A photograph of two people lying on their backs in a grassy field, looking up at the sky. The scene is bathed in warm, golden light, suggesting a sunset or sunrise. The background is a soft-focus green field under a bright sky.

What Every Patient Needs to Know

*To the world
you may be one person,
but to one person
you may be the world.*

ANONYMOUS

INTRODUCTION

What Every Patient Needs to Know has been created to help patients and their families through the process of organ transplantation and to provide the information needed to make knowledgeable healthcare decisions.

Call the United Network for Organ Sharing (UNOS) at (888) 894-6361 or visit our website at www.transplantliving.org for additional information.

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Fujisawa Healthcare, Inc.

Fujisawa Healthcare, Inc. is a leading pharmaceutical company that is working hard to better the lives of transplant patients worldwide. Fujisawa's discoveries are helping solve the mysteries of the immune system, leading to breakthrough products that offer new hope in transplantation and many diseases.

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SECTION 1

PREPARING FOR YOUR
Transplant



SECTION 1: PREPARING FOR YOUR TRANSPLANT



THE TRANSPLANT EXPERIENCE

THE TRANSPLANTATION NETWORK

- What Is The United Network For Organ Sharing?

- What We Do

COMMONLY ASKED QUESTIONS ABOUT TRANSPLANTATION

TERMS TO KNOW



THE UNOS 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 TRANSPLANT EXPERIENCE

1. Your doctor recommends that you be evaluated for a transplant.
2. You are evaluated for a transplant by the medical team at a transplant center.
3. Once you have been accepted as a transplant candidate, you are registered on the national organ transplant waiting list.
4. You begin developing your financial strategy.
5. Your waiting period begins.
6. Your transplant takes place.
7. A plan is developed for your post-transplant care.

THE TRANSPLANTATION NETWORK

What is the United Network for Organ Sharing?

- The United Network for Organ Sharing (UNOS) coordinates the nation's organ transplant system, providing vital services to meet the needs of men, women and children awaiting lifesaving organ transplants. Based in Richmond, Virginia, UNOS is a private, non-profit membership organization.
- UNOS operates the nation's Organ Procurement and Transplant Network (OPTN) facilitating organ recovery and placement under contract with the U.S. Department of Health and Human Services.

What We Do

- Manage the national transplant waiting list, matching donors to recipients 24 hours a day, 365 days a year, as needed.
- Monitor every organ match to ensure organ allocation policies are followed.
- Bring together members to develop policies that make the best use of the limited supply of organs and give all patients a fair chance at receiving the organ they need — regardless of age, sex, ethnicity, religion, lifestyle or financial or social status.
- Educate professional groups about their important role in the donation process.
- Set professional standards for efficiency and quality patient care.
- Maintain the database that contains all organ transplant data. These data are used to improve transplantation, develop organ sharing policies, support the care of patients and help patients make informed healthcare decisions.
- Educate the public about the importance of organ donation.
- Work to keep patients informed about transplant issues and policy.

SECTION 1: PREPARING FOR YOUR TRANSPLANT



COMMONLY ASKED QUESTIONS ABOUT TRANSPLANTATION

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

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

What criteria must patients meet to be placed on the waiting list?

Historically, each transplant center uses its own criteria to evaluate and list patients. To maintain uniform standards, OPTN/UNOS committees, consisting of transplant professionals, recipients and donor family members, have developed uniform guidelines to determine the minimal listing criteria a candidate must meet.

How are donated organs matched to patients awaiting transplant?

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

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

Can patients list at more than one transplant center?

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

How long does it take to receive an organ?

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

SECTION 1: PREPARING FOR YOUR TRANSPLANT

Am I a candidate for living donation?

Living donation is handled by the transplant centers. Living donors have historically been a close relative (spouse, sibling, parent, etc.) or friend of the recipient. Living non-directed (stranger-to-stranger) donation is newer. For more information patients should contact their transplant program.

Does UNOS oversee donation and transplantation around the world?

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

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

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

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

Information on policy and legislation is routinely found on

www.unos.org and www.optn.org and in UNOS publications. UNOS also maintains a mailing list of patients and members of the public who wish to receive policy proposals published for public comment. To request these resources, please contact UNOS.

How can I access data on organ transplantation and donation?

Phone toll-free (888) 894-6361 or visit www.transplantliving.org or www.optn.org.

TERMS TO KNOW — A TRANSPLANT GLOSSARY

Allograft

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

Antibody

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

Antigen

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

Anti-rejection Drugs

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

Brain Death

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

Coalition on Donation

A non-profit group of health care professionals, transplant patients and voluntary health and transplant organizations. The Coalition works to increase public awareness of the

organ shortage and create a greater willingness to donate organs and tissues.

Compliance

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

Crossmatch

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

Durable Power of Attorney

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

SECTION 1: PREPARING FOR YOUR TRANSPLANT

End Stage Renal Disease (ESRD)

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

Graft

A transplanted organ or tissue.

HLA Antigens

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

HLA System

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

Immune response

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

Immunosuppressant

A drug used following transplantation to prevent rejection of the transplanted organ by suppressing the body's defense system. Drugs commonly used include tacrolimus (Prograf, FK506), cyclosporine (Sandimmune, Neoral, Gengraf),

prednisone (Deltasone, generics), azathioprine (Imuran), basiliximab (Simulect), daclizumab (Zenapax), mycophenolate mofetil (CellCept), sirolimus (Rapamune, Rapamycin), and antithymocyte globulin (ATGAM, Thymoglobulin).

Immunosuppression

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

Informed Consent

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

MELD/PELD Score

MELD

The Model for End-Stage Liver Disease (MELD) is a numerical scale, ranging from 6 (less ill) to 40 (gravely ill), that is used for adult liver transplant candidates. It gives each individual a 'score' (number) based on how urgently he or she needs a liver transplant within the next three months. The number is calculated by a formula using three routine lab test results.

PELD

Candidates under the age of 18 are placed in categories according to the Pediatric End-Stage Liver Disease (PELD) scoring system. PELD replaced the previous Status 2B and 3 for pediatric patients; Status 1 remains in place and is not affected by PELD.

PELD is similar to MELD but uses some different criteria to recognize the specific growth and development needs of children. PELD scores may also range higher or lower than the range of MELD scores.

NOTA

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

Organ Procurement and Transplantation Network (OPTN)

In 1984, Congress passed the National Organ Transplant Act that mandated the establishment and operation of a national organ procurement and transplantation network (the OPTN). It also called for the establishment of a scientific registry of patients receiving organ transplants. The purpose of the OPTN is to manage the nation's organ procurement, donation and transplantation system and to increase the availability of and access to donor organs for patients with end-stage organ failure. Members of the OPTN include all U.S. transplant centers, organ procurement organizations (OPOs), histocompatibility laboratories, voluntary healthcare organizations, medical and scientific organizations and members of the general public. UNOS established the OPTN in 1986 under contract with the Health Resources and Services Administration (HRSA) of the U.S. Department

SECTION 1: PREPARING FOR YOUR TRANSPLANT

of Health and Human Services (HHS) and has operated it continually since that time under contracts with HRSA.

Organ Preservation

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

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

Organ Preservation Time

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

Organ and Tissue Procurement

Recovery of organs and tissues for transplantation.

Organ Procurement Organization (OPO)

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

OPO Local Service Area

Each OPO provides its services to the transplant programs in its area.

An OPO's local service area can include a portion of a city, a portion of a state or an entire state, or more than one state.

Presently, when most organs become available, a list of candidates is generated from the OPO's local service area. If a patient match is not made in that local area, a wider, regional list of potential candidates is generated, followed by a national list.

PRA

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

Rejection

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

Retransplantation

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

Required Request

Hospitals must tell the families of suitable donors that their loved one's organs and tissues can be used

for transplant. This law is intended to increase the number of donated organs and tissues for transplantation by giving more people the opportunity to donate.

Sensitization

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

Status

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

Survival Rates

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

Tissue Typing

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

SECTION 1: PREPARING FOR YOUR TRANSPLANT

U.S. Scientific Registry of Transplant Recipients

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

Waiting List

After evaluation by the transplant team a patient is added to the national waiting list by the transplant center. Lists are specific to organ type: heart, lung, kidney, liver, pancreas, intestine, heart-lung, and kidney-pancreas.

Each time a donor organ becomes available, the UNOS computer generates a list of candidates based on factors that include genetic similarity, organ size, medical urgency, proximity of the donor to potential recipients and time on the waiting list. Through this process, a match run list is generated each time an organ becomes available that best “matches” possible patients to a donated organ.

