, were developed by patients and transplant professionals to make sure 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, waiting time, 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.

Examples of 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 help with 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 waiting for your transplant, you will be asked to carry a beeper or a cell phone. The transplant team will need to contact you quickly when an organ is available. By carrying a beeper/cell phone, 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 candidate 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 some questions to determine if you have any signs of infection. These signs include a cough, a fever, or a burning feeling when you urinate. If you do not have signs of an infection, 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.
- Don't hesitate to ask your transplant team any questions.

- Ask your transplant team when you should start carrying a beeper or cell phone. Change your beeper battery monthly and keep your cell phone charged to be sure they are always working.
- To reduce the chances of getting 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 people who are sick and ask family and friends not to visit when they are sick,
 - ask your team about how to clean 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), portable music player, extra batteries, books (large print is helpful), spiritual materials, magazines, crossword puzzles, jigsaw puzzles, photographs, paper and pen, makeup, watch or small battery-operated clock, addresses and phone numbers of friends and family, and long distance calling card numbers.
- 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 status on the waiting list. Unfortunately, UNOS cannot provide this information. Patients should discuss this with their transplant team. According to OPTN policy,

- The transplant program must notify the patient in writing when he/she has been placed on the transplant patient waiting list, including the date the patient was listed. This notification must be sent within 10 business days of placement on the waiting list.
- 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 assists with communication between transplant centers and their patients.

The Organ Matching Process

An organ procurement organization (OPO) plays an important role in the organ matching process. When organ donation occurs, the OPO procurement coordinator works with many people to help the hospital staff keep the donor in the best possible medical condition until the

organs are recovered. The OPO procurement coordinator also identifies appropriate transplant candidates and arranges 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 when certain medical criteria are met.
2. The OPO procurement coordinator evaluates the potential donor.
3. Consent/authorization for donation is obtained.
4. Information about the donor is entered into the OPTN computer.
5. A list of potential recipients is generated through a “match run.”
6. The OPO procurement coordinator notifies the potential recipient’s hospital of the availability 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. For instance, the organ may not be the best possible match for a candidate. It may not be the right size or the risk of rejection may be considered to be too great. If an organ is turned down for a potential recipient, it is offered to the next person on the list generated by the computer for that particular organ. Every possible effort is made to place donated organs. Talk with your transplant surgeon about what types of organ characteristics are right for your needs.

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 a brain tumor that has not metastasized (spread to another part of the body).

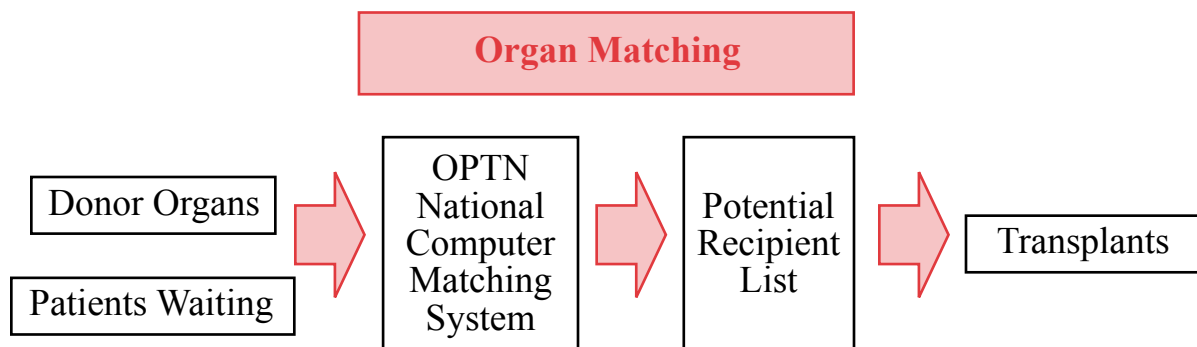
There are two legal ways to pronounce death. Death may be pronounced when a person’s heart stops beating (cardiac death) or when the person’s brain stops functioning (brain death). Brain death occurs when blood, and the oxygen it carries, cannot flow to the brain. The person’s heart is still beating 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 tissues remain viable (healthy) and can be removed for transplantation. The organs and tissues 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 involvement of many different people:

1. **The deceased organ donor.** This person has been declared dead and can now donate organs 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. A deceased person can also serve as a donor if his/her next-of-kin consented to donate the organs after the donor's death.
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 transplant team.
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 the contact information for the deceased donor's hospital (at the 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 best match the available 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 physician, transplant surgeon, transplant coordinator, social worker, and financial coordinator.
5. **The transplant candidate.** This is an individual who has been medically identified as someone who could 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 for whom an organ from a specific deceased organ donor is to be offered.

See more detailed information about the participating organizations in the section on Transplantation in America.



Organ Sharing and Factors That Affect Waiting Times

When an organ becomes available for transplantation, the donor's information is entered into the OPTN database. The database searches thousands of transplant candidates on the national waiting list and locates those matching the donor. Each organ is unique, and characteristics such as size and blood type will affect allocation (who receives the organ). The transplant candidate also has specific needs, such as medical urgency, that may affect allocation.

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.

Factors that can 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 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 are more important for you than others.

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 (who is highly sensitized) 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 match. People often have a high PRA if they have received blood transfusions, have had a prior transplant or have been pregnant.

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

Livers

Livers are allocated according to the candidate's MELD (Model for End-Stage Liver Disease) or PELD (Pediatric End-Stage Liver Disease) score, blood type, and his or her geographic location. The score (ranging from 6 to 40) represents a patient's risk of dying within 3 months. The scores are calculated by objective medical criteria that measure the patient's condition. They are updated on a regular basis so that their scores will reflect their current medical condition. Your transplant team can answer your questions about the scoring methods.

Hearts

Hearts are allocated according to the candidate's degree of medical urgency, blood type, and geographic distance from the site of donation. Medical urgency for adult and pediatric heart transplant candidates is defined by a status (i.e., status 1A, 1B, or 2) that is based upon medical criteria.

Lungs

Lungs are allocated according to the candidate's degree of medical urgency, blood type, and geographic distance from the site of donation. The lung allocation score (ranging from 0 to 100) is used for lung candidates who are 12 years of age or older. The lung allocation score accounts for medical urgency on the waiting list, as well as survival after transplant. Candidates 12 and older are allocated lungs based on their score, blood type, and geographic distance from the site of donation. Currently, candidates who are less than 12 years of age receive priority for lung offers based on waiting time, blood type, and geographic location (from the site of donation).

Intestine

Intestines are allocated according to the candidate's blood type and size-compatibility. Geographic location (from the site of of donation), the candidate's degree of medical urgency, and waiting time are also important factors when matching a donor intestine to a transplant candidate.

You can learn more about organ allocation policies by visiting www.optn.org or by calling the UNOS Patient Services line at 1-888-894-6361.

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

When you list at a transplant hospital, you are generally considered for organs from donors in the local area first. You may choose to register for a transplant at more than one transplant hospital to be considered for donor organs that become available in other areas. You may or may not benefit

from listing at multiple centers in the same local OPO allocation area. This is because waiting time priority is first calculated among candidates at all hospitals within the local donation area, not for each hospital individually.

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 listed 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. For information about transferring waiting time, contact the transplant hospital directly. The transplant teams at the original hospital and the new hospital are responsible for exchanging 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 transplant candidates 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 transplant patients. The OPTN and SRTR collect data from individual transplant centers and OPOs and make it available to patients. (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. The first successful living donor transplant was performed between identical twins in 1954. Since that time, thousands of patients have received successful transplants from living donors. In 2007, more than 6,300 living donor transplants were performed. With more than 100,000 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.

Parents, children, brothers, sisters, and other relatives may be 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.

