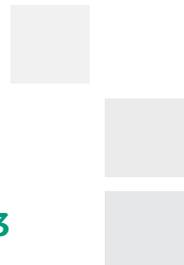


**What Every  
Patient Needs  
to Know**



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## Acknowledgements

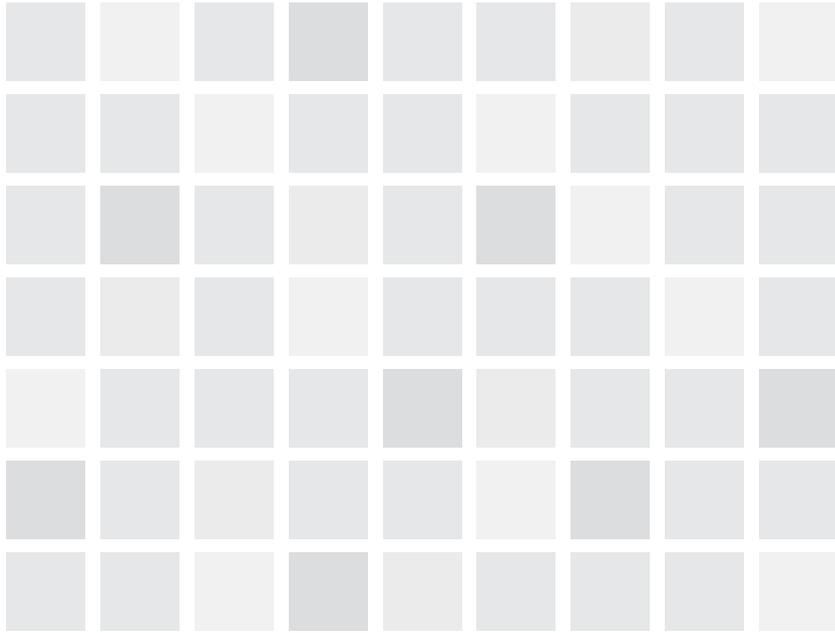
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## SECTION 1



# Introduction to the Transplant Network: The Big Picture

If an organ transplant is in the future for you or a loved one, you are not alone. Patients and transplant professionals wrote this booklet to help you understand transplantation.

If you are reading this for the first time, you may feel scared and confused. With so much information to absorb, it may help to read this booklet with someone close to you. Keep a pen and paper handy to write down questions to ask your health care team. The glossary in Section 7 explains some of the terms.

We'll start with an overview. This section covers:

- history of transplantation
- the U.S. Organ Procurement and Transplantation Network (OPTN), which is managed by United Network for Organ Sharing (UNOS)
- process for matching patients with donated organs

Later sections will cover:

- how to prepare for a transplant
- what happens while you are on the transplant waiting list
- how a loved one can become a living donor
- how to prepare a financial strategy
- what to expect after your transplant

## Understanding Transplantation

### A Brief History

In 1954, a kidney was the first human organ to be transplanted successfully. Liver, heart, and pancreas transplants were successfully performed by the late 1960s, while lung and intestinal organ transplant procedures began in the 1980s.

Until the early 1980s, the potential for organ rejection limited the number of transplants performed. Medical advances in the prevention and treatment of rejection led to more successful transplants and an increase in demand.

More than 500,000 people have received transplants in the U.S. More than 28,000 Americans receive the gift of life each year.

### National Organ Transplant Act

In 1984, Congress passed the National Organ Transplant Act, which prohibited the sale of human organs and called for a national network to facilitate organ recovery and placement. The act created the OPTN and assigned it the task of developing equitable organ distribution policies.

### The Organ Procurement and Transplantation Network

The OPTN (<http://optn.transplant.hrsa.gov>) helps to ensure the success and efficiency of the U.S. organ transplant system. Under federal law, all U.S. transplant centers and organ procurement organizations (OPO) must be members of the OPTN to receive Medicare funds for transplant. Other members of the OPTN include tissue typing labs; medical, scientific, and professional organizations; health and patient advocacy organizations; and members of the general public with an interest in organ donation and transplantation.





## The United Network for Organ Sharing

UNOS ([www.unos.org](http://www.unos.org)) is a private, nonprofit organization that coordinates the nation's organ transplant system under contract with the federal government. UNOS was first awarded the OPTN contract in 1986, and it continues as the only organization ever to operate the OPTN.

UNOS member organizations include 58 local OPOs that facilitate organ recovery and placement in the 50 states, the District of Columbia, and Puerto Rico. UNOS links the organ donor, the transplant center, and the waiting recipient.

**The UNOS mission is to advance organ availability and transplantation by uniting and supporting its communities for the benefit of patients through education, technology, and policy development.**

**Learn from  
yesterday,  
live for today,  
hope for  
tomorrow.**

*—Albert Einstein*

## What We Do

- manage the national transplant waiting list, matching donors to recipients 24 hours a day, 365 days a year
- monitor every organ match to ensure that organ allocation policies are followed
- bring together OPTN members to develop policies that make the best use of the limited supply of organs and give all patients a fair chance at getting the organ they need based on medical criteria—regardless of age, sex, ethnicity, religion, lifestyle, financial, or social status
- maintain the database that contains all organ transplant data for every transplant that occurs in the U.S. These data are used to improve transplantation, develop organ-sharing policies, support patient care, and help patients make informed health care choices
- provide patient-focused information online for transplant candidates and their loved ones ([www.transplantliving.org](http://www.transplantliving.org))
- educate professional groups about their important role in the donation process

## Organ Donation, Matching, and Allocation

### The Five Steps in Matching Organs

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 is generated. The UNOS computer system matches a list of candidates who have medical profiles compatible with the donor's. Each organ follows different criteria for allocation. The computer ranks candidates based on the allocation policy for the organ and on how closely the candidate's characteristics match the donor's.
3. Transplant centers are notified. Organ placement specialists at the OPO or the UNOS Organ Center electronically contact the transplant centers whose patients appear on the computer-generated ranked list.
4. The transplant team considers the organ for the patient. When an organ is offered, the transplant team considers many factors to determine what's best for each patient. Sometimes the team turns down an offer for an organ. This is a normal part of the process.
5. The organ is accepted or declined. If an organ is turned down for one patient, it is offered to the next patient on the match run list for that organ. These offers continue until the organ is placed.

It is common for many patients to be called about an organ offer (one patient will be the primary candidate and the others will be back-ups in case the primary is not available or eligible). Sometimes a patient reports to a transplant center for a potential offer, but then does not receive the transplant.

### How Organ Allocation Policies Are Made

Organ matching and distribution policies are developed by committees and a board of directors comprised of organ procurement and transplant professionals, patients, donor families, and the public. As the transplant field continues to advance, organ allocation policies evolve. Goals are to make the best use of every donated organ and give every transplant candidate a fair chance to receive the organ he or she needs. Organ transplantation is unique in U.S. medicine because patients have a formal role in policy making. The public can provide feedback on policy proposals by visiting <http://optn.transplant.hrsa.gov> (click on Policy Management>Public Comment). Call the UNOS patient services line at (888) 894-6361 for more information.