Xenograft

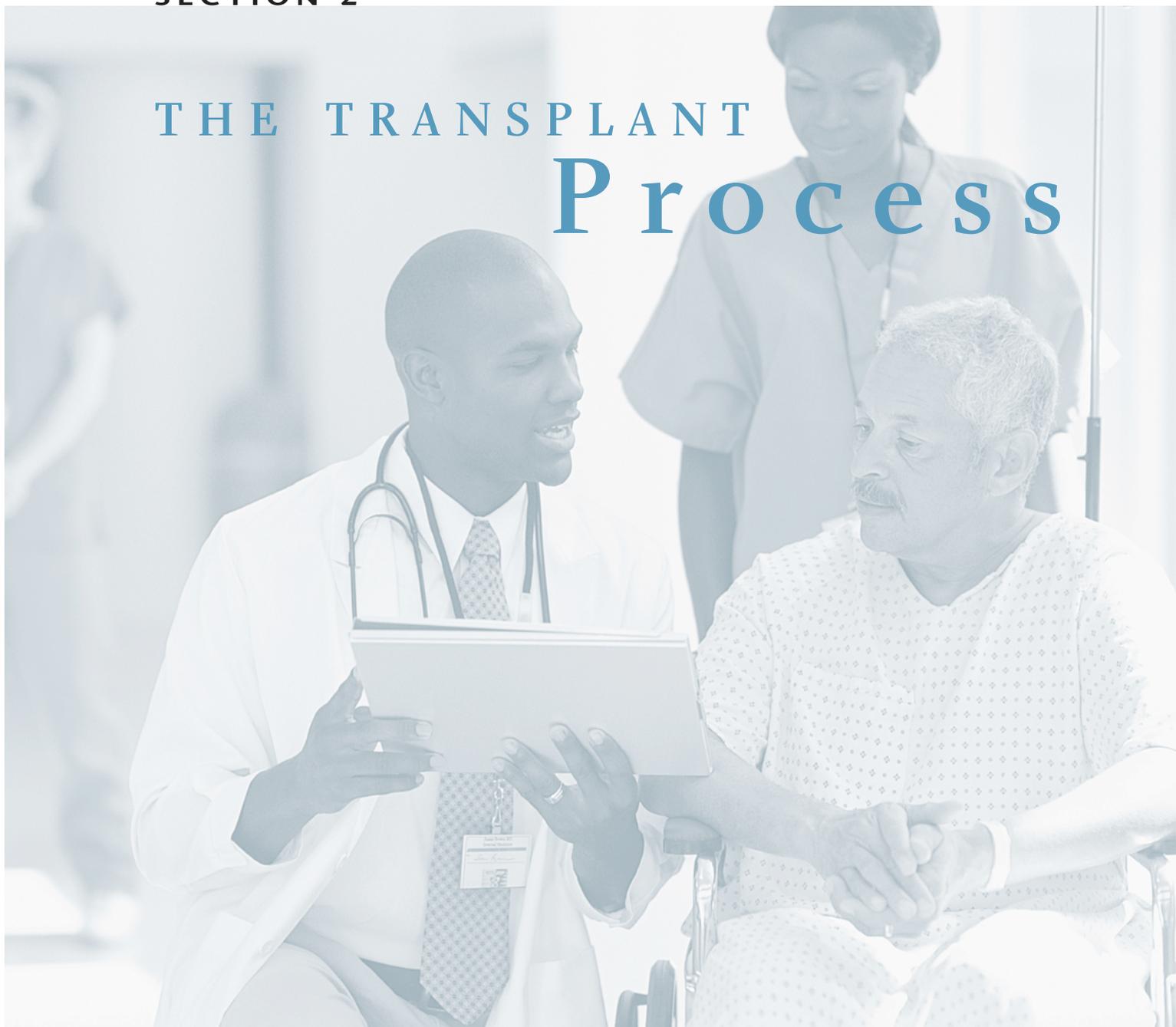
An organ or tissue procured from an animal for transplantation into a human.

Xenotransplantation

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

SECTION 2

THE TRANSPLANT
Process



SECTION 2: THE TRANSPLANT PROCESS



REGISTRATION

- Choosing A Transplant Center
- Multiple Listings

QUESTIONS A PATIENT SHOULD ASK

HOW ORGAN MATCHING WORKS

- The Transplant Waiting List
- The Matching Process
- The Organ Offer
- How Organ Allocation Policies Are Made
- Facts About UNOS



REGISTRATION

Choosing a Transplant Center

There are approximately 250 transplant centers in the U.S. These centers are fully accredited and must meet a variety of professional standards. When determining which transplant center(s) to list with, many patients simply choose the facility closest to them.

There are many things, in addition to the patient's relationship with the transplant team, which must be considered when choosing a transplant center:

- **Access Issues:** travel time and costs associated with travel.
- **Cost:** cost of living in that area before and after transplant.
- **Follow-up Care:** routine check-ups, possible emergency care.

- **Support System:** availability of family and friends for help and moral support.

Multiple Listing

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

QUESTIONS A PATIENT SHOULD ASK

Patients should ask the following questions when choosing a transplant center and its staff:

- Do I have choices besides transplantation?
- What are the benefits and risks of transplantation?
- What does the evaluation and testing process include?
- How does it affect whether I am put on the list?
- What are the organ and patient survival rates for my type of transplant at this hospital?
- How many of my type of transplant do you perform each year? How long have you been doing them?
- What are your criteria for accepting organs for transplant?
- What part of the transplant cost is covered by my insurance?
- What financial coverage is accepted by this hospital?
- What happens if my financial coverage runs out?
- How much will I have to pay in the end?
- Who are the members of the transplant team and what do they do?
- How many surgeons are available here to do my type of transplant?
- How do I find out about the transplant process?
- Is there a special hospital unit for transplant patients?
- May I tour the transplant center's units?
- Will I be asked to take part in research studies?
- What types of living donor transplants does the center do? Is a living donor transplant a choice in my case? If so, where can the living donor evaluation be done?
- What are the costs if I have a living donor?

SECTION 2: THE TRANSPLANT PROCESS

HOW ORGAN MATCHING WORKS



The Transplant Waiting List

All patients accepted by a transplant program are registered on the national organ transplant waiting list. UNOS maintains a centralized computer network linking all OPOs and transplant centers. UNOS organ placement specialists operate the network 24 hours per day, seven days a week.

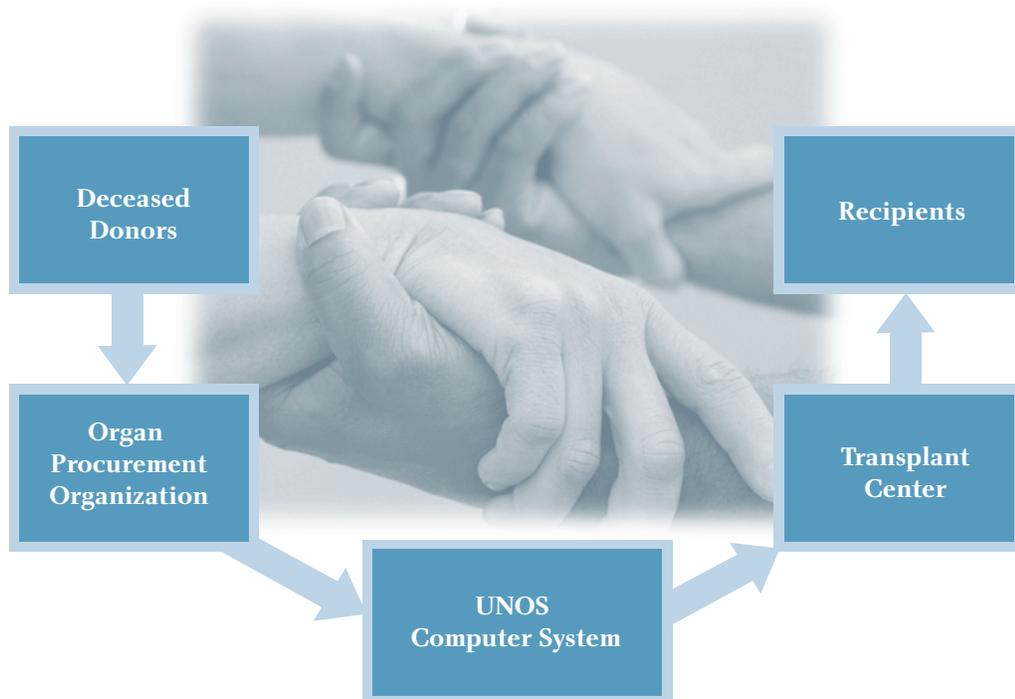
program generates a list of patients ranked according to objective medical criteria such as blood type, tissue type, size of the organ and the patient's medical urgency. Other factors include time spent on the waiting list and distance between the donor and the transplant center. Criteria differ for each type of organ.

The Matching Process

When an organ becomes available, the local OPO accesses the UNOS computer system, enters information about the donor organs, runs the match program and coordinates the surgical recovery team. This computer

The computerized matching process locates the best possible matches between donated organs and the patients who need them, but the final decision to accept an organ rests with the patient's transplant team.

ORGAN SHARING SYSTEM



SECTION 2: THE TRANSPLANT PROCESS

The Five Steps

In Organ Matching

1. An organ is donated

When an organ becomes available, the OPO managing the donor enters medical information about the donor, including organ size and condition, blood type and tissue type into the UNOS computer system.

2. A list of potential recipients is generated

The UNOS computer system generates a list of candidates who have medical and biologic profiles compatible with the donor's. The computer ranks candidates based upon how closely their medical characteristics match the donor's, medical urgency, time spent waiting and proximity of candidates to the donor.

3. The transplant center is notified of an available organ

Organ placement specialists at the OPO or the UNOS Organ Center contact the transplant centers whose patients appear on the ranked list.

4. The transplant team considers the organ for the patient

When the team is offered an organ, it bases its acceptance or refusal of the organ upon established medical criteria, organ condition, candidate condition, staff and patient availability and organ transportation. By policy, the transplant team has only one hour to make its decision.

5. The organ is accepted or declined

If the organ is not accepted, the OPO continues to offer it for patients at other centers until it is placed.

The Organ Offer

When an organ is offered, the transplant team must consider several factors to decide the best medical care for each individual patient. It is not unusual for a transplant team to say "no" to a particular organ. This is a normal part of the matching process. After being turned down for one patient, the organ is offered to the next patient on the list. These offers continue until the organ is placed.

How Organ Allocation Policies Are Made

The organ distribution and matching process is based on policies developed by organ procurement and transplant professionals with input from patients, donor families and the public. As the science of transplantation continues to advance, organ allocation policies also evolve. The goal of policy-making is to create a system that gives every transplant candidate a fair chance at receiving the organ he or she needs. Organ transplantation is the only discipline in American medicine in which patients have a formal role in the policy-making process.