NOTES:

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FINANCING YOUR TRANSPLANT

The Cost of Transplantation

Insurance

Medicare and Medicaid

TRICARE

Fundraising

Prescription Drug Assistance

The Cost of Care Following Transplantation

Did you know?

About 78 people receive organ transplants every day in the United States, however . . .

About 18 people die each day waiting for a transplant.

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
- Hospital stay and surgery
- Additional hospital stays for complications
- Follow-up care and testing
- Anti-rejection and other drugs, which can cost more than \$10,000 per year
- Fees for surgeons, physicians, radiologist and anesthesiologist
- Fees for the surgical 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 transplant center before and for a while after your transplant. Some centers offer free or low-cost lodging. You may need to make flight arrangements 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 transplant costs from a single source. For example, you may be able to finance the transplant procedure through insurance coverage and pay for other expenses through savings accounts and other private funds, or by selling some of your assets. Most likely, you will have to use 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.

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 concerns or questions, 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 the name of the person with whom you spoke, 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

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

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.naic.org.
- 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. See this website for more information: www.medsave.com/select-your-state.html

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 to see if these benefits apply to you by calling, toll-free at 1-877-267-2323 or visiting their website at www.medicare.gov.

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 requiring dialysis or a kidney transplant (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, pancreas, and intestinal transplants, if you already have Medicare due to age or disability
- Hospice care

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 and physical and occupational therapy)
- 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 below 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 Medicare and employer group health insurance, 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 health insurance program for all seven of the uniformed services. 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 1-303-676-3526.

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.

This information is only a brief summary and is not intended as complete information. New laws and rules are made every year that 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. Below 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, surgery and follow-up care? _____

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

NOTE: HRSA's Reimbursement of Travel and Subsistence Expenses Toward Living Organ Donation Program provides assistance for travel and subsistence expenses associated with living organ donation. Preference is given to those individuals most likely to be otherwise unable to meet such expenses. The program also provides reimbursement for up to two relatives or other individuals to accompany the living donor. Under the program authority, individuals may not receive reimbursement from the program if reimbursement is available: (1) under any State compensation program, an insurance policy, or any Federal or State health benefits program; (2) by an entity that provides health services on a prepaid basis; or (3) by the recipient of the organ. For more information, contact the National Living Donor Assistance Center at 1-703-414-1600 or www.livingdonorassistance.org.

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

Partnership for Prescription Assistance

Many drug companies provide medicines for patients who need financial assistance. The Partnership for Prescription Assistance can provide you with a list of participating programs in each State. To request the directory, call 1-800-762-4636 or visit www.pparx.org. Your transplant team can also provide you help.

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

A few programs and initiatives can help with finances for your care after transplantation:

- 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 your local vocational rehabilitation 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.

The following 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 make sure that the job match is successful. If you have 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 source 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 re-enter 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 three to five months. 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 \$940 (\$1,570 for people who are blind) or more a month after deducting disability-related work expenses in the year 2008.
- 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.

In 2008, if you earn more than \$670 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 \$940 (\$1,570 if you are blind) a month or less, you will continue to receive benefits. If you earn more than \$940 (\$1,570 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 \$940 (\$1,570 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 \$940 (\$1,570 if you are blind). You will not have to complete a new application within this time period to qualify.

The rules are different for people who are blind, so please contact your Social Security office.

Americans with Disabilities Act

The Americans with Disabilities Act (ADA) of 1990 prohibits discrimination against people with disabilities who wish to work. To be protected under the ADA, you must have a physical or mental impairment that restricts one or more major life activities. You must also be able to perform the essential functions of your current job or a job that you are seeking, either with or without “reasonable” accommodations (see below) from your employer. The ADA specifically excludes drug abuse from the disabilities it covers. A person who currently uses alcohol is not automatically denied protection. You can get more information by calling the ADA Information Line at 1-800-514-0301 (TTY: 1-00-514-0383) or visiting their website at www.ada.gov

Employer responsibilities

Employers are required to make reasonable accommodations for disabled workers, such as

- Improving access to work facilities for disabled persons
- Restructuring job duties or work schedules
- Reassigning disabled workers to other positions
- Buying new devices (such as a wheelchair ramp) or modifying existing ones (such as lowering wall shelves) to assist disabled workers
- Modifying job examinations, training materials or policies

If an employer can prove that an accommodation would be too difficult or expensive to provide, the employer may not have to provide the accommodation. Also, if you have failed to inform your employer of your condition, the company will be under no obligation to accommodate you, because it will have had no prior knowledge of your disability status.

The ADA does not cover all employers. The Act applies to private companies, State and local governments and employment agencies and labor unions that employ 15 or more workers for more than 20 weeks.

Under ADA regulations, an employer cannot make you take a medical examination before you are considered for employment, although pre-employment drug testing is allowed. The Act does allow a routine medical examination after a job offer has been made and before you begin work, but the examination must be given to all new employees. You may be asked to voluntarily provide a medical history.

In a job interview, you may be asked about your disability only if the company can prove that the questions relate directly to the necessities of the job and meet certain other considerations.

Federal Rehabilitation Act (FRA)

The Federal Rehabilitation Act (FRA) offers protection against discrimination by organizations that receive more than \$10,000 in Federal funds. Many State and local governments have disability laws similar to the ADA and the FRA. Most vary in coverage by jurisdiction. Check with a local attorney to determine if a State or local disability law would provide you with more protection.

LIFE AFTER A TRANSPLANT

Recovery After Your Transplant

Medications – Protecting Your Transplant

Post-Transplant Tests

Rehabilitation – Making Healthy Lifestyle Decisions

Did you know?

In 2007 more than 22,000 patients began new lives thanks to deceased organ donors who had made the decision to donate and 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.

RECOVERY AFTER YOUR TRANSPLANT

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. It is also important to work with the medical professionals involved in your care and follow your doctor's recommendations, including taking your medication as instructed. 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 problems and stay much longer. Some people feel well when they go home. Others are able to go home, but are still very ill. Your experience 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 will need to arrange for family or friends to help you. 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.

You can get additional information about the Family Medical Leave Act by calling 1-866-4-USWAGE (TTY: 1-877-889-5627) or visiting this website: www.dol.gov/esa/whd/fmla/

MEDICATIONS – PROTECTING YOUR TRANSPLANT

Your body protects itself against foreign invaders, such as germs, through 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 also try to attack (reject) it. 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 problems from all these different drugs.
- Always check with your transplant physician or coordinator before changing your medications (including changing doses).
- You should only take medications that are prescribed by a doctor who knows you have had a transplant.

Sometimes you can have adverse (bad) reactions to the medications. Many people have side effects from their anti-rejection drugs. Below are some 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	high cholesterol	swelling of feet, hands, abdomen, or face
anxiety	increased appetite	tingling hands and feet
bone disease	increased blood sugar	tremors (shaking)
diarrhea	kidney damage	trouble sleeping
gum overgrowth	mood swings	unwanted hair growth
hair loss	nausea	vomiting
headache	sensitivity to the sun	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? Whom should I call? _____

What should I do if I miss a dose of medicine? _____

Whom 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? _____

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

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

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

Which over-the-counter medicines should I avoid (such as ibuprofen)? _____

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

Should I avoid people who have had a vaccine? Which vaccines? For how long? _____

Is it OK for me to have alcohol? If so, what kind? How much? How often? _____

Questions for your pharmacy

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

What if I have no insurance coverage for medications? _____

Will you waive my co-pay? _____

Do you offer a discount if I pay with a credit card or check? _____

Do you charge for delivery? _____

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

Do you always keep my medications in stock? _____

Do you have any educational materials you can send me? _____

Tips about your medicines

- Learn everything you can about your medicines. Your physician, transplant coordinator, pharmacist, and support group 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 any of your medications.
- All medicines should be kept in their original labeled containers, in containers made for medicines or in foil wrap until used. Follow the directions carefully to ensure the potency (effectiveness) of your medicines.
- Some medicines have to stay in their original packaging. 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 pendant 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 a lot.
- 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 each customer 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 of at least 30 SPF to avoid skin cancers.
- Do not take all your medicines at one time because it is more convenient. The doses are spread out to make sure the proper drug level is in your body.