**You must do  
the thing you  
think you  
cannot do.**

*– Eleanor Roosevelt*

## Common Questions about Transplantation

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

If your physician decides that you need an organ transplant, you will be referred to a transplant center for evaluation. The medical team at the transplant center will consider your medical condition. They also will ask about your financial situation, including insurance or other resources you have to pay for the surgery and medications afterwards. Another consideration is whether you have family and friends to care for and support you. If the transplant team decides that you are a good candidate, you will be added to the waiting list and the transplant center will send you a letter to let you know.

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

Yes. This is called “multiple listing.” UNOS policy permits patients to be considered for organs that become available in other areas by being evaluated and listed at more than one center. This may reduce your waiting time in some cases, but not always. There is no advantage to listing at more than one transplant center in the same OPO local area. Each center has its own criteria for listing transplant candidates, and each center can refuse to evaluate patients seeking to list at multiple centers. If you wish to list at more than one center, inform your primary center and other centers you contact.

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

Once you are added to the national organ transplant waiting list, you may receive an organ that day, or you may wait many years. Factors affecting how long you wait include how well you match with the donor, how sick you are, and how many donors are available in your local area compared to the number of patients waiting.

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

You can obtain national, regional, state, and center data by visiting <http://optn.transplant.hrsa.gov> (click on Data>View Data Reports>Center Data) and you can find survival data at the Scientific Registry of Transplant recipients website at [www.srtr.org](http://www.srtr.org). If you need help accessing data reports, please call UNOS patient services at (888) 894-6361.

**For more information, call UNOS patient services at (888) 894-6361 or go to [www.transplantliving.org](http://www.transplantliving.org).**

### What is living donation?

Kidneys and parts of livers, lungs, intestines, and pancreata can be donated from one living person to another. Medical personnel at transplant centers determine who is a candidate for living donation. Living donors have historically been a close relative (such as a spouse, sibling, or parent) or friend of the recipient. Living non-directed (stranger-to-stranger) donation is newer. Other types of living donation are paired donation, positive crossmatch, and blood type incompatible donation. Contact your transplant center to discuss living donation. Section 3 contains more details.

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

No. UNOS only oversees transplantation in the U.S. and its territories.

### **Can a patient from another country receive a transplant in the United States?**

Yes. Patients can travel from other countries to the U.S. to receive transplants. Once a transplant center lists them, non-resident aliens are considered based on the same factors as U.S. citizens. Non-resident aliens comprise roughly 0.8% of the U.S. waiting list. They also comprise 0.4% of deceased donors and 1.8% of living donors in the U.S. based on the most recent available data. Transplantation of non-U.S. citizens is at the discretion of each transplant center.

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

Information on policy proposals can be found at <http://optn.transplant.hrsa.gov> (click on Policy Management>Public Comment) and in various 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, contact UNOS at (888) 894-6361.

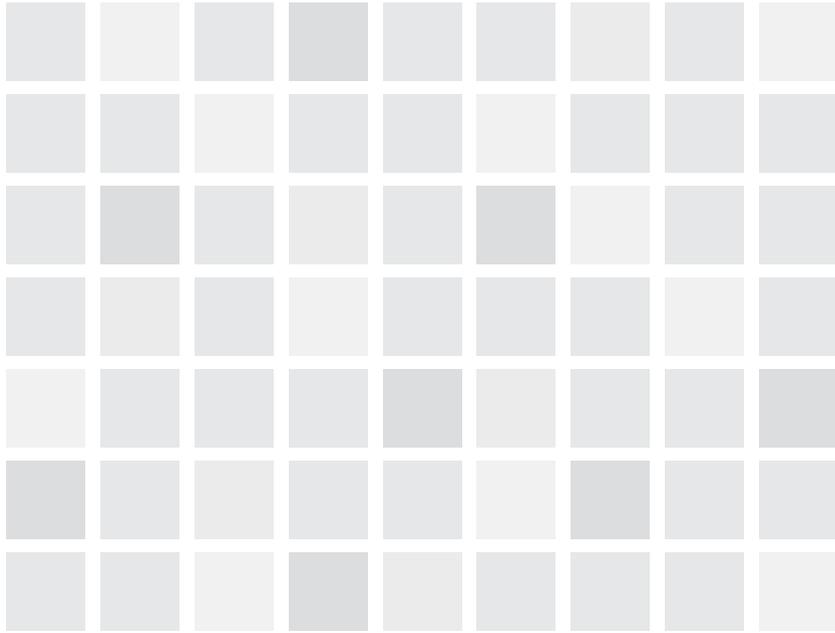
### **What does UNOS do to increase the supply of organs?**

Due to the shortage of organs, slightly more than 50% of those on the waiting list receive a transplant within five years of listing. The OPTN has 21 committees with healthcare professionals, scientists, statisticians, patients, and the public who meet regularly to create policies to increase the number of patients who are transplanted and reduce deaths on the waiting list. They come up with creative ideas to use all viable organs from deceased donors, reduce geographic disparities, and encourage living donation.

**Heroism...is  
endurance for  
one moment  
more.**

*– George F. Kennan*

## SECTION 2



# Preparing for Your Transplant

Each person's journey to transplant is unique. Some people wait for extended periods of time, hoping for the day when they will be called for a transplant. Others come to transplant with compatible living donor candidates and move quickly to surgery and life with their new organ. No matter the circumstances, nearly everyone finds it difficult to completely absorb that they have an end-stage disease that can best be treated with a transplant.

The fear and anxiety that nearly every transplant candidate feels are further compounded by the complex system for transplant evaluation and organ matching. To make the process easier to understand, here's what you can expect when your doctor recommends that you be evaluated for a transplant and refers you to a transplant center.

**Practice self-advocacy by stating, 'I think, I feel, I need, I want.'**

*– Transplant Social Worker*

### The Transplant Process

1. You are evaluated for a transplant by the medical team at a transplant center.
2. If accepted as a transplant candidate, you are registered on the national organ transplant waiting list. A living donor may also be identified and evaluated for living donation.
3. You begin organizing your support system.
4. You begin developing your financial strategy.
5. Your waiting period begins.
6. Your transplant takes place.
7. Your medical team manages your post-transplant care.

In the following sections we'll present step-by-step instructions to get you started, based on experiences of transplant recipients and their donors.

### Transplant Centers

A transplant center is a hospital that has staff that specializes in transplant medicine.

Your primary doctor or organ specialist can refer you to a transplant center that:

- is near your home
- specializes in your medical situation
- accepts your insurance

### Choosing a Transplant Center

One of the biggest decisions you will make as a transplant candidate is choosing a transplant center. There are nearly 250 transplant centers in the U.S. and all of them must meet strict professional standards. Go to <http://optn.transplant.hrsa.gov> (click on Members>Member Directory) to access transplant center listings and links. Many patients simply choose the facility closest to them, but there are several questions to ask when choosing a transplant center:

- Can you easily reach the transplant center for all appointments before and after the transplant?
- Can you easily reach the transplant center when called to receive an organ?
- If the center is a distance from your home, can your caregivers stay near the transplant center without causing an undue burden?
- Is the center within the network of your health insurance?
- Do you feel comfortable with the transplant team?