POLICY DEVELOPMENT



SECTION 2: THE TRANSPLANT PROCESS



Facts About UNOS

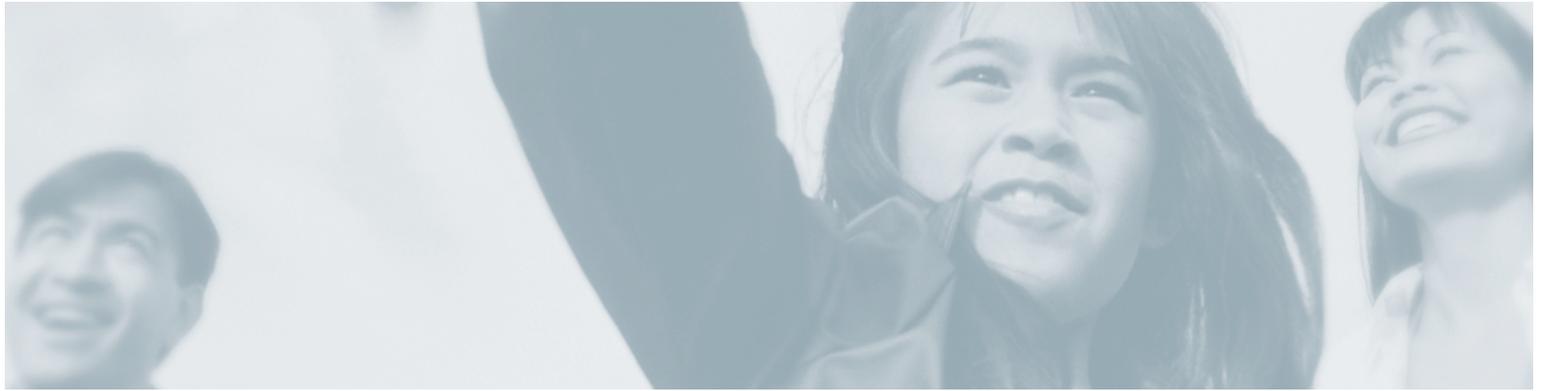
- Organ sharing policies forbid favoritism based upon ethnicity, gender, religion, political influence or financial or social status. Sharing is based upon medical and scientific criteria.
- UNOS data has records of every organ transplant since October 1, 1987. This is the most comprehensive database for a single medical therapy anywhere in the world.
- UNOS data are available on request. However, to protect the privacy of all transplant patients and ensure privacy each patient's name is replaced with a code number at registration.
- UNOS data enable scientists and physicians to exchange information vital for the progress of transplantation and help patients make informed decisions about their care.

SECTION 3

LIVING
Donation



SECTION 3: LIVING DONATION



AN OVERVIEW

FACTS ABOUT LIVING DONATION

- Organs A Living Donor May Give

QUALIFICATIONS FOR LIVING DONORS

- Blood Type Compatibility Chart
- Tests Performed

RISKS INVOLVED IN LIVING DONATION

POSITIVE ASPECTS OF LIVING DONATION

COSTS RELATED TO LIVING DONATION



AN OVERVIEW

In addition to deceased (person declared brain dead) donor transplants, patients may also receive organs from living donors. In 2002 there were 24,899 organ transplants performed in the United States. More than 6,600 of these were living donor transplants. Living donation offers an alternative for individuals awaiting transplantation and increases the existing organ supply.

FACTS ABOUT LIVING DONATION

Since the first successful living kidney donor transplant performed between 23-year old identical twins in 1954, thousands of patients have received transplants from living donors. Living donation is coordinated by the center doing the transplant. Parents, children, siblings and other relatives can donate organs to family members. Unrelated donors (for example, spouses or friends) may also donate their organs if they provide a match for the candidate.

Living non-directed (stranger-to-stranger) donation is a newer and growing source of donors. Those wishing to look into what's involved should contact their local transplant program. Transplant program contact information can be accessed by visiting www.transplantliving.org and selecting Community and Member Directory or calling (888) 894-6361.

Organs a Living Donor May Give:

- single kidney
- lobe of a lung
- segment of the liver, or
- portion of the pancreas
- portion of the intestine

Living donor transplants are a viable alternative for patients in need of new organs. For kidney donors, there is little danger in living with one kidney; the remaining kidney enlarges to do the work both kidneys once shared. The liver has the ability to regenerate the segment that was donated. Lung lobes do not regenerate.

QUALIFICATIONS FOR LIVING DONORS

In order to qualify as a living donor, an individual must be physically fit; in good general health; and free from high blood pressure, diabetes, cancer, kidney disease and heart disease. Individuals considered for living donation are usually between 18-60 years of age. Gender and race are not factors in determining a successful match.

The living donor must first undergo a blood test to determine blood type compatibility with the candidate.

Blood Type Compatibility Chart

Recipient's Blood Type	Donor's Blood Type
O	O
A	A or O
B	B or O
AB	A, B, AB or O

If the donor and the candidate have compatible blood types, the donor then undergoes a medical history and a complete physical examination.

Tests Performed

- Tissue Typing: The donor's blood is drawn for tissue typing using the white blood cells in the blood.

- Crossmatching: A blood test done before the transplant to see if the candidate will react 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 for kidney and pancreas transplants.
- Antibody Screen: An antibody is a protein substance made by the body's immune system in response to an antigen (foreign substance, for example a transplanted organ,

SECTION 3: LIVING DONATION

blood transfusion, virus or pregnancy). Because the antibodies attack the transplanted organ, the antibody screen tests for panel reactive antibody (PRA). The white blood cells of the donor and the blood serum of the candidate are mixed to see if there are antibodies in the recipient that react with the antigens of the donor.

- **Urine Tests:** In the case of a kidney donation, urine samples are collected for 24 hours to assess the donor's kidney function.

- **X-rays:** A chest x-ray and an electrocardiogram (EKG) are performed to screen the donor for heart and lung disease.

- **Arteriogram:** This final set of tests involves injecting a liquid that is visible under x-ray into the blood vessels to view the organ to be donated. This procedure is usually done on an outpatient basis, but in some cases it may require an overnight stay.

- Finally, the donor and the candidate may undergo a psychiatric and/or psychological evaluation. A transplant physician, coordinator or social worker answers their questions and addresses any concerns they may have about the procedure.

The decision to become a living donor is a voluntary one, and the donor may change his or her mind at any time during the process. The donor's decision and reasons are kept confidential.

RISKS INVOLVED IN LIVING DONATION

As with any major operation, there are risks involved in donating an organ. All patients experience some pain and discomfort after an operation. It is possible for any living donor to develop infections or bleeding. In donation of a portion of the liver or pancreas, the liver or spleen may be injured.

Although many donors report a very positive experience, it is possible for negative psychological consequences to result from living donation. Living donors may feel pressured by their families into donating an organ. They may feel guilty if they are reluctant to go through with the procedure. Feelings of resentment may occur if the recipient rejects the donated

organ. Living donors must be made aware of the physical and psychological risks involved before they consent to donate an organ. They should discuss their feelings, questions and concerns with a transplant professional and/or social worker.

POSITIVE ASPECTS OF LIVING DONATION

- Living donation eliminates the candidate's need for placement on the national waiting list. Transplant surgery can be scheduled at a mutually agreed upon time rather than performed as an emergency operation. Because the operation can be scheduled in advance, the candidate may begin taking immunosuppressant drugs two days before the operation. This decreases the risk of organ rejection.
- Transplants from blood-related living donors are often more successful, because there is a better tissue match between the living donor and the recipient. This higher rate of compatibility also decreases the risk of organ rejection.
- In recent years, a laparoscopic surgical technique has been accepted as an alternative for recovering a kidney from a living donor. The former surgical procedure involved a 4-8 inch incision in the donor's lower back. The laparoscopic approach allows the surgical instruments to be inserted into the donor's body through a series of small incisions. This innovative approach involving smaller incisions, affords the donor a potentially shorter recovery time. As with all surgical procedures, the transplant surgeon will decide which procedure will offer the fewest potential risks and the greatest likelihood for success for the donor.
- Perhaps most importantly, there can be a psychological benefit in living donation. The recipient can experience positive feelings knowing that the gift came from a loved one or a caring stranger, and the donor experiences the satisfaction of knowing that he or she has contributed to the improved health of the recipient.

COSTS RELATED TO LIVING DONATION

Health insurance coverage varies for living donation. If the candidate is covered by a private insurance plan, most insurance companies pay 100 percent of the donor's expenses. Insurance companies, however, do not cover transportation expenses, food, lodging, long distance phone calls, childcare or lost wages. If the candidate is covered by Medicare's end-stage renal disease program,

Medicare Part A pays all of the donor's medical expenses, including preliminary testing, the transplant operation and post-operative recovery costs. Medicare Part B pays for physician services during the hospital stay. Medicare covers follow-up care for one full year beyond the donation. This coverage may be extended if complications arise following the donation.