Tips about organizing your medications

To keep your medication schedule from interrupting your daily routine, plan ahead, organize your time and consider the following tips:

- To help organize your medicines, use tools 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 resealable 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 they 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.
- 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. Some medications need to be kept in the refrigerator.

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 APPOINTMENTS AND TESTS

Office or Clinical Visits

It is very important to keep all of your follow-up appointments with the transplant team. You will have many appointments right after the transplant. Your transplant team will usually provide all of your health care in the first few months after the transplant. When you are stable and doing well, the team will advise you to set up a regular schedule of visits with your primary care doctor, specialist, or family doctor. Most transplant teams will want to see you at least once a year for life, but it is important to understand they are not your primary doctor.

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 on page 47 gives a description of tests you may be required to complete, 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 let you and these professionals know about problems before they are too serious. Also, treatments can be started early. Depending on the test, here are a few questions to ask:

Can I eat or drink before blood is drawn? _____

If not, how many hours before the test should I stop eating or drinking? _____

Can I take all of my medications before I have blood drawn? If no, which ones should I not take?

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 Tests and Other Procedures	Description of Test	My Normal Value
ALT: alanine aminotransferase	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 ₂)	Measures respiratory and kidney 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 blood clotting	
AST; aspartate aminotransferase	Monitors liver function	
Serum amylase	Monitors pancreas function	
Sodium	Measures kidney function	
Urine amylase	Monitors pancreas function	
Biopsy (small amount of tissue from the transplanted organ removed)	Assesses condition of organ (function, rejection, damage)	
Bronchoscopy	Visualizes airway healing and diagnoses lung infection or rejection	
Cholangiogram	Visualizes liver and bile duct function	
Endoscopic retrograde cholangiopancreatography (ERCP)	Visualizes bile and pancreatic duct function	

Other Tests

You may need to complete several tests yourself on a regular basis. Your transplant team will show you how to complete 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)
Weight		
Temperature		
Blood Pressure		
Pulse		
Blood Sugar		
Home Spirometry		

Daily Vital Signs

Date	Temperature		Weight	Blood Pressure	Pulse
	AM				

REHABILITATION – MAKING HEALTHY LIFESTYLE DECISIONS

Exercise

While you are in the hospital after your surgery, you will slowly increase your activity. 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 every day. Check with your transplant team before you begin an exercise program. This is especially important if you enjoy aggressive sports (like tackle football or boxing) or high impact activities (like jogging and high level aerobics).

It is common for transplant recipients to be afraid they may harm their new organs. Regular exercise will not harm your new organ. It helps your heart, muscles and circulation, and helps you control your weight and blood pressure. Exercise burns calories, lowers cholesterol and helps you maintain strong bones. It can also help you relax, sleep better, and improve both your overall physical and emotional well-being.

Tips about exercise

Be realistic about your goals. The longer you have been ill, the longer it will take to get your strength back. Your transplant team can refer you to a physical therapist or help you plan an exercise program. You can begin with walking. Start out gradually and add to your program as your strength and endurance increase.

Listen to your body. If you feel pain or extreme tiredness, you have done too much. Be sure to warm up and cool down with each session. Drink extra fluids on hot days and carry water with you. Ask your transplant team about public pools, hot tubs, and spas. You may not be able to use them if you are at risk for infection due to the anti-rejection medicines.

We all have good days and bad days. If you're feeling tired, exercise for a shorter period of time or take the day off. If you have pain or pressure in your chest, neck or jaw, unusual shortness of breath, a rapid or irregular heart beat, dizziness or light headedness, unusual sweating, nausea or abnormal pain, **stop your exercise and call 911 if you feel it is an emergency. At the very least, call your transplant team and tell them about your response to exercise.**

Tips to make exercise more fun: First, there's nothing to it, but to do it!

- Join a nearby community center or health club and take a friend with you.
- Exercise with a friend—your dog is always up for a walk.
- Schedule exercise when it is convenient and when you feel energetic, not tired.
- Walking costs nothing more than a good pair of walking shoes. It can be done anywhere, even in shopping malls during bad weather.
- Choose activities you enjoy. Have fun and reward yourself.

Diet

You are what you eat

A healthy diet plays an important role in healing. Controlling your weight and cholesterol is important for everyone, not just transplant patients. The good news is that after your transplant, you will probably be on less severe dietary restrictions than you were before— but you still must make sensible choices. Your dietician can help you plan a diet that fits your needs, likes and dislikes.

In general, you may have a better appetite after your transplant. Some of the drugs you will be taking may cause your body to use and store foods differently. Some drugs may increase your appetite, causing you to gain weight. Maintaining a normal weight will help keep you from developing heart disease, high blood pressure and diabetes. Learn to read food labels, eat plenty of fruits and vegetables, and drink plenty of water (unless you are told to limit fluids), especially during hot weather and strenuous exercise.

Proteins help build and repair muscles and tissue, help you heal after surgery, and are found in meat, poultry, fish, eggs, nuts and beans.

Carbohydrates provide fuel and energy. Since steroids make it difficult for your body to use carbohydrates, you may gain weight. Eat fewer “simple” carbohydrates like sugar, sweets, and carbonated soda. Eat more “complex” carbohydrates like cereals, vegetables, whole grain pasta, bread, brown rice, and potatoes.

Fats should be eaten sparingly. Limit saturated fats and cholesterol to control your weight and your cholesterol levels. Choose skim milk and low fat dairy products. Eat lean meat, poultry and fish, and trim the fat from meat. Avoid fried foods. Use vegetable oils and limit the number of eggs yolks (high in cholesterol) that you eat. Some medicines can increase your cholesterol level. Fiber can decrease cholesterol and keep your heart healthier.

Salt (sodium) makes you thirsty. Consequently, you drink and retain more water. This can increase your blood pressure. Some immunosuppressive medicines, such as steroids may make your body hold water. You may need to stay away from salty foods such as smoked meat and fish, canned soups, convenience foods and snack foods. Ask your doctor if you should limit salt in your diet.

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

Arbor Research Collaborative for Health

Did you know?

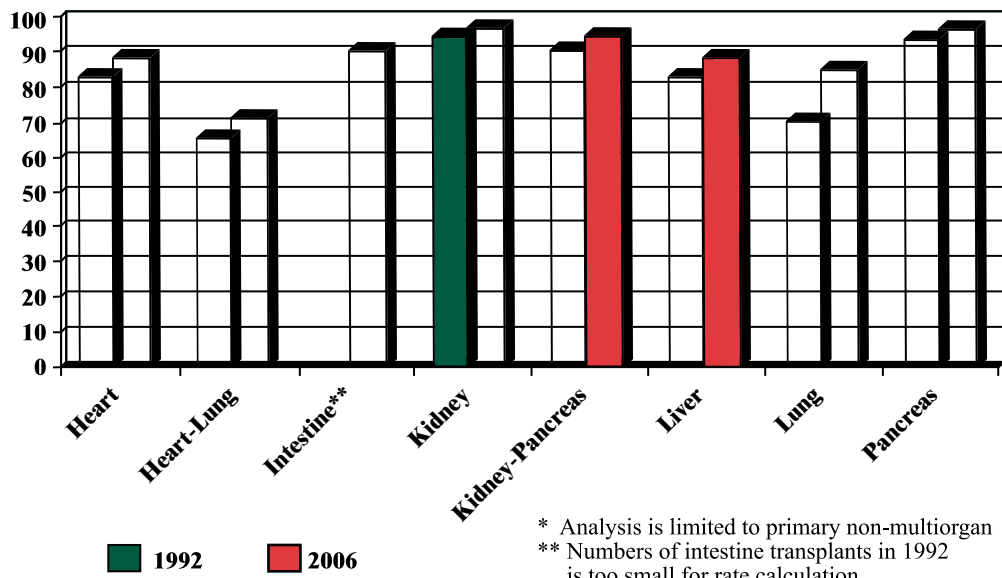
Organs that can be donated while donors are alive include the kidney, parts of the liver, lung, pancreas and intestine.