**For more information, call UNOS patient services at (888) 894-6361 or go to [www.transplantliving.org](http://www.transplantliving.org).**

### For More Information

When choosing a transplant center, you may want to compare the number of transplants performed, waiting list size, and survival rates at the centers you are considering. There is more data available to patients about transplants than for other procedures.

- Go to <http://optn.transplant.hrsa.gov> (click on Data>View Data Reports>Center Data) for the number of transplants and waiting list size by center.
- Visit [www.srtr.org](http://www.srtr.org) for median wait time and survival rates by center.

### The Transplant Evaluation

The transplant evaluation process involves long days of tests and clinic visits and can be stressful. The transplant team will test every major system in your body. Tests could find other medical conditions that could complicate your transplant or make it less likely to succeed.

It's perfectly normal to feel anxious or vulnerable, like your life is in the hands of the medical team. They understand and can help. These are some questions to ask as you go through the process:

### Questions for the Transplant Center and Team

- Do I have choices other than transplantation?
- What are the benefits and risks of transplantation?
- What are your criteria for accepting organs for transplant?
- 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 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?



### Questions about Your Evaluation

- What should I bring with me?
- What should I do to prepare for the appointment?
- Does your center offer parking permits or overnight accommodations?
- What does the evaluation and testing process include? How does it affect whether I am put on the list?

### Financial Questions

- What part of the transplant cost is covered by my insurance?
- What if my insurance does not pay for medications?
- 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?

### Questions about Living Donation

- 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 occur?
- What are the costs if I have a living donor?

Write your questions down and bring them to the appointment. You might also want to bring a trusted friend or family member with you and ask them to take notes.

### The Standard Transplant Evaluation

The standard transplant evaluation usually includes the following tests:

- blood typing
- tissue typing
- dental exam
- chest x-ray
- cardiac work-up
- pulmonary work-up
- infectious disease testing
- gender-specific testing
- psychological evaluation to determine emotional preparedness
- evaluation of social and financial supports and ability to care for yourself and your new organ after transplant

Other testing may be required depending on the organ you need and your health history.

**Life is 10%  
what you make  
it and 90% how  
you take it.**

*– Irving Berlin*



# It's always too early to quit.

– Norman Vincent Peale

## After the Evaluation

You will likely receive a huge amount of information during your evaluation. Afterward, spend some time alone to let it all sink in. It may also be helpful to talk with others who have had a transplant. This is a good way to spend your time as you wait for insurance approval and test results.

It is normal to feel unsure if you want a transplant, even though you may need one. You may doubt your ability to get through the process. Or you may be frozen with fear. Your transplant team is there for you. It is okay if you decide that a transplant is not for you—it is your decision to make.

## The Waiting List

The waiting list is a computer database that contains medical information on every person who is waiting for any type of organ transplant in the U.S. and Puerto Rico. You will not have a number ranking for transplant based on all the other persons who are waiting for your organ. You also will not move up or down each time someone receives a transplant.

Each organ has different criteria for allocation, but wealth, social status, and citizenship are never factors. To learn more about OPTN/UNOS policies, visit <http://optn.transplant.hrsa.gov> (click on Policy Management>Policies).

- **Livers:** medical test results and geography determine priority for transplant.
- **Hearts, lungs, intestines:** priority is based on clinical or medical status and geography.
- **Kidneys and pancreata:** waiting time is a factor, but others such as tissue type matching are also considered.

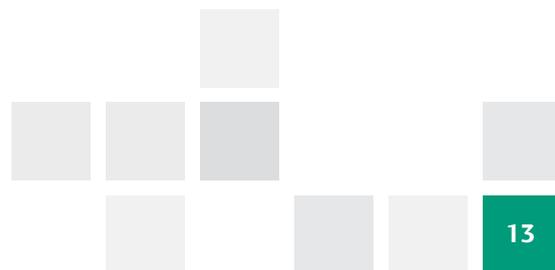
## You're on the List

*Congratulations!* The evaluation is over and you're on the organ transplant waiting list. Your transplant center will confirm your waiting list status in writing, and they will do so any time there is a change in status. It is normal to feel relief and hope, and also fear and regret.

Now the waiting begins. Waiting for a donor organ can be stressful, since you don't know how long that wait will be. Now is the time to mobilize your resources so you're ready when the call comes.

While you wait, others may get their transplants quickly. Transplant is not a first-come, first-served process. Organ allocation is based on many criteria. Often a sicker patient will get an organ in a very short time. Each patient is unique and is handled as such.

Being on the waiting list simply means that your transplant team found you to be a good candidate for transplant and you're being considered for organs.



**You want to be sick enough to be listed, but well enough to survive the transplant.**

*– Heart recipient*

### Multiple Listing

After talking with staff and other patients and doing your own research, you may decide to be on the waiting list at more than one center. Listing at centers in different geographic regions can provide advantages:

- You will have access to multiple donor pools.
- There may be different rules in other regions (pilot projects or other agreements).
- Average wait times for your organ may be shorter in another region.

Each center decides who it accepts as a candidate and a center can refuse patients who are listed elsewhere. Every center can require that tests be redone at their own center. Insurance may not pay for duplicate tests so confirm your health plan's stance on coverage before going forward.

Inform both your primary center and any others you contact of your plans. There is no advantage to listing at more than one transplant center in the same OPO's local service area. Waiting time starts after a center evaluates you and adds you to the list.

### Transferring Waiting Time

If you would like to change transplant centers, you can transfer your primary waiting time to the new center when you list there. Notify your original center that you want to transfer to a new one, so they can remove you from that center's list.

### What if I am not accepted?

Ask your transplant team about your options. You may need to manage other medical conditions first. You may be too healthy for a transplant now but might need one in the future. You may still be a candidate at another transplant center. If a transplant is not an option, you should commend yourself on putting forth your best effort to survive. This may now be a time for personal, spiritual, and emotional reflection.

### What If I Have a Living Donor?

If your transplant center identifies you as a good candidate and you also have a compatible living donor, the center will work with you and your donor to coordinate surgery. The timing of your transplant depends on your and your donor's health, the schedules of all involved, and administrative factors like the availability of operating rooms.

**For more information on living donation, see Section 3 of this booklet or go to [www.transplantliving.org](http://www.transplantliving.org).**

# Transplant is not for wimps.

– *Transplant surgeon*

## Preparing for Your Transplant

Wait times for transplants vary. Not everyone who needs a transplant will get one. Because of the shortage of organs that are suitable for donation, only slightly more than 50% of people on the waiting list will receive an organ within five years.

After your evaluation, it's important to prepare for your transplant while you are waiting. Work closely with your transplant team. Keep all scheduled appointments. Build a solid support system of family, friends, clergy, and medical professionals. Let people know what's going on in your life. They can be a tremendous source of support and information. Taking these steps puts you in control.

To help yourself prepare, address the following areas:

- medical
- practical
- emotional
- educational
- financial
- spiritual

## Preparing Yourself Medically

While you are on the waiting list, your transplant team will monitor you continuously to make sure you remain suitable for transplant. If your condition improves or complications arise, you may be taken off the transplant list. Always discuss any concerns with your transplant team. If you need to make lifestyle changes before getting a transplant, you should continue with them after your transplant to ensure the best outcome. Remaining healthy and active before the transplant will make recovery easier.