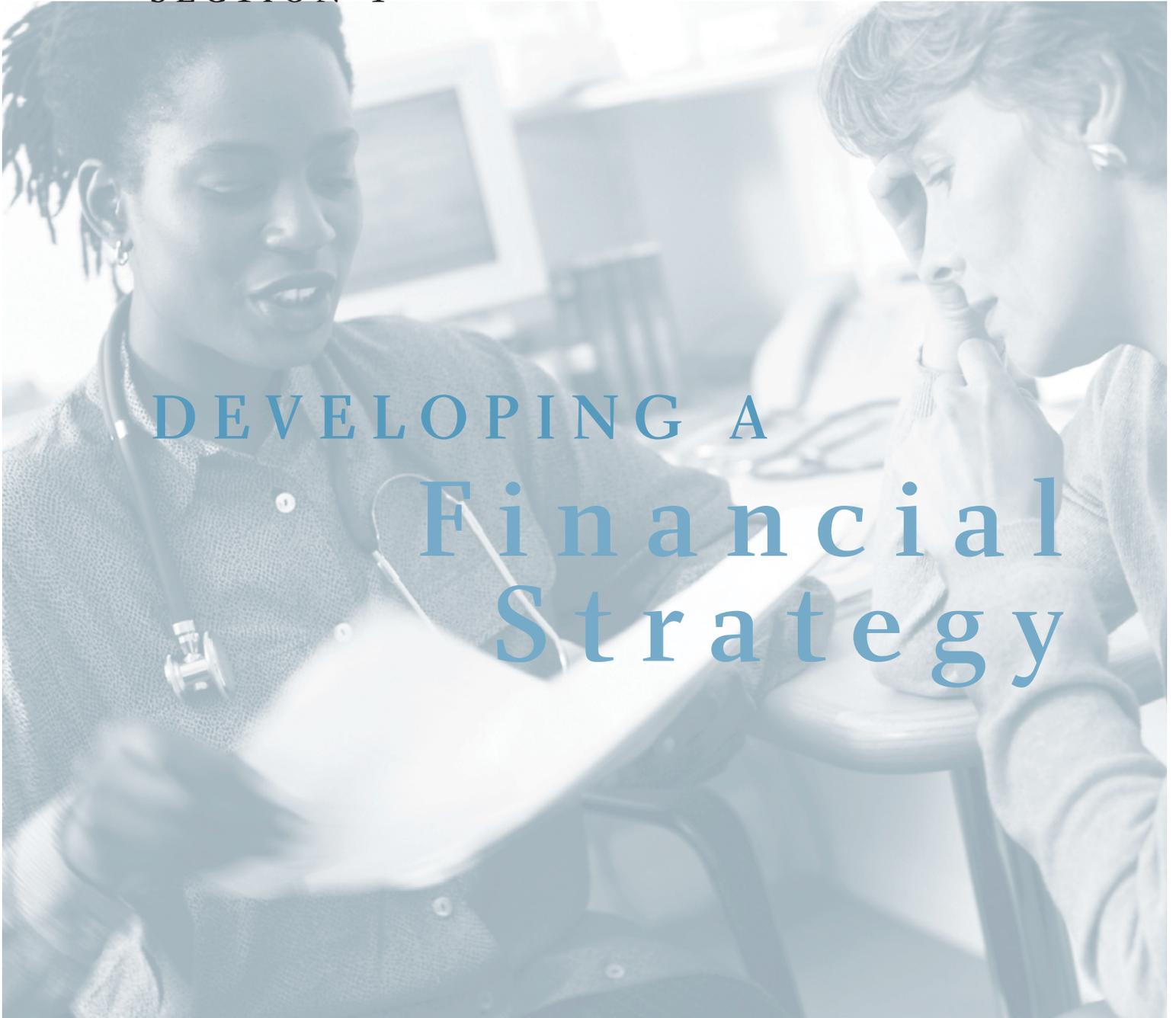
*Challenges are what
make life interesting;
overcoming them is what
makes life meaningful.*

JOSHUA J. MARINE

SECTION 4

DEVELOPING A

Financial
Strategy



SECTION 4: DEVELOPING A FINANCIAL STRATEGY

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SOCIAL SERVICES AVAILABLE FOR TRANSPLANT PATIENTS

No matter where you are in the transplant process, you do not have to face your concerns alone. Your transplant team recognizes that preparing for and living with a transplant will affect your lifestyle in many ways. Your transplant team will help you maintain and resume many of your activities and become involved in new ones.

Transplant Social Workers

Most transplant programs are staffed with social workers who are ready to help you. Transplant social workers can counsel you and your family and provide a variety of helpful resources. They can also help you begin to develop your financial plan.

Through an informal interview, your social worker will determine your

needs and help you understand and cope with basic problems associated with your illness, such as:

- inability to pay your medical bills;
- lack of funds to meet daily needs;
- lack of reliable transportation to and from the transplant facility;
- referrals for re-employment services;
- help in caring for children or other family members.

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

Financial Coordinators

Although the social worker may have knowledge about government funding and disability programs, financial

issues are only a part of his or her responsibilities. The financial coordinator has detailed knowledge of financial matters and hospital billing methods.

Social workers and financial coordinators work together to determine how you can best afford the cost of your transplant.

Transplant costs include:

- transplant evaluation and testing;
- transplant surgery;
- follow-up care, lab tests and medication.

Even before the transplant, these costs add up quickly.

THE COSTS OF TRANSPLANTATION

One of the biggest expenses can be time spent in the hospital's intensive care unit (ICU). The ICU is staffed by critical care nurses and is equipped to monitor and treat critically ill patients. Patients are generally taken to the ICU after the transplant operation. Some patients are also treated in the ICU before the transplant.

When travelling any distance to receive a transplant, the cost of food, lodging and transportation need to be considered. Patients need to include the cost of food and lodging for family while they are in the hospital. Know that these costs can vary greatly from city to city. Some transplant centers offer families lodging

at reduced or no cost, while other centers do not. More than likely, food and lodging expenses will not be covered by insurance.

In addition, there may be lost earnings to consider if an employer does not pay for the time patients and families spend away from work.

Other costs directly associated with transplantation include:

- transplant surgeons, anesthesia and operating room personnel;
- recovery and in-hospital stay;
- patient transplant evaluation;
- recovery of organs;
- transportation to and from the transplant center — not only for

the transplant, but for patient evaluation and check-ups;

- laboratory tests;
- physical or occupational therapy and other rehabilitation;
- the cost of anti-rejection drugs and other medications, which can easily exceed \$10,000 per year for the rest of the recipient's life;
- Medicare Part B Premiums;
- insurance co-pays and deductibles; and
- non-covered medical costs.

SECTION 4: DEVELOPING A FINANCIAL STRATEGY

Estimated Charges for Organ Transplantation

The following chart, developed by Milliman USA, Inc., provides a summary of the estimated first-year and follow-up charges associated with each type of organ transplant. Transplants can cost much less or much more, depending on how many of the services are included in the bill and

the area in which the transplant takes place. Some transplant patients and families find that even with good sources of funding, they may have difficulty covering all of the costs associated with transplantation. The following sections will help in exploring options for covering transplant costs.

**Estimated U.S. Average Billed Charges Per Transplantation (as of July 1, 2002)
First Year Following Transplantation**

Transplant	Evaluation	Procurement	Hospital	Physician	Follow Up	Immunosuppressants	Total
Heart	\$16,800	\$57,000	\$210,000	\$29,300	\$68,100	\$10,200	\$391,800
Liver	17,200	54,100	131,800	42,700	58,400	9,400	313,600
Kidney	9,500	45,700	32,800	13,500	31,200	10,600	143,300
Kidney-Pancreas	9,500	89,600	39,400	15,200	31,200	10,600	195,500
Pancreas	9,500	43,900	40,200	15,200	31,200	8,900	148,900
Heart-Lung	17,100	115,200	253,800	37,400	68,100	12,800	504,400
Lung	17,400	58,200	170,400	27,100	57,100	12,800	343,000
Intestine	31,000	69,600	593,500	55,100	58,400	6,900	814,500

FINANCING TRANSPLANTATION

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

The most common funding sources are:

- Insurance
- Extending Insurance Coverage through COBRA
- Medicare Coverage
- TRICARE (formerly CHAMPUS)
- Charitable Organizations
- Advocacy Organizations
- Fund Raising Campaigns

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

SECTION 4: DEVELOPING A FINANCIAL STRATEGY

INSURANCE

You or 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 extent of insurance coverage vary widely. Read your policy carefully and contact the insurance company if you have questions.

Usually, insurance companies will pay about 80 percent of your hospital charges. This means that you are responsible for the remaining 20 percent from other sources until you reach your “out-of-pocket” limit. Be sure to pay your premiums so that your policy will not lapse. In addition to deductibles, you may also have co-payments for medications and other services, such as doctor’s office visits.

Most insurance policies have some sort of lifetime maximum amount, or “cap.” After a patient has reached this amount, the insurance company does not have to pay any additional benefits. The amount of the cap varies greatly, depending on the individual policy. The cap may apply to a single procedure or treatment or to all combined procedures and treatments. Even after the actual trans-

plant, the ongoing cost of care may exceed the cap, so it is important to be familiar with the amount and terms of your insurance cap and how your insurance dollars are spent.

Some insurers consider certain transplant procedures “experimental” or “investigational” and do not cover these cases. If you have any doubts about how your coverage is determined, contact your insurance company. If you still have questions, contact the office of your state insurance commissioner. Some potential insurers may consider you “uninsurable” if you have certain medical conditions. This may be a particular problem if you work for a small business or are self-employed. More than 25 states have “risk pools,” which are state programs that provide benefits to people who are otherwise declared uninsurable.

In other states, you may qualify for a “community rate” plan, which some insurers offer as a non-profit service. You must still pay insurance premiums to participate in these plans. These premiums may be more expensive than the average insurance

premium. Your state insurance commissioner can tell you if these options are available to you.

Many companies require prior authorization (approval) for organ transplant procedures. Make sure you are not in a waiting period for coverage for conditions you may have had before joining the insurance plan. Delays in insurance payments can cause you unnecessary stress, so make arrangements with your insurance company prior to the transplant. Transplant center social workers and financial coordinators will help you with the information you need to complete this process.

You may want to seek help from an advocacy or charitable organization or a legal advisor to negotiate with your insurer. For example, if the company does not wish to cover your transplant, you may be able to prove that they have covered similar procedures in the past or that a transplant would be more cost-effective than your current care (especially in the case of dialysis). If you can, you may have a better chance of getting coverage for your particular case.

EXTENDING INSURANCE COVERAGE THROUGH COBRA

If you are insured by a group health plan (medical, dental or vision) through your place of work and you must leave your job or have your work hours reduced, you and your family may qualify for extended coverage through COBRA.

COBRA stands for the Consolidated Omnibus Budget Reconciliation Act of 1985. This is a federal law that requires certain group health plans to allow participating employees and their dependents to extend their insurance coverage for 18 to 36 months when benefits would

otherwise end. This requirement is limited to companies employing 20 or more people. While you may receive extended coverage through COBRA, you would still be fully responsible for premium payments to your group health plan. These premiums can be up to 102%

SECTION 4: DEVELOPING A FINANCIAL STRATEGY

of the full cost for your plan for the initial period and up to 150% for any extended periods of coverage. Learn more by contacting your employer's employee benefits office.

Qualifying for Extended Coverage

As an employee covered by a group health plan, you may continue your coverage for up to 18 months in the following cases:

- you leave your job voluntarily or involuntarily (for reasons other than misconduct), or
- your working hours are reduced beyond the minimum amount to qualify for health benefits.