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 have either increased or remained stable across all organ transplants. Within the following graph the green bars show the percentage of transplant recipients who received various organs in 1992 and survived one year after their transplant. The red bars show the rates 15 years later.

One-Year Post-Transplant Patient Survival Rate*



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 sometimes feel helpless, you can actually do a lot to help promote awareness of the organ shortage and increase organ donation.

Many transplant candidates, recipients and their families are very active in the community, spreading the word about the importance of becoming an organ donor. You can help create donation 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 Donate Life America, OPOs, the National Kidney Foundation, the Transplant Recipients International Organization (TRIO), or the Minority Organ and Tissue Transplant Education Program (MOTTEP), and other groups listed 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 with others to be an organ and tissue donor is as important as making the decision itself. 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 help you in educating your family, friends and community.

Who can become a donor?

Everyone should consider being an 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, islet cells, connective tissue (bones, tendons, cartilage, ligaments,) bone marrow, blood vessels and blood.

Will my decision to donate affect the quality of my medical care as a patient?

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. The doctors who are working to save your life are entirely separate from the transplant team.

Will donation interfere with having an open-casket funeral?

Donation does not change the way one looks in a casket. Organ removal takes place in an operating room and under sterile conditions like any other surgery.

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 if they are medically suitable to be donated. Therefore, people of any age wishing to become organ and tissue donors should sign up on a donor registry and tell their family that they wish to donate.

What medical conditions exclude a person from donating organs?

Organs are evaluated at the time of death. HIV and cancer normally prevent people from donating organs. Those with other medical conditions who wish to donate should sign up on their state's donor registry 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. As indicated earlier, 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 deciding who receives an organ.

A PUBLIC HEALTH PARTNERSHIP

The following section describes 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 11 different agencies with hundreds of 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.

Office of the Secretary (OS) of HHS

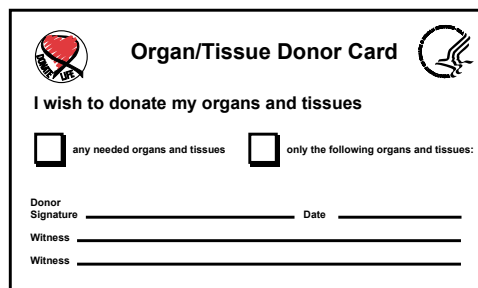
The Secretary of HHS advises the President about the health and welfare of the country and administers these functions through the OS and the agencies within HHS. The Secretary also makes sure that the programs operate in the public's best interest. Through the National Organ Transplant Act (NOTA) of 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, including patient and graft organ survival rates. The SRTR also tracks all transplant patients from the time of transplant through hospital discharge, and then annually 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.

The “Gift of Life Donation Initiative” includes:

- The ***Workplace Partnership for Life***: Workplace campaigns educate employees and organizational members about the need for organ, tissue, blood stem cell, and blood donation. It involves partnerships with businesses, organizations, unions, associations, government offices, and other places of business and volunteerism. For example, corporations and organizations of all types and sizes can sign up as *Workplace Partners* with the Division of Transplantation at www.organdonor.gov and can obtain free educational materials for local campaigns. As of July 2008, approximately 11,300 partners have joined the Workplace Partnership for Life.
- The ***Model Donor Card***: This card provides options for designating whether all or only certain organs and tissues will be donated, as well as space for two witnesses’ signatures. Donor cards are available from the Health Resources and Services Administration by calling 1-888-ASK-HRSA or by downloading from www.organdonor.gov.



- ***Donor Registries: An Exploration of Mechanisms to Assure Communication of an Individual’s Intent to Donate***. A national forum on donor registries was held in November 2001, and a consensus was reached that a national donor registry was not needed at that time because of the development of state donor registries. As of July 2008, more than 40 states have donor registries and more states have registries that are under development.
- ***Education Program for Secondary Schools***: Decision: Donation, an education program

for driver's education or other high school classes was created in 2004, and contains lessons appropriate for science, health, English, social studies, and math classes, as well as a core lesson for any class. It is available at www.organdonor.gov.

- ***Organ Donation and Transplantation Breakthrough Collaborative:*** The goal of the *Breakthrough Collaboratives* is to increase the number of deceased donor organs transplanted in the U.S. to 35,000 by the year 2013. In collaboration with the Institute for Healthcare Improvement, organ procurement organizations, donor hospitals, and national organ donation and transplantation organizations, the best practices that lead to high rates of organ donation are being shared and adopted by the Nation's largest hospitals. To reach this ambitious goal, each donation service area must achieve the following: 75% donation rates; 3.75 organs transplanted per donor; and at least 10% of its donors result from donations after cardiac death (DCD).

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. CMS also has some responsibility to provide oversight of transplant programs and OPOs.

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 by CMS. 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.

In 2007, to enhance quality transplantation and efficient usage of donated organs, CMS issued a regulation to set forth the conditions of participation for Medicare-approved transplant centers. This rule is outcome-focused. It updates outcome measures of Medicare-covered transplants, safeguards the health and safety of patients and living donors, and strengthens oversight of transplant centers.