- **Take care of your health.** Take your prescribed medicines. Notify your transplant coordinator about all of your health issues and any other prescriptions.
- **Keep your scheduled appointments with your physicians.** Until your transplant, you will need to meet with the transplant team so that they can evaluate your overall health.
- **Follow diet and exercise guidelines.** Weight management is important while waiting for your transplant. A dietician and physical therapist can help you develop a program that will give you the best results. Ask about ways to reduce the use of painkillers and how to manage issues with alcohol, tobacco, or drugs.
- **Make sure you are available.** Your transplant team needs to know how to reach you at all times. Cell phones, pagers, or answering machines may be required by your transplant center. Your transplant coordinator may ask you to stay within a certain geographic range.
- **Complete medical tests and procedures.** Ask your transplant team about other elective or required surgeries (not related to your organ failure) before your transplant.
- **Women of childbearing age:** Ask your medical team about birth control and pregnancy and what precautions you should take before and after your transplant.
- **Stay organized.** Keep a binder of your records to help you manage your medical information. Stay in contact with your transplant team to learn about your waiting list status.

### Preparing Yourself Practically

Select your primary support person. Choose someone you feel close to who has the time, health, and flexibility to be your caregiver. You need to know you are not a burden to this person.

- **Prepare a phone/email tree.** This will make it easier for your caregiver to update friends and family and cut down on phone or email volume.
- **Organize your personal affairs.** Consider filling out an advanced directive, writing a will, and sharing access to bank accounts, email, or blogs. You may also need to fill out Family Medical Leave Act, insurance, or loan deferment paperwork.
- **Consider dependent care.** Find someone you trust and set up a plan to take care of your children and/or pets. Ask your doctor when you can expect to see your children and pets after your transplant.
- **Arrange transportation.** When you are on the organ waiting list, your first responsibility is to plan how to get to the transplant center quickly when you get the call that an organ is available. Make arrangements well in advance. Plan the driving route and think about traffic conditions. If you are relocating, make housing arrangements in advance.
- **Pack your bags.** You'll need to be ready to leave as soon as you get the call that an organ is available. Include insurance information, a list of medications, an extra 24-hour supply of medication, and other necessities.

I made sure I had my glasses, Chapstick™, and a box of chocolates packed for after surgery.

– Pancreas recipient

### Preparing Yourself Emotionally

Many portrayals of the transplant process in the media are inaccurate or sensationalized. In the real world you get sick, you wait, and hopefully, you get a transplant. Your transplant team should be the main source of information about your care. You'll find a wealth of information on [www.transplantliving.org](http://www.transplantliving.org), a UNOS website designed for transplant candidates, patients, and loved ones.



## Preparing Yourself Educationally

Transplantation is a whole new world with a whole new language to learn—one filled with medical terms, abbreviations, and acronyms. The best way to navigate this world is to choose to become a lifelong learner. Carefully review any educational materials provided by your transplant center. Many organ- or disease-specific organizations provide patient education. This book is just one example of the patient-focused resources that are available through UNOS. Join a transplant support group, either in person or online, for information and support. As you learn about the transplant and what to expect, you will gain control of your transplant experience and your life. Education leads to empowerment!

For more information go to [www.transplantliving.org](http://www.transplantliving.org) or [www.unos.org](http://www.unos.org) (click on Donation & Transplantation > Patient Education), or to request printed materials call (888) 894-6361.

## Preparing Yourself Financially

Major health problems can impact your finances. Success in transplant includes having a realistic financial plan. It can be scary to face concerns about loss of income, employment, or insurance; high medical bills; and the need to apply for financial help. Yet facing these possibilities helps you gain a degree of control over the unimaginable. A good financial plan begins by talking with your loved ones about your situation. Also inform your transplant team about financial issues of your transplant. See Section 4, Developing a Financial Plan, for details.

## Preparing Yourself Spiritually

Spiritual growth and challenges await many transplant candidates and recipients. Some find that life-threatening illness makes them question their faith; others find their faith strengthened through the transplant process. Your second chance at a healthy life may come with the knowledge that another life was lost. Receiving a donor organ may create a sense of spiritual rebirth. This may create a profound change in your beliefs, and spiritual guidance and counseling can help you deal with these issues. Just as every patient has different medical issues, spiritual needs vary as well. Talking to your pastor, your rabbi, or the hospital chaplain may help.

## Preparing for Your Loved One's Transplant

A caregiver may be a family member or friend. Some caregivers have been supporting a medically fragile loved one for years. The transplant team social worker may be able to suggest resources for caregivers, but here are some basic tips:

- **Physical health.** Ask the transplant team and your own doctor what you need to do to stay healthy in your care-giving role, such as using medications or vaccinations. Make sure you are in good physical condition.
- **Mental health.** Spending time with one person can be the best of times and the worst of times. Make sure you arrange some respite time to take a walk, call friends, or do something for yourself. This can keep you from feeling burned out.
- **Living arrangements.** Where will you stay while the patient is in the hospital? If you are away from home, be sure your mail and phone calls are forwarded and you've packed necessities.
- **Support network.** Caregivers need support too! Find people to help you with respite care, errands, or meals. The best resource for caregivers may be other caregivers who have "survived" a transplant. Ask your social worker if your transplant center offers these types of support groups.

- **Financial arrangements.** Make financial and insurance plans or take leave from work or other duties.
- **Manage expectations.** To avoid questions and stress later, find out the hospital's visiting hours, limits on visitation, storage, parking, hygiene requirements, and cafeteria hours.
- **Saying no.** Being a caregiver is a great reason to cut back on other responsibilities and de-stress your life. You have enough on your plate.

A transplant is a life-saving gift for both the recipient and the caregiver. It is what you have hoped for during the long wait and time of illness. Transplant is not only life-saving; it is life-altering.

A transplant will help the patient become more independent so he can return to work and other activities. For the caregiver, transplant may mean a big change in roles. This can bring on feelings of sadness, resentment, and stress. All of this is perfectly normal and can be resolved with open communication and a little adjustment time. If more is required, talk to your transplant social worker about counseling and support groups.

**I'm ready  
for the right  
lungs at the  
right time.**

*– Lung candidate*

### Receiving “The Call”

Answer your phone at all times of day and night, especially if it's from the hospital. If they call to tell you that an organ is available, you will likely have to stop eating and drinking to get ready for surgery. You may wish to shower or bathe. You may be asked whether you have a cold, cough, fever, or other infection. Your doctor will explain which medications and treatments to stop or continue.

You will be asked to go to the hospital within a certain window of time. Plan ahead and have directions to the hospital handy, and find out where to park. Ask where your caregiver will stay during the surgery. Bring the bag you packed and your insurance card. Your caregiver should also bring his or her packed bag. When you arrive at the hospital, be ready for medical tests and possibly a long wait for surgery.

You may feel a surge of adrenalin, excitement, eagerness, a peaceful state of readiness, or a sense of dread, shock, and disbelief. You may also feel sadness for the family who lost someone at the same moment you are thrilled to receive the gift of life. All of these feelings are normal.