If you are considered disabled under Social Security guidelines at the time you leave your job, you may choose to continue your health coverage for up to 29 months, after which you become eligible for Medicare. If you leave your job because of your disability, you may be able to keep your life insurance if your policy has a disability waiver. You may do this as long as you notify your insurer and provide proof of your disability.

In addition, the spouse and dependent children of a qualified employee are eligible for up to 36 months of COBRA coverage. Additional qualifying events for spouse:

- covered employee being entitled to Medicare;
- divorce or legal separation;
- death of covered employee.

In addition to the above, dependent children qualify if they lose their dependent status under the plan rules.

Deadline for Choosing Extended Coverage

By law, you have 60 days from the day you leave your job to decide whether to continue participating in your health plan through COBRA. When you leave your job, your employer must notify you of your right to continue coverage, how much your premium will be and where payment should be made. If you do not respond within 60 days, you cannot extend your benefits.

You may be able to convert your policy to an individual policy at the end of your coverage period. If you are eligible to continue coverage through COBRA, you should receive information from your employer telling you how to participate. If you have additional questions, check with your employer. Coverage may end before the maximum time limit in any of the following cases:

- the premium is not paid;
- the company holding the policy stops offering an employee group health plan;
- a covered beneficiary joins another group health plan;
- a covered beneficiary becomes eligible for Medicare; or
- the company holding the policy goes out of business.

These are only brief summaries and are not intended to provide complete information.

Portability and Accountability Act of 1996

On August 21, 1996, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) was enacted. The HIPAA changed the continuation of coverage requirements under the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA). It also required that qualified beneficiaries be notified of certain HIPAA changes to COBRA that may affect their COBRA rights. The new requirements are generally effective as of January 1, 1997, regardless of whether the qualifying event occurred before, on or after that date.

Under COBRA, if the qualifying event is a termination or a reduction in hours, qualified beneficiaries are allowed to continue coverage for up to 18 months, subject to timely premium payments. In addition to changing some of the COBRA requirements, HIPAA restricts the extent to which group health plans may impose limits on pre-existing conditions, enabling workers to change jobs without a lapse in coverage of these conditions, in many cases.

When you leave your health plan, your employer must provide proof regarding when you were covered under the employer's group plan.

MEDICARE AND MEDICAID COVERAGE

State and federal government funding is another possibility for coverage under two programs: Medicare and Medicaid are available to patients and families with no other resources to meet their expenses.

- Medicare is operated by the federal government. You may qualify for Medicare as part of your Social Security disability benefits or if you are age 65 or older.
- Medicaid is administered by each state with federal assistance. Some states do not cover transplants through Medicaid.

Medicare

Medicare is a federally-funded health insurance program available to people who are age 65 or older, have certain disabilities; or have permanent kidney failure referred to as End Stage Renal Disease (ESRD); and other qualifying individuals, such as dependents of Medicare beneficiaries. Medicare offers two basic plans: Part A and Part B.

Part A covers basic hospital care and some types of follow-up treatment. It is funded by tax money and is offered free to those who qualify. Part B covers additional services such as doctor bills, and in some cases, immunosuppressive drugs. It is supported partly by federal funds and partly by premiums paid by those who wish to participate.

Medicare, like most private insurance plans, does not pay 100 percent of your costs. In most cases, it pays hospitals and health providers according

to a fixed fee schedule, which may be less than the actual cost. You must pay deductibles and various other expenses. Many people choose to buy a private insurance policy, often called a supplemental or “Medigap” policy, to pay for expenses Medicare does not cover. Check with a local insurance agent for further information on the availability of these policies.

Medicare currently offers coverage for kidney, kidney-pancreas and pancreas (after a kidney transplant) transplants. It also covers certain heart, lung, heart-lung, liver and intestinal transplants if you already have Medicare due to age or disability. Medicare covers liver transplants due to Hepatocellular Carcinoma (HCC) under certain conditions, as of September 1, 2001. This coverage includes payment for a number of the direct costs of the transplant operation. As of December 21, 2000, Medicare helps with the cost of the anti-rejection drugs for the life of the transplanted organ if the transplant was originally covered by Medicare and the patient is age 65 or older or disabled according to Medicare for reasons other than ESRD. Those patients who only qualify for Medicare due to ESRD will still be eligible for up to 36 months of immunosuppressive drug coverage through the Omnibus Budget Reconciliation Act (OBRA) of 1993.

To receive full Medicare benefits for a transplant, you must go to a Medicare-approved transplant program. These programs meet Medicare criteria for the number of trans-

plants they perform and the overall quality of patient outcomes. Nearly all kidney transplant programs meet these criteria. Medicare has also approved more than 60 heart programs and more than 30 liver programs nationwide and certifies additional programs as they qualify.

You may have to meet certain patient selection criteria to be eligible for Medicare coverage. These criteria may include your age and the medical condition for which you need a transplant.

If you have additional questions regarding Medicare eligibility, Medicare benefits for transplants or Medicare-approved transplant programs, contact your local Social Security office.

Medicaid

Medicaid is a health insurance program for certain low-income people. Individual states can decide who is eligible, determine what benefits and services to cover and set payment rates.

Some Medicaid programs will not cover a transplant if a patient goes to a transplant center that is outside of the state they reside in, unless there are no centers in their home state that can transplant that particular organ.

For more information, call Social Security at (800) 772-1213, your local Social Security office or financial coordinator at your transplant center.

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TRICARE (FORMERLY CHAMPUS)

Government funding for families of active duty, retired or deceased personnel may be available through TRICARE. TRICARE may share the cost of heart, lung, heart-lung, heart-kidney, liver, kidney, liver-kidney, kidney-pancreas and living-related liver donor transplants for patients with end-stage organ disease. Patients must receive pre-authorization from the TRICARE medical director and meet TRICARE selection

criteria. Pre-authorization is based on a narrative summary submitted by the attending transplant physician.

Veterans of the Armed Forces who first became ill while in service or who are indigent as defined by the Veterans Administration (VA) may be eligible to receive a transplant at a VA Medical Center. Some veterans may also receive medications funded by the VA. For further information,

contact your local VA office or your nearest VA Medical Center.

For more information regarding TRICARE transplantation benefits, contact the health benefits advisory at your nearest military healthcare facility, call the TRICARE Benefits Service Branch at (303) 676-3526 or visit their website at www.tricare.osd.mil.

CHARITABLE ORGANIZATIONS

Charitable organizations offer different types of support. Some provide information about diseases of certain organs or about a particular type of transplant and encourage research into these diseases and treatments.

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. An organization may have limits on using available funds and may only be able to help with direct transplant

costs, food and lodging or medication costs.

Many groups can help you explore other funding sources, ask an insurance company to reconsider a case or help you sort out difficulties with Medicaid funding.

ADVOCACY ORGANIZATIONS

Advocacy organizations advise transplant patients on financial matters. They should be able to provide supporting information and background documentation to prove they are legally recognized to help those in need. Ask them to provide you with copies of the following documents:

- a current federal or state certification as a charitable, non-profit organization;
- a current by-laws, constitution and/or articles of incorporation; and

- a financial statement for the preceding year, preferably one that has been audited by an independent organization.

Brochures and other background information should never serve as substitutes for the documents listed.

You should review each document before entering into a commitment with any of these organizations. This is important because patient financial needs must be met in a timely, agreed-upon fashion. It is a good idea to ask the organization for references. You may also want to ask members of your transplant team about their

knowledge of the organization.

If you agree to a financial arrangement, make sure that the funds are available in a manner that suits your needs. Since this is so important, you may want legal assistance in reviewing the written agreement before signing. Your bank can also help you review the arrangement.

Review all documents, including insurance policies and funding agreements, very carefully. Inspect the fine print and make sure that all of your questions are answered to your satisfaction. Your needs must come first.

FUNDRAISING CAMPAIGNS

Patients and families often use public fundraising to help cover expenses not paid by medical insurance. This may be a key source for financing transplantation.

Proceed with caution and plan carefully before you begin, as there are many legal and financial issues to consider. For example, if you and your family have been accepted for Medicaid benefits and funds are raised for you, the donated money could be counted as income, and you may then lose your Medicaid eligibility.

Before you begin accepting donations, keep the following points in mind: you must have some place to put the money you receive, such as a trust fund or a special account. Public donations must never be mixed with personal or family money. Also, if donated money has to be counted as income, it is taxable.

There may be legal requirements regarding solicitation of donations from the public. Check with your

city and county governments and with your legal advisor before seeking or accepting donations.

Publicly donated money can be handled through a special trust account at a bank, or a local volunteer or service group may be willing to hold the funds in trust for you if the group is legally able to do this.

Another possibility is placing donated funds with one of the advocacy/charitable organizations — again, with a clear, written agreement that the money will be used to benefit the patient needing the transplant.

It is essential to have timely access to the money. It is inappropriate to have only a partial release of funds that is less than the amount you will need to take care of an expense.

State and local laws may set additional guidelines for fundraising; therefore, you may wish to seek legal advice or assistance.

Planning and Organizing Fundraising Campaigns

It is a good idea to ask for assistance in planning, publicizing and carrying out your fundraising activities.

You may want to contact local newspapers and radio or television stations. Try to enlist the support of local merchants and other sponsors to promote or contribute to your events. This can benefit both you and your sponsors. Your friends and neighbors, your religious congregation, local chapters of volunteer or service groups and other community groups can help with your fundraising efforts. Local political leaders and other officials may also be willing to assist you.

To honor their contributions and maintain the trust of those who donated money, these funds should only be used for the direct costs of transplant surgery and patient care, as well as for transplant-related costs such as transportation, food, lodging and patient medication before and after the transplant.

IMPORTANT CONTACTS

It is helpful to seek information and assistance from a number of individuals and groups before making financial decisions. Some may be able to provide funding or other direct assistance; others may be useful as patient advocates or information sources. The most common contacts are listed below. You may have other resources available, depending on your needs and circumstances.