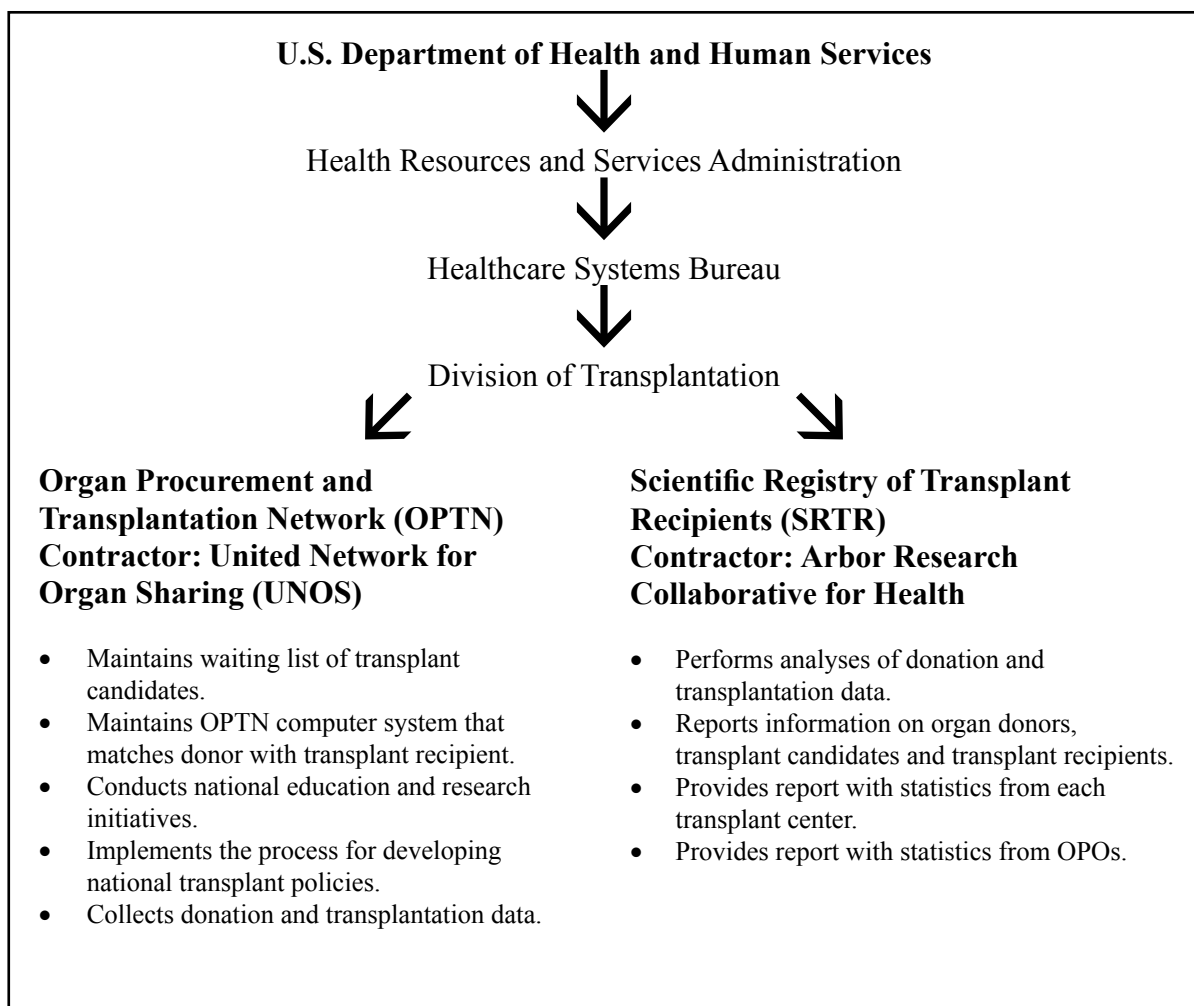
A related CMS rule was issued in 2006 which addresses OPOs. The OPO final rule establishes conditions for coverage for OPOs that include process and outcome performance measures, which are intended to further improve OPO performance.

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 services 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 Healthcare Systems Bureau, Division of Transplantation (DoT). HRSA encourages donation of organs, tissues and blood stem cells 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 currently with UNOS for the operation of the OPTN, and with Arbor Research Collaborative for Health for the operation of the SRTR. The Blood Stem Cell Transplantation Program at HRSA oversees the C.W. Bill Young Cell Transplantation Program and the National Cord Blood Inventory. The Public and Professional Education Branch develops and implements numerous programs to increase public commitment to become donors and to increase understanding of organ donor and transplantation issues.

Grant programs

The Public and Professional Education Branch and The Operations and Analysis Branch of DoT are responsible for helping to develop programs that will increase awareness of the critical need for organs and tissue, support the development of organ donor registries, increase knowledge of donation and transplantation clinical issues, and provide some support for living donors.

These grant programs include:

- *Social and Behavioral Interventions to Increase Organ and Tissue Donation*
- *Public Education Efforts to Increase Organ and Tissue Donation*
- *State Donor Registry Support*
- *Clinical Interventions to Increase Organ Procurement*
- *Reimbursement of Travel and Subsistence Expenses Toward Living Organ Donation*

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 improved transplant survival rates. At the same time, the number of people placed on the waiting list to receive an organ increased. Because there were not enough organs for all who needed them, a system had to be developed to fairly and appropriately allocate 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, people to receive transplants and it helps assure the best use of each organ. Unfortunately, the number of organs donated is still not enough to meet the demand.

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?

- Transplant candidates
- Transplant recipients
- Family members of transplant candidates and recipients
- Family members of organ donors
- Living organ donors
- Nurses, social workers, surgeons, physicians and lab technicians who specialize in transplantation
- Members of the general public who have an active interest and involvement in donation/transplantation
- Transplant hospitals
- Organ procurement organizations
- Transplant organizations

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.

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 Donate Life America at 804-782-4920 or visit its Web site at 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 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 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 OPTN:

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 21 standing committees within the OPTN system:

- Ad-Hoc International Relations Committee
- Disease Transmission Advisory Committee
- Ethics Committee
- Executive Committee
- Finance Committee
- Histocompatibility Committee
- Kidney Transplantation Committee
- Liver/Intestinal Transplantation Committee
- Living Donor Committee
- Membership and Professional Standards Committee
- Minority Affairs Committee
- Operations Committee
- Organ Availability Committee
- Organ Procurement Organization Committee
- Pancreas Transplantation Committee
- Patient Affairs Committee
- Pediatric Transplantation Committee
- Policy Oversight Committee
- Thoracic Organ Transplant Committee
- Transplant Administrators Committee
- Transplant Coordinators 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 proposed policies and send your comments back to UNOS. This is perhaps the most important way you can participate in the policy making process. Your voice will be heard!

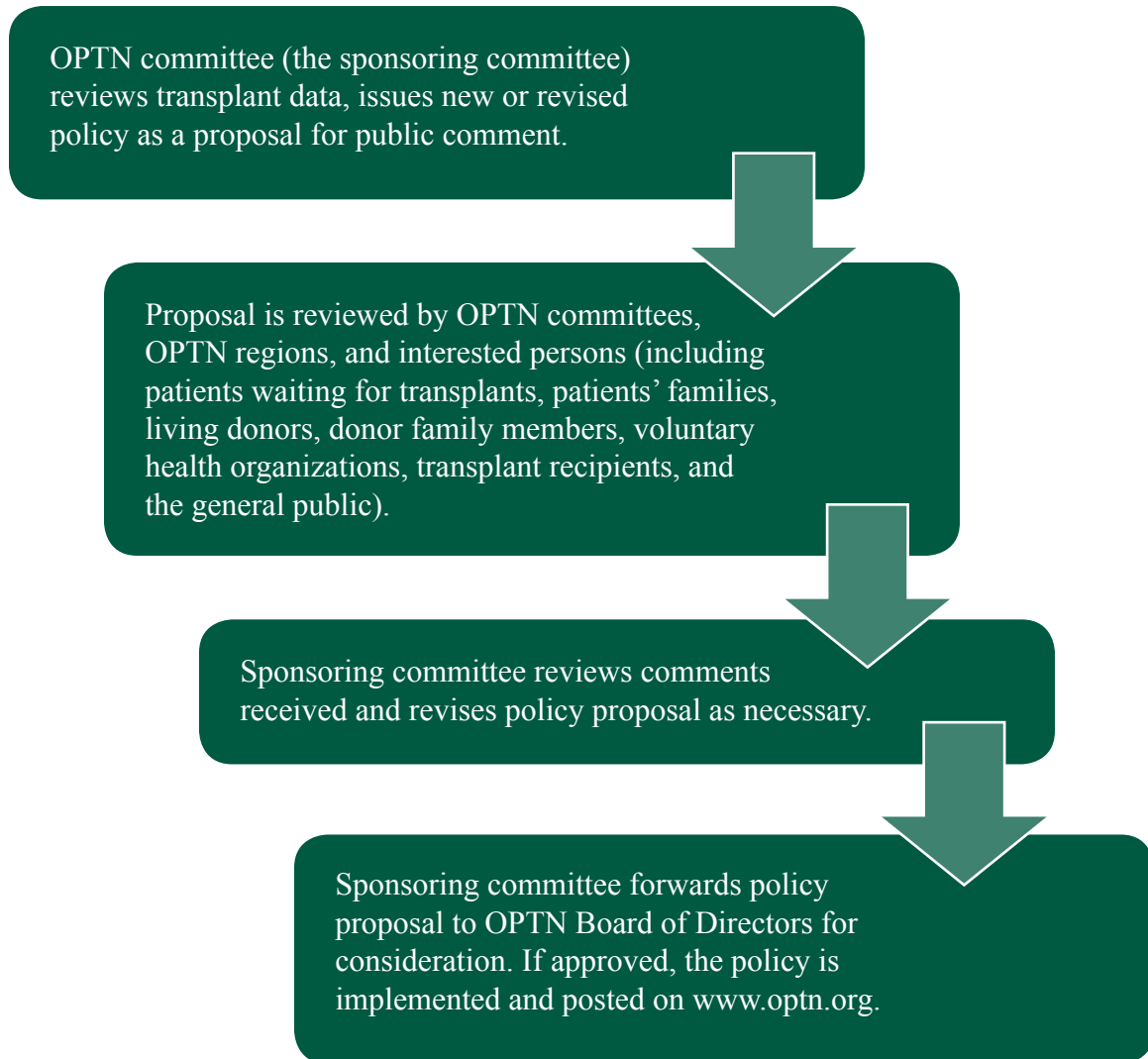
4. Visit the OPTN or UNOS Web sites and read and respond to issues that are available for public comment. These can be found at www.optn.org (Choose Policies and Bylaws > Public Comment) and at www.unos.org (Choose What We Do > Policy Management > Public Comment).