After receiving the call, contact your support person to make sure he or she can be with you. Your support person can help you contact other close family or friends and take care of children, pets, and other matters such as paying bills.

## A “Dry Run”

Sometimes an organ may be evaluated more closely after you’ve arrived at the hospital, and it is found to be in poor condition for transplant. You could be told that you will not receive a transplant and must go home. This can be very disappointing after a long wait. Your transplant team is looking out for your best interests and outcome, and maybe this organ just wasn’t right for you. *Be patient.*

One patient suggested thinking of this waiting time as a sort of sabbatical during which you get to consider your plans and goals for the potentially “very long and reasonably healthy life” you will have after transplant.

## The Surgery

Transplant surgery can last from four to nine hours, but each transplant is unique. Most patients are placed on a breathing machine. You will likely spend some time in intensive care or intermediate care. It is normal to go through some challenges, which your medical team will manage. Everyone adjusts to surgery and medications differently. Ask your transplant team when you can expect to eat, walk, use the bathroom, and go home after transplant.

**See Section 5, Life after Transplant, for details on how to live your best life after transplant surgery.**



### Going Home

Going home after a transplant is something to celebrate! You made it through the hardest part, and now you can start to recover and live again. Make sure you and your caregiver know your medication routine, clinic visit schedule, and diet and exercise restrictions. Ask your medical team what your caregiver needs to do to prepare your home for your arrival for your health and safety.

Most patients feel more like themselves within six months of transplant, although this varies by age, health, and the organ they receive.

I was there for my one-year post-transplant treadmill stress test. I had completed the required health history forms before the test. Of course, I included my heart health history from before the transplant. Much to my amazement, the technician excitedly stated, “Oh, not with this heart, you didn’t!” as she crossed out that entire section. That section related my old heart’s history! What a revelation! That old heart history, with all its problems, didn’t apply to my NEW heart!

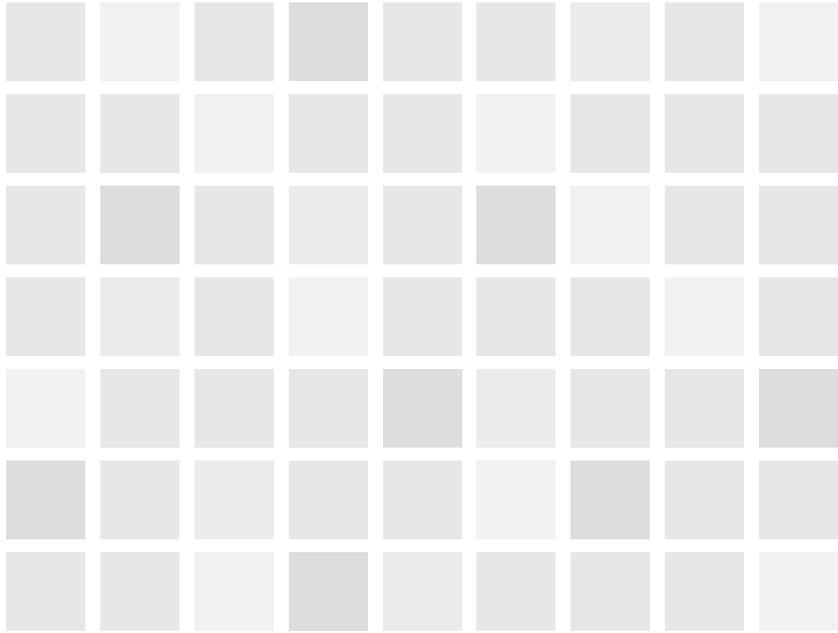
– Heart recipient

**I’ve seen and met  
angels wearing the  
disguise of ordinary  
people living  
ordinary lives.**

– Tracy Chapman



## SECTION 3



# Living Donation

Living donation offers another choice for transplant candidates. In 2010 there were 28,662 organ transplants performed in the U.S. More than 6,500 of these were living donor transplants. With more than 112,000 people waiting for transplants in the United States as of 2011, the demand for organs far exceeds the supply. Living donation extends the supply of organs.

**Need more information?  
Visit [www.transplantliving.org](http://www.transplantliving.org)  
(click on Living Donation).**

### History

- The first successful living-donor transplant was done between 23-year-old identical twins in 1954.
- Living donor kidney transplants did not become routine until the development of modern immunosuppressive medications to prevent rejection.
- The first successful living-donor liver transplant was performed in 1989.
- The first successful living-donor lung transplant was performed in 1990.

### Facts about Living Donation

#### Who can be a Living Donor

Parents, children, husbands, wives, friends, co-workers—even total strangers—can be living-donor candidates.

#### Organs a Living Donor may Give

- one kidney
- segment of the liver
- lobe of a lung
- portion of the pancreas
- portion of the intestine

### Donor Relationship with Transplant Candidate

#### Directed Donation

- **related:** healthy blood relatives of the transplant candidate.
- **unrelated:** healthy people who are not blood relatives of the candidate. They may or may not have a social connection to the transplant candidate.

#### Non-Directed Donation

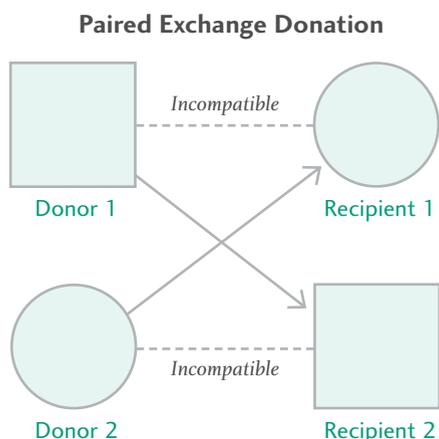
Non-directed living donors are not related to or known by the recipient, but donate purely from selfless motives. This type of donation is also called anonymous, altruistic, altruistic stranger, and stranger-to-stranger living donation.

I am a living donor from Rhode Island. In 2002 my good friend, Bonnie, confided over coffee that she had been sick with kidney disease for a long time. She needed a kidney. Her relatives were not viable donors. I privately thought about her predicament and a few days later told Bonnie that I would give it a shot.

– Directed unrelated living donor

## When the Living Donor and Candidate Don't Match

**Paired exchange donation** consists of two or more kidney donor/recipient pairs whose blood types are not compatible. The two recipients trade donors so that each recipient can receive a kidney with a compatible blood type. Once all donors and recipients have been tested, the kidney transplant surgeries can be scheduled to occur simultaneously.



**Blood type incompatible donation** allows candidates to receive a kidney from a living donor who has an incompatible blood type. To prevent immediate rejection of the kidney, recipients undergo specialized medical treatments before and after the transplant to remove harmful antibodies from the blood. The surgeon also removes the spleen during transplant.

### Blood Type Compatibility Chart

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

**Positive crossmatch donation** involves a living donor and a transplant candidate who are incompatible because antibodies (a protein substance) in the candidate will immediately react to the donor's cells, causing loss of the organ. The candidate receives specialized treatment to prevent rejection.