- **Transplant center:** social workers, financial coordinators and hospital administration representatives
- **Legal services:** your lawyer or legal assistance programs
- **Organizations:** patient advocacy/support groups, charitable/advocacy organizations, your employer, service organizations, churches and local merchants
- **Community members:** social workers, pharmacists,

bank officials and religious leaders in your community

- **Government agencies/officials:** The Social Security Administration, the Centers for Medicare and Medicaid Services (CMS) and your local and state departments of health. Also your local and state legislators, your governor and your U.S. senators and congressional representatives.

SECTION 4: DEVELOPING A FINANCIAL STRATEGY

TRANSPLANT FINANCIAL RESOURCES

The following organizations may provide financial assistance to transplant candidates or recipients and their families.

This is a sample listing and should not be interpreted as a comprehensive list or an endorsement.

American Kidney Fund

**6110 Executive Blvd., Suite 1010,
Rockville, MD 20852
(800) 638-8299
www.akfinc.org**

Provides limited grants to needy dialysis patients, kidney transplant recipients and living kidney donors to help cover the costs of health-related expenses, transportation and medication. Provides information and support for kidney donation and transplantation, as well as general education and information on kidney disease.

American Liver Foundation

**75 Maiden Lane, Suite 603,
New York, NY 10038
(800) 465-4837
www.liverfoundation.org**

Voluntary agency dedicated to fighting liver disease through research, education and patient self-help groups. The group acts as trustees for trust funds.

American Organ Transplant Association

**P.O. Box 441766
Houston, TX 77244
(281) 493-2047
www.a-o-t-a.org**

A private, non-profit group that provides reduced or free airfare and bus tickets to transplant recipients and

their families. AOTA publishes a newsletter for its members. Patients interested in AOTA's services must be referred by their physician. The association also assists with setting up trust funds and fundraising. No administrative fee is charged.

Angel Flight America, Inc. National Headquarters

**P.O. Box 17467,
Memphis, TN 38187-0467
(877) 858-7788
www.angelflightamerica.org**

Provides, through its members, access for people in need seeking free air transportation to specialized health care facilities or distant destinations due to family, community or national crisis.

Children's Organ Transplant Association

**2501 COTA Dr.,
Bloomington, IN 47403
(800) 366-2682
www.cota.org**

A national, non-profit agency raising funds for individuals and families to assist with transplant and related expenses. Works with adults as well as children. All funds raised go to the individual. No administrative fees are collected.

National Transplant Assistance Fund

**3475 West Chester Pike, Suite 230,
Newton Square, PA 19073
(800) 642-8399
www.transplantfund.org**

Offers fundraising guidance to patients' families and friends while

assuring fiscal accountability as trustee. Awards matching medical assistance grants to eligible transplant candidates. Prints and distributes organ donor awareness materials.

Medicare Hotline

(800) MEDICARE/(800) 633-4227

National Insurance Consumer Hotline

(800) 942-4242

Call to obtain the phone number of your state insurance department.

National Organization of Social Security Claimants' Representatives

**6 Prospect Street
Midland Park, NJ 07432-1691
(888) 431-2804
www.nosscr.org**

Committed to providing the highest quality representation and advocacy on behalf of persons who are seeking Social Security and Supplemental Security Income.

National Foundation for Transplants, Inc.

**1102 Brookfield, Suite 200,
Memphis, TN 38119
(800) 489-3863
www.transplants.org**

Assists transplant candidates and recipients nationwide in obtaining transplants and follow-up care, as well as providing essential support and referral services. Provides clients with fund raising expertise and materials and assures that funds raised are properly dispensed. Limited emergency grants are available for medications and transplant-related expenses.

Prescription Drug Patient Assistance Programs

1100 15th St, NW
Washington, DC 20005
(800) 762-4636
www.helpingpatients.org

Many pharmaceutical manufacturers provide medications for low income

patients through patient assistance programs. Most programs require that patients meet certain income requirements. The Directory of Prescription Drug Patient Assistance Programs describes more than 55 programs and includes who is eligible, what prescription medications are covered and

how to receive assistance. To request a free copy, write or call Pharmaceutical Research and Manufacturers of America. The entire directory is also available on their website.

CARE FOLLOWING TRANSPLANTATION

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

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

REHABILITATION

If you have a disability that prevents you from working, you may be a candidate for vocational rehabilitation. The goal of rehabilitation is to prepare people with disabilities for work. It is important to enter rehabilitation as soon as you are released from the hospital in order to protect your disability coverage.

Both public and private agencies provide rehabilitation services. Public providers offer these services to anyone meeting their eligibility criteria. Often, public agencies serve people who did not become disabled as a result of their job.

Private rehabilitation companies often work with people who become disabled because of job-related injuries or illnesses and who are collecting worker's compensation. Their fees are usually paid by insurance carriers.

Rehabilitation Services

Each state provides rehabilitation services through its Department of Vocational Rehabilitation. These agencies are funded by the federal and state governments. State agencies accept referrals from any source and often provide services to those who have never been able to work because of a disability and may arrange sheltered or rehabilitation employment for people with special needs. State agencies occasionally offer employers partial reimbursement for hiring and providing initial training for their rehabilitation clients. Other state programs offer employment preparation training and help their clients establish contacts with potential employers.

Disabled persons often find employment through agencies that provide:

- evaluation of rehabilitation potential;
- counseling, guidance, referral and placement services;
- vocational training;
- services to help families adjust to disability;
- physical and mental restoration services;
- support for rehabilitation efforts;
- recruitment and training for employment opportunities in areas such as rehabilitation, health and welfare, public safety and law enforcement;
- occupational licenses, tools and equipment;
- transportation to rehabilitation activities;
- physical and technological aids and devices;
- rehabilitation engineering; and
- resumé development.

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Application and Eligibility

Whether you contact a rehabilitation service on your own or you are referred by another person or agency, you must complete an application. Your case will be reviewed to determine your eligibility for service and your potential for employment after completing rehabilitation. Generally, you are considered eligible if you have a physical or mental condition that limits your ability to work, but you would be able to work after receiving rehabilitation.

Assessment and Rehabilitation Plan

If you are eligible, the service will assess your job skills, abilities and attitudes. 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;
- a schedule of specific services to be provided;
- intermediate objectives to achieve vocational goals;
- the process for evaluating a client's participation and progress;
- rehabilitation equipment or devices;
- client assistance (including financial services); and
- post-employment services.

Training and Assistance

Depending on your needs, as specified in the rehabilitation plan, 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/or remedial reading or math courses. You will also receive skills training for the specific type of work you can perform. This involves classroom instruction, individual tutoring and simulated work.

Job Seeking and Placement

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



SOCIAL SECURITY COVERAGE FOR THE DISABLED

The Social Security Administration provides general financial assistance and medication grants to transplant patients. Supplemental Security Income (SSI) makes monthly payments to disabled individuals with few assets and low incomes. Social Security Disability Income (SSDI) provides assistance for individuals who are working and paying Social Security taxes. If you are considered disabled, you may begin receiving SSDI benefits while you are involved in an approved rehabilitation program. Contact the Social Security Administration at (800) 772-1213 to apply for these programs.

If your medical condition keeps you from working, you may qualify for disability benefits. Disability programs are offered by a number of private and public agencies, and their eligibility requirements and benefits vary considerably. Social Security provides federally-mandated benefits to people who meet its definition of disability. 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 during this time. There are a number of incentives available to help you return to work.

Who Can Receive Benefits?

Unlike some programs, Social Security does not credit partial or short-term disability. Under its definition, you are disabled if you are unable to perform any work for which you are qualified. Also, your

disability must be expected to last at least a year or result in death. To qualify for benefits, you must have earned enough work credits for the time you were able to work, and you must file a formal application.

You may receive disability benefits at any age. If you are on disability when you reach age 65, your benefits become retirement benefits. The amount you receive remains the same.

Other members of your family may also qualify for benefits. They include: unmarried dependent children (including stepchildren, adopted children or, in some cases, grandchildren); unmarried children with a disability; or your spouse (if he or she is age 62 or older, disabled or caring for a child of yours who is under age 16).

When you die, your widow or widower may receive your benefits. To qualify, he or she must be age 50 or older and must become disabled within seven years of your death. A widow or widower caring for dependent children may also qualify if he or she becomes disabled.

Applying for Disability

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

The claims process takes 60 to 90 days. During that time, Social Security will gather your medical information and assess your ability to work.

Filing an Application

You may apply for disability by telephone, mail or a personal visit to any Social Security office. The Social Security office can help you access the information you need to apply. You may also file for Social Security disability benefits online by going to www.ssa.gov/applyforbenefits.

Reviewing the 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.

Social Security disability guidelines differ from those of other programs. 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. Social Security may review and consider the findings of the other agency or program.

SECTION 4: DEVELOPING A FINANCIAL STRATEGY

You will receive written notice from the Social Security Administration about your claim.

Review Periods and Termination of Benefits

Your case will be reviewed periodically to verify your disability. The review period depends on whether your condition is expected to improve. Social Security will stop paying benefits if you are working on a regular basis and are earning an average of \$810* (\$1,350 for people who are blind) or more per month, after deducting disability-related work expenses. Your benefits will also end if your medical condition improves and you are no longer considered disabled.

You must report any improvements in your condition or change in work status to Social Security. Before you receive benefits, Social Security will send you information on how and what to report.

Work Incentives

Social Security continues to offer some benefits if you attempt to work after you have been declared disabled. If you earn more than \$580* in one month, it will be considered a “trial” month. You may work for up to nine trial months at any time over a five-year period and earn as much as possible without affecting your benefits. After the trial period ends, Social Security will evaluate your work. Generally, if your earnings average \$810* (\$1,350 if blind) a month or less, you will continue to receive benefits. If you

earn more than \$810* (\$1,350 if blind) a month on average, you will receive benefits for an additional three-month grace period before they end. Any work expenses related to your disability will be discounted when your earnings are considered.