5. Contact the Division of Transplantation within HHS at 301-443-7577, or send postal mail to the Division of Transplantation, Room 12C-06, Parklawn Building, 5600 Fishers Lane, Rockville, MD 20857, or send email to comments@hrsa.gov.

NOTES:

How OPTN Policies Are Made

Transplant patients and professionals face 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.

The UNOS community includes 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 data about every transplant occurring in the U.S. 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, the OPTN Contractor. The OPTN collects and provides the data to the Arbor Research Collaborative for Health 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 are collected is not connected to a patient's name).

The SRTR reports that are available to patients online at www.ustransplant.org 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

give you a general idea of how many other patients of your same age and gender are waiting for or have received a transplant. This report is available online at www.optn.org/data/annualReport.asp.

- *The Scientific Registry of Transplant Recipients' Transplant Program-Specific Report.* This report is available online at www.ustransplant.org (Choose Information for Patients and Families). The report covers topics such as the demographics and activity of each transplant center's waiting list, the number of transplants performed at each center, the center's graft and patient survival rates, and the number of donors and organs recovered for transplantation by each OPO. Patients can explore information about their own transplant center in order to prepare their questions for the transplant team.

Many patients use this information to help them make certain choices about their health care. For example, you may be interested in registering at more than one center. These reports can answer some of the questions you might have and help you select a transplant center. You can find data on patients like you (in the same age range and of the same ethnic background, gender, blood type, geographical location, etc.) who are waiting for organs or who have received transplants.

Data products from the SRTR may provide the patient (and his/her family members) and all transplant professionals involved in the treatment and care of the individual with information that can be used in the decision-making process.

Research Continues

Transplantation is very successful, but researchers still have a lot of work to do. Transplant research has focused mostly on three areas:

Organ matching: Creating effective methods for making the closest possible genetic match between the donated organ and the transplant candidate in order to reduce the chance of organ rejection.

Organ preservation: Creating ways of keeping the donated organ healthy while it is being transported to the transplant candidate's hospital.

Immunosuppression: Creating drugs that prevent or stop organ rejection after the organ has been transplanted.

By studying these areas of transplantation, researchers hope to discover new ways to make transplants even more successful. These topics, along with other areas of research, are described in various chapters of the OPTN/SRTR Annual report and other SRTR publications (available online at www.ustransplant.org).

ARBOR RESEARCH COLLABORATIVE FOR HEALTH

Arbor Research Collaborative for Health is a not-for-profit research organization established for the purpose of conducting major studies in epidemiology and public health.

Mission Statement

Arbor Research is committed to improving patient care through epidemiologic, clinical, and economic research that shapes medical policies and practices. Our scientific and educational activities provide valuable and timely information to the global health care community. We conduct health outcomes research with multidisciplinary expertise in advanced biostatistical analysis, clinical oversight, health economics, data management, and project coordination.

The Scientific Registry of Transplant Recipients (SRTR) is administered by Arbor Research with the University of Michigan. The SRTR is an ever-expanding national database of transplantation statistics. Founded in 1987, the registry exists to support the ongoing evaluation of the scientific and clinical status of solid organ transplantation, including kidney, heart, liver, lung, intestine, and pancreas. Data in the registry are collected by the Organ Procurement and Transplantation Network (OPTN) from hospitals and organ procurement organizations (OPOs) across the country. The SRTR contains current and past information about the full continuum of transplant activity, from organ donation and waiting list candidates to transplant recipients and survival statistics. This information is used to help develop evidence-based policy, to support analysis of transplant programs and OPOs, and to encourage research on issues of importance to the transplant community.

NOTES:

RESOURCES

Where To Look for Transplant Information

Contacts

Legal Framework for Transplantation

The American Hospital Association's *Patient Care Partnership*

Did you know?

Today, more than 100,000 patients are waiting for a transplant.

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 Federal Government Organ Donation Web Site — 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 providing information about various educational events and grant programs. You can download organ donation cards and brochures and order organ donation pins; brochures; Passports for Health, a medical record keeper; and other materials to use as handouts for community activities to promote organ and tissue donation.

The OPTN Web Site — www.optn.org

This site was created to provide education and clarification about the organ transplant process for all those affected by and/or interested in organ donation and transplantation. It contains information about the history of the OPTN, its current members, and the policy development process.

The Scientific Registry of Transplant Recipients (SRTR) Web Site — www.ustransplant.org

This site contains information about the role of the registry in the transplant system. It also provides important transplant and donation data.

The UNOS Patient Web Site — www.transplantliving.org

This site can help patients through the transplant process. It includes information about the waiting list, OPTN policies, the matching process, living donation, support group contacts, and other important patient resources.

Other Web Sites

See the list of transplant-related organizations in the Contacts section below. 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. You may want to consider visiting the website of the National Library of Medicine at www.nlm.nih.gov.

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 also 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

Web address: www.aakp.org

American Diabetes Association

Customer Service

1701 North Beauregard Street

Alexandria, VA 22311

Phone: 1-800-342-2383

E-mail: AskADA@diabetes.org

Web address: www.diabetes.org

American Heart Association

7272 Greenville Avenue

Dallas, TX 75231-4596

Phone: 1-800-242-8721

Web address: 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

Web address: www.liverfoundation.org

American Lung Association

61 Broadway, 6th Floor

New York, NY 10006

Phone: 1-800-548-8252

E-mail: info@lungusa.org

Web address: www.lungusa.org

American Medical Association

515 North State Street

Chicago, IL 60610

Phone: 312-464-5000

Web address: www.ama-assn.org

American Society of Multicultural Health and Transplant Professionals

700 N. 4th Street
Richmond, Virginia 23219
Phone: 1-866-ASMHTP (1-866-276-4871)
E-mail: info@asmhpt.org
Web address: <http://www.asmhpt.org/>

Association of Organ Procurement Organizations

1364 Beverly Road, Suite 100
McLean, VA 22101
Phone: 703-556-4242
E-mail: aopo@aopo.org
Web address: www.aopo.org

Children's Liver Association for Support Services

25379 Wayne Mills Place, Suite 143
Valencia, CA 91355
Phone: 1-877-679-8256
E-mail: info@classkids.org
Web address: www.classkids.org

Children's Organ Transplant Association

2501 COTA Drive
Bloomington, IN 47403
Phone: 1-800-366-2682
E-mail: cota@cota.org
Web address: www.cota.org

Donate Life America

700 North 4th Street
Richmond, VA 23219
Phone: 804-782-4920
E-mail: donatelifeamerica@donatelife.net
Web address: www.donatelife.net