### Living Donor Criteria

Living donor candidates should be:

- in good physical and mental health.
- free from high blood pressure, diabetes, cancer, HIV, hepatitis, or organ-specific diseases.
- at least 18 years old.

These medical/physical criteria are very important for organ donation, but there are others. They play a critical role in finding good candidates for transplant. A good donor should also:

- **be willing to donate:** No one should feel that they **MUST** donate.
- **be well informed:** A good donor candidate has a solid grasp of the risks, benefits, and potential outcomes, both good and bad, for both the donor and recipient.
- **have good support:** Significant others should support your decision.
- have no alcohol or substance abuse problems.
- have psychiatric diagnoses well controlled over an extended period of time.

**I trusted what I felt  
in my gut. I trusted  
my decision to do  
what I chose to do.  
I chose to donate  
a kidney.**

*– Non-directed living donor*

## Getting Started

If you want to donate to someone you know, contact their transplant center. If you want to donate to anyone who needs an organ, contact the transplant program of your choice. Consult the OPTN/UNOS member directory page at <http://optn.transplant.hrsa.gov> (click on Members>Member Directory) for a list of transplant centers by state. Once you find a transplant program, call to let them know you want to be a living donor. To find out more about being a living donor, go to [www.transplantliving.org](http://www.transplantliving.org) (click on Living Donation>Being a Living Donor).

## Moving Forward

After your first contact with the transplant team, if you still want to go forward, you will begin an extensive series of tests to determine if you can donate an organ without harming your own health, and to provide the best outcome for the candidate.

As part of the process you will be asked to talk about:

- Why you want to donate
- Your current relationship with the recipient (where applicable)
- How you believe donation will impact (change) your relationship with the transplant candidate (where applicable)
- Who will provide support for you (financial, physical, social, and emotional) during the transplant process
- Plans with your employer while you recover from donation
- Plans for childcare or other responsibilities during your recovery period
- Your emotional preparation for a less-than-optimal transplant outcome
- How you handle stress and disappointment
- Future plans for having children
- Future plans for schooling or employment

Every donor should have someone other than the transplant candidate to support them during the process.

## Things to Remember

- You should receive the same quality of care and attention that the recipient does.
- Your donor work-up is confidential. Information cannot be shared with the transplant candidate or anyone else.
- You may stop the donor work-up at any time and the transplant program will help to identify a blameless reason for not continuing.

## What You Should Know about Living Donation

### Risks

Living donation is major surgery. All complications of major surgery apply. These include:

- pain
- infection at the incision site
- incisional hernia
- pneumonia
- blood clots
- hemorrhaging
- potential need for blood transfusions
- side effects associated with allergic reactions to the anesthesia
- death

You may also have negative psychological symptoms right after donation or later. You and/or your recipient may face surgical complications. The transplanted organ may not work right away. There is also the chance it will not work at all.

Donors may feel sad, anxious, angry, or resentful after surgery. Donation may change the relationship you have with the recipient.

### Positive Aspects of Donation

Living donation provides an unparalleled opportunity to give someone a second chance at life. Through donation, many recipients may be able to resume many of their normal activities: working, playing sports, independent self-care, and living life to the fullest. Not only do you impact the life of one person or one family, but by taking a single person off the waiting list, you open the door for others who don't have a living donor.

### Legal Aspects

In 1984 Congress passed the National Organ Transplant Act (NOTA), which prohibits the sale of human organs. However, the payment of "the expenses of travel, housing, and lost wages incurred by the donor of a human organ in connection with the donation of the organ" is expressly permitted by section 301 of the NOTA.

### Financial Aspects

Living donor medical costs are generally covered by the recipient's insurance. This includes customary costs associated with the donor evaluation and follow-up. However, some post-operative costs, especially those incurred after the initial post-surgical visit, may not be covered. Living donation may also impact your ability to obtain health insurance in the future.

Here are some expenses that may not be covered by the recipient or his/her insurance:

- annual physicals
- lodging
- travel costs
- lost income from work
- health problems identified as part of the donor evaluation
- non-medical expenses

Your health insurance also may not cover these expenses either. Talk to the transplant program's financial counselor about any of your financial concerns before the transplant. You may also call the National Living Donor Assistance Center at (703) 414-1600 or go to [www.livingdonorassistance.org](http://www.livingdonorassistance.org). They help qualifying donors with uncovered expenses.



### Questions to Ask

Questions to consider as you give careful consideration to becoming a living donor include the following:

- How do I feel about organ donation?
- Can I afford to be a living donor?
- What will my insurance cover?
- Do I know enough to make an informed decision?
- Am I being psychologically pressured to be a living donor?
- Is there someone else who could donate?
- If there is more than one possible donor, how will the living donor be chosen?
- Will donation impact my relationship with the recipient?
- What are the medical risks involved?
- How does my religion view organ donation?
- Am I up to it physically? Are there aspects of my health that should keep me from donating?
- Do I have a support network to help me through this process?
- How will I feel if I am rejected as a result of the screening process?
- Am I prepared to deal with the possible rejection of the organ?

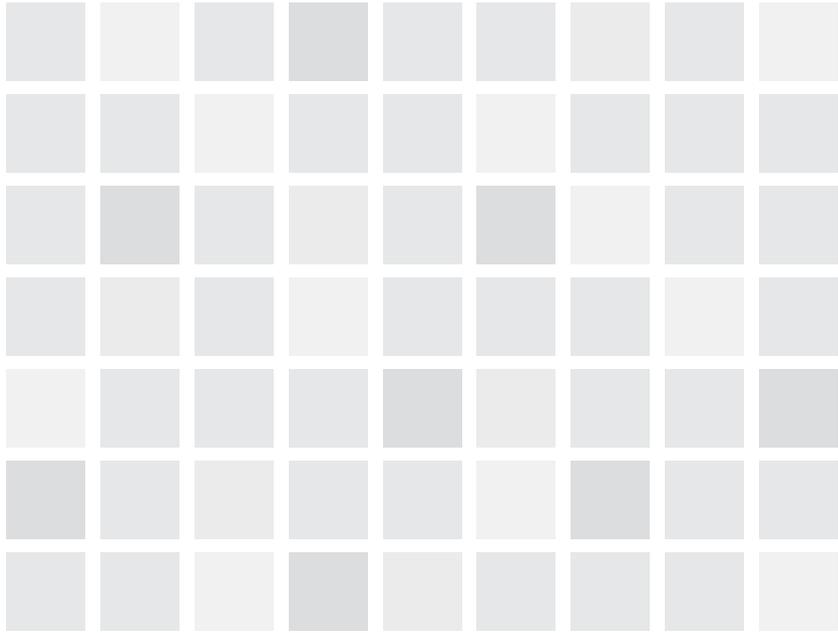
I donated a kidney to my son, Tyler, in 1993 after an accident destroyed his kidneys. The nephrologist encouraged me to consider donating a kidney. My biggest concern during my transplant work-up was, 'What if I can't donate?' I feared, 'Who else could we find to donate? What if they find something wrong with me?'