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 your earnings drop below \$810* (\$1,350 if blind). You will not have to complete a new application within this time period to qualify.

This is a brief summary and is not intended to provide complete information.

**In 2004*

AMERICANS WITH DISABILITIES ACT

The Americans with Disabilities Act (ADA) of 1990 protects disabled workers from discrimination in job hiring, firing, promotion, pay and other job-related issues if the discrimination is based on a worker's disability. To be protected under the ADA, you must:

- have a disability as defined by the ADA; and
- be able to perform the essential functions of your current job or a job that you are seeking, either with or without “reasonable” accommodation from your employer.

The ADA's Definition of Disability

The ADA broadly defines disability as a physical or mental impairment that restricts one or more major life activ-

ities. You are considered disabled if you have a record of such an impairment or if others commonly believe you have a disability. The ADA specifically excludes drug and alcohol abuse among the disabilities it covers, but it does protect those who have stopped using illegal drugs and have enrolled in or completed a drug rehabilitation program.

Employer Responsibilities

Employers are required to make reasonable accommodations as needed for disabled workers. Reasonable accommodations include a number of possible actions:

- improving access to work facilities for disabled persons;
- restructuring job duties or work schedules;

- reassigning disabled workers to other positions;
- buying new devices or modifying existing ones to assist disabled workers; and
- modifying job examinations, training materials or policies.

Note that the ADA specifies only “reasonable” accommodations. If an employer can prove that an accommodation would pose an undue hardship to the business (too difficult or expensive to provide), the employer may not have to provide it. 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.

SECTION 4: DEVELOPING A FINANCIAL STRATEGY

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

Filing a Claim

If you wish to file a claim regarding a potential ADA violation, contact your local Equal Employment Opportunity Commission office, listed under “United States Government” in the telephone book. By law, an employer cannot retaliate against anyone filing a claim or participating in an investigation.

FEDERAL REHABILITATION ACT (FRA)

The Federal Rehabilitation Act (FRA) offers protection against discrimination by organizations that receive more than \$2,500 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.

ESSENTIAL QUESTIONS TO ASK

QUESTIONS TO ASK YOUR TRANSPLANT CENTER FINANCIAL COORDINATOR

- If I have questions or problems, how can I contact you?
- What is your average cost for a pre-transplant evaluation?
- What is your average cost for the transplant I need? What is the average cost of follow-up care?
- Do you require a deposit or a down payment for my pre-transplant evaluation or transplant? If so, how much is required? What if I have no resources?
- If I run out of funds before I get a transplant, what actions will you take? Will I be made inactive on the patient waiting list or removed from it completely?

- When can I expect to be billed? What kinds of payment options do I have?
- Do you know of any local organizations that can assist us with transportation or lodging?
- Do you have, or know of, any support groups for patients or families?

If You Have Private Insurance

- Do you participate in a “managed care” contract or a “centers of excellence” network with my insurer?

If You Have Medicare Coverage

- Is your program Medicare approved for the type of transplant I need?

If You Are Raising Funds

- Have you worked with fundraising or charitable organizations for

transplant patients? If so, which one(s)?

QUESTIONS TO ASK YOUR INSURANCE COMPANY

If you have private insurance, you may want to give your policy a “check-up.” Do not hesitate to ask your insurance representatives questions. They are there to help you understand your coverage and its limitations. Some of the coverage limitations and conditions may be negotiable, either directly or through your employer.

- Is transplantation a “covered service” under my policy?
- Do you require pre-authorization for a transplant or for any pre-transplant treatment? Do I need to supply any information?

SECTION 4: DEVELOPING A FINANCIAL STRATEGY

- Do you select “centers of excellence” for the type of transplant I need? If so, must I go to one?
 - Does the plan cover the cost of travel for me to go to these centers if they are not nearby? What about my family’s transportation? What about transportation for follow-up care?
 - Is there a waiting period for coverage? If so, how long is it? Am I currently in the waiting period?
 - Are there any permanent exclusions to my policy? If so, what are they?
 - Is a second opinion required? If so, does my policy cover it?
 - What percentage of costs are paid by my policy? Does it vary by the type of service provided (i.e., surgery, tests, prescriptions)?
 - Are there any deductibles or co-payments? What is my total “out of pocket” per year?
 - Are there separate deductibles or co-payments for prescriptions, physician/professional services or surgery? If so, what are they?
 - Do you have a maximum amount or “cap” on my coverage? Can this limit be extended?
 - Will you pay for my medications after the transplant?
 - Is there any time limit on coverage of my medications?
 - Are prescription medications included in the maximum? If not, what is the prescription maximum?
 - What else is included in the maximum?
 - Who should I call for questions or problems with my coverage?
 - Are there any rehabilitation incentives?
- QUESTIONS TO ASK FUNDRAISING ORGANIZATIONS**
- If you are hoping to raise funds for your transplant procedure, here are some questions to ask any organization that is planning to assist you.
- How are donated funds kept? How are they released?
 - How can I find out the status of my funds?
 - Are any fees deducted from actual funds?
 - If I do not receive a transplant, what will happen to the funds already raised?
 - What if the funds exceed the cost of the operation?
 - How many patients and families have you worked with?
 - Can you offer references from other patients you have helped?
 - Whom should I call if I have any questions or problems?
 - Are you a 501C (3) charitable organization, so that money raised on my behalf is tax deductible by those who contribute?

QUESTIONS ABOUT CARE AFTER YOUR TRANSPLANT

If You Are Receiving Disability Benefits

- Will my benefits end if I am able to return to work? If so, can I resume getting benefits when I need them?
- Do you have incentives to ease my transition back to work?

If You Take Part in Occupational Therapy or Rehabilitation

- How will my program be structured and evaluated?
- Will you help with job placement?

Questions for Your Physician About Medications

- What medications will I need? Will the dosages change?
- What if I miss a dose?
- How should I notify you if I have problems with my medication?
- Are all my medications available from commercial pharmacies? If not, how do I receive them?

SECTION 5

LIFE AFTER
Transplant



SECTION 5: LIFE AFTER TRANSPLANT



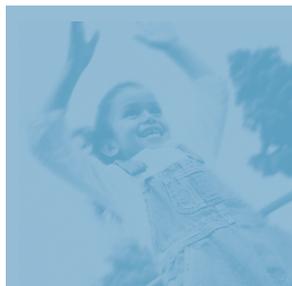
QUESTIONS TO ASK YOUR TRANSPLANT TEAM

MEDICATION TIPS

POST-TRANSPLANT MEDICATIONS

- Helpful Hints

INFORMATION AND SUPPORT: RESOURCES FOR TRANSPLANT RECIPIENTS



QUESTIONS TO ASK YOUR TRANSPLANT TEAM

- What medications will I take after transplant?
- What does each medication do?
- How and when will I take them?
- Are there any special instructions for these medications?
- Is there anything I should avoid while I'm taking these medications?
- Is there any written information available for me to read?
- What if I miss a dose?
- What are the most common side effects of these medications?
- When should I call in about side effects or problems?
- Are there alternative medications to choose from?
- How long will I need to take these medications?
- Are there any programs for obtaining medications at no charge or at a discount?

MEDICATION TIPS

- *Be certain you can read the labels on your medication bottles.*
- *Be familiar with what your medications look like (their color and size).*
- *Make sure you understand the directions.*
- *Take your medications exactly how and when your doctor or pharmacist tells you.*
- *Do not change the dose, skip a dose or stop taking your medications without your doctor's approval.*
- *If you experience any unusual side effects, notify your transplant team.*

POST-TRANSPLANT MEDICATIONS

It is possible your body will recognize your new organ as different and attempt to reject it. You can help prevent rejection by taking immunosuppressant drugs, which will help your immune system accept the transplanted organ. You may have to take these anti-rejection drugs for the rest of your life. In addition to immunosuppressants, your doctor will prescribe other medications to treat side effects and prevent complications.

After your transplant, you may be taking many medications daily. It is extremely important for patients to take all their medications correctly.

Here are some helpful hints:

- Learn everything you can about

your medications. Consult your physician, transplant coordinator, pharmacist and/or support groups and attend educational seminars.

- Use reminder tools to help you take your medications. For example a pill box, sandwich baggies labeled with days of the week and dosage times, an alarm clock or a calendar may work for you.
- Fit medication into your schedule. Work with your transplant team to create a medication schedule that fits your lifestyle.
- Keep track of your medication supply. It is dangerous to run out of medications even for one or two doses.

■ Understand your finances and insurance. Let your healthcare providers know if you are having trouble paying for your medications.

- Ask your family and friends to help. Having a support network will help make the job of taking your medications a little easier.
- Find a pharmacy that will help you manage your medications and provide educational resources designed for your needs. Your transplant coordinator or social worker will have a list of pharmacies for you.

Taking your medication the right way plays a key role in staying healthy and taking care of yourself after your transplant.