Hepatitis Foundation International

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

Immune Tolerance Network

185 Berry Street, Suite 3509
San Francisco, CA 94107
Phone: 415-278-0705
E-mail: aprado@immunetolerance.org
Web address: www.immunetolerance.org

International Transplant Nurses Society

1739 East Carson Street, Box 351
Pittsburgh, PA 15203-1700
Phone: 412-343-4867
E-mail: itns@msn.com
Web address: www.itns.org

Juvenile Diabetes Research Foundation International

120 Wall Street, 19th Floor
New York, NY 10005-4001
Phone: 1-800-533-2873
E-mail: info@jdrf.org
Web address: www.jdrf.org

Living Bank

P.O. Box 6725
Houston, TX 77265-6725
Phone: 1-800-528-2971 or 713-528-2971
E-mail: info@livingbank.org
Web address: www.livingbank.org

Latino Organization for Liver Awareness

P.O. Box 842
Throggs Neck Station
Bronx, NY 10465
Phone: 1-888-367-5652
E-mail: mdlola@aol.com
Web address: 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

National Kidney and Urologic Diseases Information Clearinghouse

Office of Communications and Public Liaison
NIDDK, NIH Building 31, Room 9AO4
Center Drive MSC 2560
Bethesda, MD 20892-3580
Phone: 1-800-891-5390 or 301-496-3583
E-mail: dkwebmaster@extra.niddk.nih.gov
Web address: www.niddk.nih.gov

National Kidney Foundation

30 East 33rd Street
New York, NY 10016
Phone: 1-800-622-9010
Web address: 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
Web address: www.rarediseases.org

Organ Procurement and Transplantation Network (OPTN)

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

Scientific Registry of Transplant Recipients (SRTR)

Arbor Research Collaborative for Health
315 West Huron, Suite 260
Ann Arbor, MI 48103
Phone: 734-665-4108
E-mail: mail@ustransplant.org
Web address: www.ustransplant.org

Second Wind Lung Transplant Association

300 South Duncan Avenue, Suite 227
Clearwater, FL 33755-6457
Phone: 1-888-855-9463
Web address: www.2ndwind.org

The Forum of ESRD Networks

P.O. Box 70835
Richmond, VA 23255
Web address: www.esrdnetworks.org

TransWeb: All About Transplantation and Donation

The Northern Brewery
1327 Jones Drive, Suite 201
Ann Arbor, MI 48105
Phone: 734-998-7314
E-mail: transweb@umich.edu
Web address: www.transweb.org

U. S. Department of Health and Human Services

Health Resources and Services Administration
Healthcare Systems Bureau
Division of Transplantation
5600 Fishers Lane, Room 12C-06
Rockville, MD 20857
Phone: 301-443-7577
E-mail: rlaeng@hrsa.gov
Web address: 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

Byerly Terminal
6100 W. Dirksen Parkway, Suite 302
Peoria, IL 61607
Phone: 1-888-260-9707
E-mail: mail@aircareall.org
Web address: www.aircareall.org

American Kidney Fund

6110 Executive Blvd., Suite 1010
Rockville, MD 20852
Phone: 1-800-638-8299
E-mail: helpline@kidneyfund.org
Web address: 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
Web address: 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
Web address: www.a-o-t-a.org

Angel Flight

4620 Haygood Road, Suite 1
Virginia Beach, VA 23455
Phone: 1-800-296-3797 or 757-318-7149
Web address: www.angelflightmidatlantic.org

Children's Organ Transplant Association

2501 West COTA Drive
Bloomington, IN 47403
Phone: 1-800-366-2682
Web address: www.cota.org

Medicare Hotline

Phone: 1-800-633-4227

Web address: www.medicare.gov

National Foundation for Transplants

5350 Poplar Avenue, Suite 430

Memphis, TN 38119

Phone: 1-800-489-3863

Web address: www.transplants.org

National Insurance Consumer Helpline

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: nosscr@att.net

Web address: www.nosscr.org

National Transplant Assistance Fund

150 N. Radnor Chester Road, Suite F-120

Radnor, PA 19807

Web address: www.transplantfund.org

Pharmaceutical Research and Manufacturers of America

1100 15th Street, NW

Washington, DC 20005

Phone: 1-800-762-4636 or 202-835-3400

Web address: www.helpingpatients.org

LEGAL FRAMEWORK FOR TRANSPLANTATION

Many 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) 1987 UAGA revised	<ul style="list-style-type: none"> • Established legality of the organ and tissue donor card. • Provided for legality of organ and tissue donation.
1978 Uniform Determination of Brain Death Act 1980 Uniform Determination of Death Act	<ul style="list-style-type: none"> • Expanded traditional definition of death (cardiopulmonary) to include brain death. • Confirmed legality of brain death.
1984 National Organ Transplant Act	<ul style="list-style-type: none"> • Established a national Organ Procurement and Transplantation Network (OPTN). • Prohibited sale of human organs.
1986 Omnibus Budget Reconciliation Act (OBRA) 1987 OBRA revised 2000 The OPTN Final Rule 2004 Organ Donation and Recovery Improvement Act	<ul style="list-style-type: none"> • Established hospital procedures that require a designated person to approach family members about donation at the time of a patient's death (routine request). • Required that organ procurement organizations be notified by hospitals regarding potential donors. • Published by the U.S. Department of Health and Human Services, the Final Rule (federal regulation) governs the operation of the OPTN. • Authorized grants and contracts to establish public education programs to increase organ donation through awareness and education campaigns. Authorized use of hospital-based organ procurement coordinators, grants to States for assistance with donor awareness and public education, and reimbursement of travel and subsistence expenses incurred by living donors.
2006 Uniform Anatomical Gift Act (UAGA, 2006 version)	<ul style="list-style-type: none"> • Strengthened a person's wishes to donate organs and tissues by allowing anyone to document a legal consent for donation prior to death. The Act also set standards for electronic donor registries, allowing OPO employees instant access to individual consents for donation.

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*. Below 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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NOTES:

APPENDIXES

Glossary

Abbreviations and Acronyms

List of Contributors

Did you know?

In 2007, more than 2,400 living organ donations were made between unrelated (non-biological) 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.

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

adverse reaction - An unintended side effect of 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 is based upon a 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 from a deceased or living human donor into a living human recipient.

antibody - A protein substance made by the body's immune system to attack a foreign substance, such as, 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.

Arbor Research Collaborative for Health - 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 to the Health Resources and Services Administration of the U.S. Department of Health and Human Services. Located in Ann Arbor, Michigan, Arbor Research is made up of researchers, biostatisticians, programmer analysts and research assistants who have experience in studying health-related issues.

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 - The removal (usually with a needle) of a tiny piece of tissue from the body for examination 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 - The irreversible cessation of all functions of the entire brain, including the brain stem. Brain death is not the same as a coma or persistent vegetative state. Brain death occurs when there is permanent, irreversible brain injury due to a hemorrhage, stroke, trauma or prolonged lack of oxygen to the brain.

cadaver - A dead body.

cardiac - Having to do with the heart.

cardiac death - The irreversible cessation of all heart, blood circulation, and breathing functions. A person declared dead by cardiac criteria (the heart has stopped and can not be restarted) is in some cases able to donate some organs and tissues.

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.

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 organ or organs and/or tissues are 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 blood stem cell 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 for the Health Resources and Services Administration include oversight of the contracts for the national Organ Procurement and Transplantation Network (OPTN), the U.S. Scientific Registry of Transplant Recipients (SRTR), the C.W. Bill Young Cell Transplantation Program, and the National Cord Blood Inventory. The DoT also provides professional and public education to increase organ and tissue donation, and technical assistance to organ procurement organizations (OPOs).