– *Living donor mom*

**Unless someone  
like you cares a  
whole awful lot,  
nothing is going  
to get better.  
It's not.**

– *Dr. Seuss*

## SECTION 4



# Developing a Financial Plan

Transplants are expensive. Patients and families are understandably concerned about how the cost of transplant will affect them. Your concerns are valid, but many tools are available to help you develop a financial plan for your care, both before and after the transplant. Your transplant team will share these resources with you.

### Support Services

Most transplant programs have social workers and financial coordinators who can help you with the financial details of your transplant. Depending on the structure at your center, one or both will help you develop a strategy.

### Transplant Social Workers

There are two types of financial challenges in transplant. There are the obvious issues, such as paying for the surgery and medications necessary after transplant. Also, there are unexpected financial issues, such as:

- inability to pay your medical bills
- lack of funds to meet daily needs
- lack of transportation to and from the transplant facility
- lack of housing for out-of-town patients and family members
- re-employment issues

Your social worker can help you find resources to manage your issues and decrease your anxiety. Information you share with your social worker will remain confidential, as long as it is not vital to your medical care.

### Financial Coordinators

Your transplant financial coordinator focuses on insurance issues related to the transplant surgery and medical follow-up. They are experts in insurance and hospital and physician billing issues who can help with insurance requirements and coordinate benefits. They might also suggest other ways to manage the costs of your care.

### Financial Questions

- If I have questions or problems, how can I contact you?
- What is the average cost for a pre-transplant evaluation?
- What is the average cost for the transplant I need?
- What is the average cost of follow-up care?
- How much will my insurance cover and what portion do I have to pay?
- Do you require a deposit or a down payment for my pre-transplant evaluation or transplant? If so, how much?
- What if I have no resources? What are my options for community assistance?
- 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? Does your hospital have a payment plan?
- Do you know of any local organizations that can assist us with transportation or lodging?



# Hope is patience with the lamp lit.

– Tertullian

## Transplant Costs

You, the transplant recipient, are responsible for the following charges (along with your insurance or other coverage):

- candidate testing and evaluation for transplant
- transplant surgery (surgeons, anesthesia, and operating room personnel)
- follow-up care, lab tests, and medication

**Note:** *The recipient is NOT personally responsible for any costs related to the recovery of deceased donor organs and the donor's medical expenses.*

## Donor Expenses

All costs associated with the recovery of deceased donor organs or tissue are assumed by the OPO. These charges are then paid by the recipient's insurance. Living-donor medical costs and immediate follow-up also are paid by the recipient's insurance. Non-medical expenses (housing, transportation, etc.) are not covered.

## Other Costs

- food, lodging, and transportation near the transplant center if required
- lab tests
- physical or occupational therapy and other treatment
- the cost of anti-rejection drugs and other medications, which can easily exceed \$10,000 per year for the lifetime of the transplanted organ
- non-covered medical costs (blood pressure monitors)
- loss of income while out of work
- insurance or Medicare premiums, copays, and deductibles

## Charges for Organ Transplant

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

**TABLE 1: ESTIMATED U.S. AVERAGE 2011 TRANSPLANT COSTS PER MEMBER PER MONTH (PMPM)**

TRANSPLANT	TOTAL ESTIMATED NUMBER OF TRANSPLANTS	ESTIMATED BILLED CHARGES	Under Age 65			Ages 65 and Over			
			ESTIMATED NUMBER OF TRANSPLANTS	ESTIMATED ANNUAL UTILIZATION PER 1,000,000	ESTIMATED COSTS PMPM	ESTIMATED NUMBER OF TRANSPLANTS	ESTIMATED ANNUAL UTILIZATION PER 1,000,000	ESTIMATED COSTS PMPM	
SINGLE ORGAN/TISSUE	BONE MARROW – ALLOGENEIC	6,894	\$805,400	6,460	23.82	\$1.60	434	10.47	\$0.70
	BONE MARROW – AUTOLOGOUS	13,263	363,800	10,969	40.82	1.22	2,294	55.32	1.68
	CORNEA	46,081	24,400	15,806	75.69	0.12	30,275	730.02	1.48
	HEART	2,161	997,700	1,878	6.76	0.57	283	6.82	0.57
	INTESTINE	74	1,206,800	72	0.24	0.03	2	0.05	0.01
	KIDNEY	16,571	262,900	13,815	53.03	1.11	2,756	66.46	1.46
	LIVER	5,898	577,100	5,302	19.79	0.94	596	14.37	0.69
	LUNG – SINGLE	734	561,200	443	1.73	0.08	291	7.02	0.33
	LUNG – DOUBLE	1,050	797,300	892	3.29	0.22	158	3.81	0.25
	PANCREAS	286	289,400	285	1.10	0.03	1	0.02	0.00
MULTIPLE ORGAN	HEART-LUNG	30	1,248,400	30	0.11	0.01	0	0.00	0.00
	INTESTINE WITH OTHER ORGANS	107	1,343,200	106	0.35	0.04	1	0.02	0.00
	KIDNEY-HEART	66	1,296,500	59	0.21	0.02	7	0.17	0.02
	KIDNEY-PANCREAS	867	474,700	865	3.38	0.13	2	0.05	0.00
	LIVER-KIDNEY	369	1,026,000	325	1.21	0.10	44	1.06	0.09
	OTHER MULTI-ORGAN	42	1,707,500	41	0.16	0.02	1	0.02	0.00
<b>TOTAL</b>					<b>\$6.24</b>			<b>\$7.28</b>	

Source: Milliman 2011 U.S. Organ and Tissue Transplant Cost Estimates and Discussion: <http://publications.milliman.com/research/health-rr/pdfs/2011-us-organ-tissue.pdf>

## Financing your Transplant

The first step in developing a financial strategy is to figure out how much of your costs insurance will cover. Your financial coordinator or social worker can help. Then you can begin to explore other funding sources.

Most patients use a combination of sources. Some patients can finance the transplant procedure through their primary insurance coverage and use savings and other private funds to pay for other expenses. Many patients work with community fundraising groups to complete their transplant financial strategy.

Common sources of transplant funding:

- private insurance
- Medicare coverage
- Medicaid coverage
- TRICARE (formerly Champus)
- Veterans Administration
- state “high-risk” insurance pool
- prescription drug assistance programs
- personal fundraising campaigns
- charitable organizations

## Private Health Insurance

Even if you have health insurance, the terms and extent of coverage vary widely. Read your insurance policy carefully to see what types of transplant costs (lab tests, medications, and follow-up appointments) are covered. If you have questions, contact your employer’s human resources department or contact your insurance company directly.

Some insurance questions to consider:

- Is my transplant center in-network with my insurance company?
  - If my transplant center is out-of-network, do I have an out-of-network benefit for transplant?
- What deductibles will apply?

- What are my co-payments for
  - doctor visits?
  - hospitalizations?
  - medications?
- Does my plan require prior authorization?
- Who needs to get prior authorization?
- Does my plan have a lifetime maximum or “cap” for transplant services?
- Do any pre-existing-condition requirements apply to coverage for a transplant?

Regardless of how much your insurance covers, you are responsible for any unpaid costs, unless you have made other plans. Keep up with your insurance premiums so that you do not lose your coverage. Include these costs in your financial strategy.