SECTION 5: LIFE AFTER TRANSPLANT

INFORMATION AND SUPPORT: RESOURCES FOR TRANSPLANT RECIPIENTS

American Heart Association National Center

7272 Greenville Avenue
Dallas, TX 75231
(800) 242-8721
www.americanheart.org

American Liver Foundation

75 Maiden Lane
Suite 603
New York, NY 10038-4810
(800) 465-4837
www.liverfoundation.org

National Kidney Foundation

30 E. 33rd St.
New York, NY 10016
(800) 622-9010
www.kidney.org

American Lung Association

61 Broadway, 6th Floor
New York, NY 10006
(212) 315-8700
www.lungusa.org

Transplant Recipients International Organization

2117 L St., NW
Suite 353
Washington, DC 20037-1524
(800) 874-6386
www.trioweb.org

American Diabetes Association

1701 North Beauregard St.
Alexandria, VA 22311
(800) Diabetes
or
(800) 342-2383
www.diabetes.org

National Institute of Diabetes & Digestive & Kidney Diseases/NIH

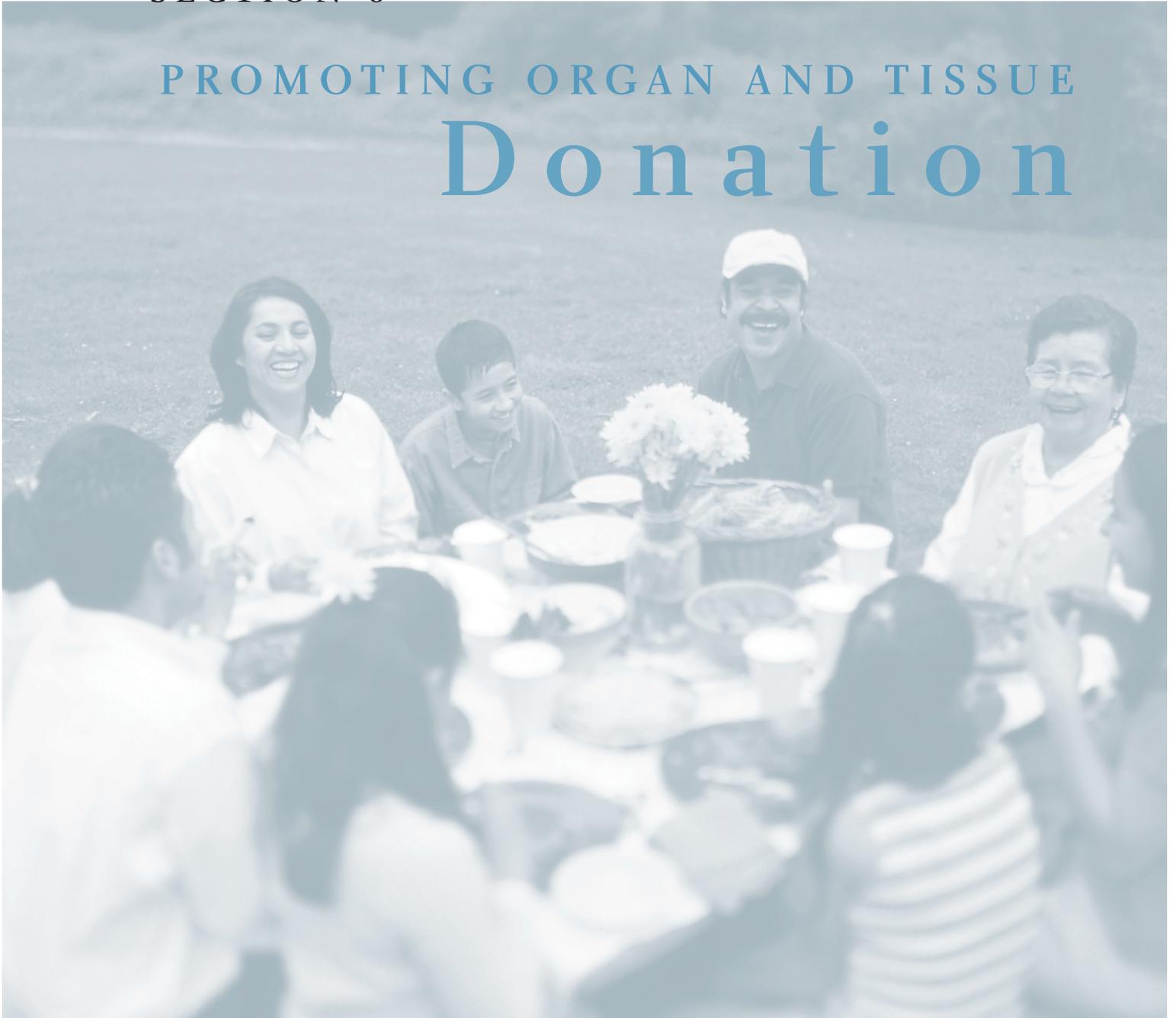
Office of Communications
and Public Liaison
NIDDK, NIH
Building 31, Room 9A04
Center Drive, MSC 2560
Bethesda, MD 20892-2560
www.niddk.nih.gov

Division of Transplantation

Parklawn Building
5600 Fishers Lane
Rockville, MD 20857
(301) 443-7577
www.hrsa.gov/osp/dot

SECTION 6

PROMOTING ORGAN AND TISSUE
Donation



SECTION 6: PROMOTING ORGAN AND TISSUE DONATION



PROMOTING ORGAN AND TISSUE DONATION IN YOUR COMMUNITY

ORGAN AND TISSUE DONATION FACTS AND STATISTICS

HOW THE ORGAN AND TISSUE DONATION PROCESS WORKS

WHO RECEIVES DONATED ORGANS AND TISSUE

FAMILY NOTIFICATION CARD



SECTION 6: PROMOTING ORGAN AND TISSUE DONATION

PROMOTING ORGAN AND TISSUE DONATION IN YOUR COMMUNITY

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

Many transplant patients, recipients and their families are very active in the community, spreading the word about the vital importance of becoming an organ donor. A great deal of

good can come 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.

To find out how you can help in your area, contact your local Coalition on Donation or your local OPO. To locate your local chapter call the Coalition on Donation at

(804) 782-4920 or visit www.donatelife.net. To locate your local OPO, call UNOS Patient Services at (888) 894-6361 or visit www.transplantliving.org and select Community and Member Directory.

The following section is designed to give you some of the information you need to become a spokesperson for organ and tissue donation.

ORGAN AND TISSUE DONATION FACTS AND STATISTICS

- People of all ages and medical histories should consider themselves potential donors. Your medical condition at the time of death will determine what organs and tissue can be donated.
- Donated organs including the heart, pancreas, kidneys, liver, lungs, and intestines restore life.
- Tissue is needed to replace bone, tendons and ligaments lost to trauma, cancer and other diseases in order to improve strength, mobility, and independence. Corneas are needed to restore sight. Skin grafts help burn patients heal and often mean the difference between life and death. Heart valves repair cardiac defects and damage.
- All major religions support organ and tissue donation as an unselfish act of charity.

- There is no cost to the donor's family or estate for organ and tissue donation. The donor family pays only for medical expenses before death and for funeral expenses.
- It is illegal to buy or sell organs and tissue in the United States.
- It is possible to donate life to others as a living kidney or partial liver, lung, pancreas or intestine donor. Visit www.donatelife.net for more information.

Each year more than 6,000 deceased donors make possible nearly 20,000 organ transplants. In addition, there are nearly 7,000 transplants from living donors.

There are also 25,000 tissue donors and 40,000 cornea donors annually providing more than 900,000 tissue and corneal transplants.

The need for donated organs and tissue continues to grow. Nearly 84,000 men, woman and children currently await life-saving organ transplants. Sadly, an average of 17 people die each day due to a lack of available organs.

Every organ and tissue donor can save and enhance the lives of up to 50 people.

SECTION 6: PROMOTING ORGAN AND TISSUE DONATION

HOW THE ORGAN AND TISSUE DONATION PROCESS WORKS

- Organ and tissue donation becomes an option only after all life-saving efforts have been made and death has been declared. Your commitment to donation will not interfere with your medical care.
- Consent for donation is confirmed and your family is asked to participate in the process by providing your medical history.
- A surgical procedure is used to recover donated organs and tissue. The body is always treated with great care and respect.
- Donation should not delay or change funeral arrangements. An open casket funeral is possible.

WHO RECEIVES DONATED ORGANS AND TISSUE

Organs are distributed based upon medical information like blood type, body size and tissue type matching through a national computer network operated by the United Network for Organ Sharing (UNOS). It is illegal to distribute organs based on non-medical information such as wealth, citizenship or celebrity status. Tissue is distributed based upon patient need, availability and medical criteria.



SECTION 6: PROMOTING ORGAN AND TISSUE DONATION

FAMILY NOTIFICATION CARD

To ensure that your family understands your wishes, it is important that you share your decision to donate LIFE.

<p><i>Complete and give to your next of kin</i> FAMILY NOTIFICATION CARD</p> <p>Dear Family, I want you to know about my decision to become an organ and tissue donor. Upon my death, if I am a candidate for organ and tissue donation, I ask that you honor my wishes. It is important to me that others are given the opportunity to live full and productive lives.</p> <p>I wish to donate the following: <input type="checkbox"/> any needed organs and tissue <input type="checkbox"/> only the following organs and tissue: _____</p>	<p><i>Complete and give to your next of kin</i> FAMILY NOTIFICATION CARD</p> <p>Dear Family, I want you to know about my decision to become an organ and tissue donor. Upon my death, if I am a candidate for organ and tissue donation, I ask that you honor my wishes. It is important to me that others are given the opportunity to live full and productive lives.</p> <p>I wish to donate the following: <input type="checkbox"/> any needed organs and tissue <input type="checkbox"/> only the following organs and tissue: _____</p>
<p>Thank you for honoring my commitment to donate LIFE through organ and tissue donation.</p> <p>Donor Name _____</p> <p>Donor Signature _____</p> <p>Date _____</p> <p>To learn more about organ and tissue donation, please visit www.donatelife.net.</p>	<p>Thank you for honoring my commitment to donate LIFE through organ and tissue donation.</p> <p>Donor Name _____</p> <p>Donor Signature _____</p> <p>Date _____</p> <p>To learn more about organ and tissue donation, please visit www.donatelife.net.</p>
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<p>Thank you for honoring my commitment to donate LIFE through organ and tissue donation.</p> <p>Donor Name _____</p> <p>Donor Signature _____</p> <p>Date _____</p> <p>To learn more about organ and tissue donation, please visit www.donatelife.net.</p>	<p>Thank you for honoring my commitment to donate LIFE through organ and tissue donation.</p> <p>Donor Name _____</p> <p>Donor Signature _____</p> <p>Date _____</p> <p>To learn more about organ and tissue donation, please visit www.donatelife.net.</p>

*You have the power to donate life.
Be an organ and tissue donor.*



UNITED NETWORK FOR ORGAN SHARING

P.O. Box 2484 • Richmond, VA 23218

www.unos.org