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

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 - 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.

fungus disease - An infection that often 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. Typically 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 the surface of white blood 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's system will accept an organ from a specific 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 the 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, NeoraI), OKT3, mycophenolate mofetil (CellCept) and tacrolimus (Prograf, FK506).

immunosuppressive - Relating to the weakening or reducing of the 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 the body, causing the 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, the common cold and the flu.

inflammation - The swelling, heat and redness the 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 one's own organs or 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 specialized monitoring devices and equipment for the care of 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 range from \$150,000 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 some patients without health insurance. Individual States decide who is eligible and what benefits and services to cover. Programs vary greatly from State to State.

medically necessary - A specific healthcare service or supply your insurance company supports as being required for your medical treatment and as being 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 in the United States.

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 organ procurement organization (OPO) provides organ recovery services for designated 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 OPTN/UNOS 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 varies 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 1984, 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 administer the Nation's organ sharing system and ensure that organs are allocated in a fair and just manner. Members of the OPTN include transplant centers, OPOs, histocompatibility laboratories, voluntary healthcare organizations and the general public. UNOS operates the OPTN under contract to the U.S. Department of Health and Human Services.

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 of Transplant Recipients. OPOs also engage in public and professional education to increase the rate of organ donation in their communities. Currently, there are 58 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 - A disease, illness, sickness, or injury considered to be a condition requiring medical treatment that existed before the effective date of a health insurance contract. If a condition is pre-existing, it may not be covered for a specific period of time or covered at all under some contracts.

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 attacks 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 - When death is declared or about to happen, hospitals are required 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 or until graft failure or death. Arbor Research Collaborative for Health 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 a previous 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, with Status 1 being most urgent.

steroids - Naturally occurring substances, such as hormones, found in the 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.

systolic 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, as section of an organ, or a 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 that provides transplantation of a particular type of organ.

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

transplant surgeon - A physician who performs transplants and provides surgical care to transplant recipients.

United Network for Organ Sharing (UNOS) – A non-profit organization that administers and maintains the Nation’s organ transplant waiting list under contract to 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 for the OPTN.

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 grow and reproduce themselves only while living within cells of the body. After reproduction, the new viruses look for new cells to enter.

waiting list - After evaluation at the transplant center, a patient is added to the national waiting list by the transplant center. Lists are specific to each organ type: heart, lung, kidney, liver, pancreas, intestine. Each time a donor organ becomes available, the OPTN/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.

ABBREVIATIONS AND ACRONYMS

Your transplant team may use these abbreviations and acronyms 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 of the Health Resources & Services Administration,
U.S. Department of Health and Human Services

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 of the U.S. Department
of Health and Human Services
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
O₂ - 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
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

LIST OF CONTRIBUTORS

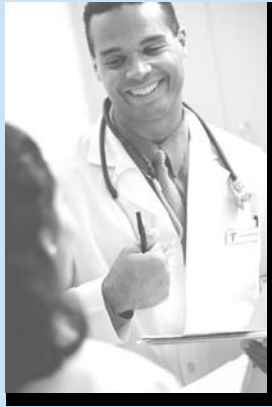
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Tammi Wright	Lifesharing Community Organ Donation	San Diego, CA
Barry Friedman	University of Minnesota Medical Center	Minneapolis, MN
Marian O'Rourke	Mt. Sinai Medical Center	New York, NY
Sandra Cupples	Washington Hospital Center	Washington, DC
Eva Fung	Center for Medicare and Medicaid Services	Baltimore, MD
Anna Kucheryavaya	United Network for Organ Sharing	Richmond, VA
Cindy Richards	Children's Hospital of Alabama	Birmingham, AL
Betty J. Wilson	Baptist Medical Center	Little Rock, AR
Nancy G. Edling	University Medical Center	Tucson, AZ
Tina Kress	Sharp Memorial Hospital	San Diego, CA
Rose Otto	Presbyterian-St. Luke's Medical Center	Denver, CO
Judith A. Smith	University of Miami	Miami, FL
Jan S. Maxwell	Medical College of Georgia	Augusta, GA
Donna K. Pacheco	The Transplant Institute	Honolulu, HI
Bob Yoder	The Transplant Institute	Honolulu, HI
C. Michelle Privett	Loyola University Medical Center	Maywood, IL
Patricia J. Gaddis	University of Illinois Hospital	Chicago, IL
Linda L Beatty	Lutheran Hospital/NIHI	Fort Wayne, IN
Alicia R. Currin	Methodist Transplant Center	Indianapolis, IN
Sherrie Carter	St. Vincent Hospital	Indianapolis, IN
Carol Garman	University of Kansas Medical Center	Kansas City, KS
Marsha K. Richardson	Via Christi Regional Medical Center	Wichita, KS
Melody Kazee	University of Kentucky Medical Center	Lexington, KY
Debi Dumas Hicks	Ochsner Transplant Center	New Orleans, LA
Debbie Vay	Ochsner Transplant Center	New Orleans, LA
Susan Noska	Massachusetts General Hospital	Boston, MA
Judith A. Bloom	New England Medical Center	Boston, MA
Jacquelin Darmondy	Johns Hopkins Hospital	Baltimore, MD
Debora Evans	University of Maryland Hospital	Baltimore, MD
Frances M. Hoffman	Abbott Northwestern Hospital	Minneapolis, MN
Lin Jones	Barnes-Jewish Hospital	St. Louis, MO
Cathy L. Pratt	Dartmouth Hitchcock Medical Center	Lebanon, NH
Rachel Dowell Cherry	Saint Barnabas Medical Center	Livingston, NJ
Sandra Bausback Aballo	Newark Beth Israel Medical Center	Newark, NJ
Sheryl Powell	University Hospital	Albuquerque, NM
Anita L. Principe	Montefiore Medical Center	Bronx, NY
Maritza Rozon Solomon	Mt. Sinai Medical Center	New York, NY

Dianne LaPointe Rudow	Columbia Presbyterian Medical Center	New York, NY
Jo Stecher	NYU Medical Center	New York, NY
Marilyn Rossman Bartucci	University Hospitals of Cleveland	Cleveland, OH
Teresa Duke	University Hospitals of Cleveland	Cleveland, OH
Patricia A. Farmer	Hillcrest Medical Center	Tulsa, OK
Cheryl Smith	Integrus Baptist Medical Center	Oklahoma City, OK
Linda Ohler	Medical College of Virginia	Richmond, VA
Cheryl F. Wannstedt	VA Medical Center	Pittsburgh, PA
Bette Hopkins Garcia	Rhode Island Hospital	Providence, RI
Jill Maxfield	Tennessee Donor Services	Nashville, TN
Terri Cochran	Tennessee Donor Services	Nashville, TN
Susan Fredenberg	Tennessee Donor Services	Nashville, TN
Charles Bearden	Tennessee Donor Services	Nashville, TN
Elaine M. Vuyosevich	Sierra Medical Center	El Paso, TX
Roberta (Bobby) Richards	Seton Medical Center	Austin, TX
Helen "Gigi" Spicer	Henrico Doctors' Hospital	Richmond, VA
Kevin Myer	LifeNet	Virginia Beach, VA
Kristi J. Ross	Swedish Medical Center	Seattle, WA
Cassie Conover	University of Washington Medical Center	Seattle, WA
Mary J. Douglas	University of Wisconsin Hospital	Madison, WI
Shari Drehel	Charleston Area Medical Center	Charleston, WV
Jude Guess	WVU Medical Center	Morgantown, WV
Shari Huffman	Charleston Area Medical Center	Charleston, WV



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