## COBRA Extended Employer Group Coverage

If you are insured by an employer group health plan and you must leave your job or reduce your work hours, you may qualify for extended coverage through COBRA (Consolidated Omnibus Budget Reconciliation Act of 1985). This federal law requires certain group health plans to extend coverage for 18 to 36 months after benefits end. This requirement is limited to companies employing 20 or more people. You pay the full cost of the premiums for the group health plan. Learn more by contacting your employer’s benefits office or visit the federal Department of Labor site at [www.dol.gov](http://www.dol.gov) (click on Health Plans & Benefits>COBRA).



### Medicare

Medicare is a federal health insurance program available to people:

- age 65 or older and those under age 65 with certain disabilities
- of any age with permanent kidney failure (“end-stage renal disease” or ESRD)

Medicare, like most private insurance plans, does not pay 100% 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 other expenses. Medicare currently offers coverage for transplant of:

- kidneys
- kidney-pancreas
- pancreas, either after a kidney transplant or for certain indications

If you already have Medicare due to age or disability, Medicare also covers other transplants:

- heart, in certain circumstances
- lung
- heart-lung
- liver, including transplants necessitated by hepatocellular carcinoma (HCC)
- intestines

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 transplants they perform and the quality of patient outcomes.

If you have questions about Medicare eligibility, benefits, or transplant programs, contact your local Social Security office, go to [www.medicare.gov](http://www.medicare.gov) on the Web, or call (800) MEDICARE/ ([800] 633-4227)/ TTY: (877) 486-2048.

### Medicare Prescription Drug Plans

Medicare Part D covers costs for prescription drugs. To get this coverage you must choose and join a Medicare drug plan. For more information call (800) MEDICARE ([800] 633-4227)/ TTY: (877) 486-2048 or visit [www.medicare.gov](http://www.medicare.gov) (click on Medicare Basics>Part D).

### MediGap Plans

Many people on Medicare also choose to buy a private “Medigap” policy to pay for costs not covered by Medicare. Check with a local insurance agent or go to [www.medicare.gov](http://www.medicare.gov) (click on Resource Locator>Medigap).

### State Health Insurance Assistance Program

The State Health Insurance Assistance Program (SHIP) is a national program that offers one-on-one counseling and assistance to people with Medicare and their families. Your transplant social worker or financial coordinator can provide information on your state’s SHIP program, or go to <https://shiptalk.org> (click on Find a State SHIP).

### Medicaid

Medicaid is a federal and state government health insurance program for certain low-income individuals. Each state determines criteria for:

- eligibility
- benefits
- reimbursement rates

Most Medicaid programs only cover transplants performed in their state, unless there are no centers that can transplant that organ. For more information, contact your local human services department or the financial coordinator at your transplant center.

## Pharmaceutical Company Patient Assistance Programs (PAPs)

Most pharmaceutical companies provide assistance for persons who have difficulty purchasing medications through company-based programs known as patient assistance programs or PAPs. Guidelines for participation can include the following:

- an application signed by the prescribing physician
- income below a certain level, set by each company, usually by medication
- confirmation that the applicant does not have other coverage and that they are a U.S. citizen

Guidelines are specific to each drug company, and there may be different guidelines for different medications. Talk to your transplant social worker about accessing PAPs. You can find more information on each drug company's website. Links are in Section 8: Resources.

## TRICARE (Formerly Champus) and Veterans Administration

Government funding for families of active-duty, retired, or deceased military personnel may be available through TRICARE. TRICARE standard may share the cost of most organ transplants and combinations. TRICARE also covers living donor kidney, liver, and lung transplants. 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.

For more information about TRICARE, contact the health benefits advisor at your nearest military health care facility, call the TRICARE Benefits Service Branch at (303) 676-3526 or visit [www.tricare.mil](http://www.tricare.mil).

For more information about the Veterans Administration (VA) National Transplant Program, contact your VA specialist or primary care provider. For questions about the VA National Transplant Program, call (800) 60-HEART ([800] 604-3278) or (202) 461-7130, or visit [www.va.gov/transplant/](http://www.va.gov/transplant/).

## State “High Risk” Insurance Pool

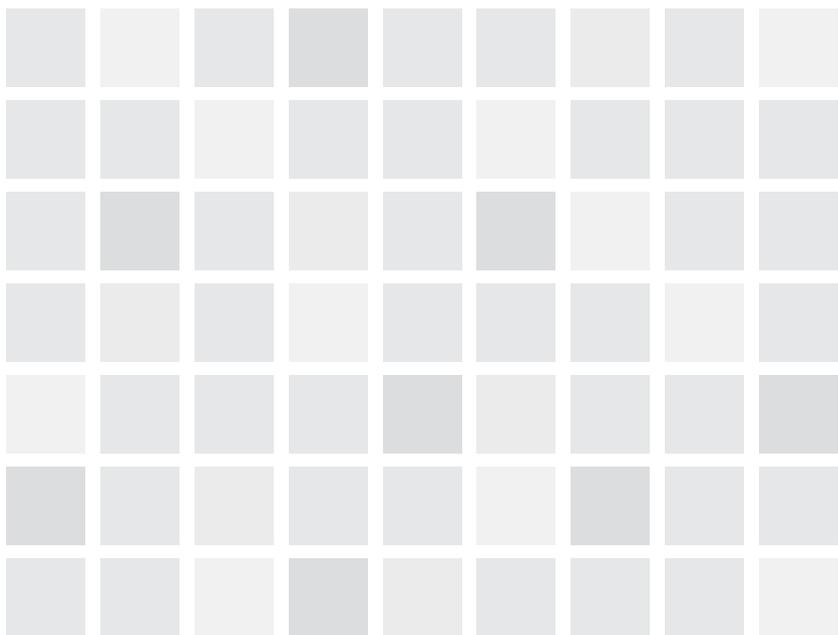
Many states offer a high-risk health insurance pool to provide access to coverage to individuals with serious pre-existing medical conditions. Typically the premiums are higher, and the coverage may be more limited. Ask your transplant center social worker or financial coordinator if your state has a high-risk insurance pool or visit [www.healthinsurance.org](http://www.healthinsurance.org) (click on Risk Pools).

Go to [www.transplantliving.org](http://www.transplantliving.org) (click on Before the Transplant > Financing a Transplant > Financial Resources Directory) for more resources.

Every day holds  
the possibility  
of a miracle.

– Elizabeth David

## SECTION 5



## Life after Transplant

Every transplant candidate has a dream of what life will be like on the day after transplant surgery. Those dreams can be both thrilling and frightening, so it helps to know what you might expect.

Transplant recipients will tell you two truths: no two transplants are alike, and a transplant is not a cure. Even after your transplant, you may still have a serious chronic illness that must be closely managed.

### Immediately after Transplant

After dealing with the effects of long-term illness (lack of energy, shortness of breath), you may feel euphoric when you awake after surgery to find those symptoms gone. Anesthesia often protects you from post-surgical pain for a short time. Follow your team's pain management instructions to make the overall experience as comfortable as possible.

Transplant is major surgery. It may take time to get back to eating normally, moving around, and managing your own care. Don't be discouraged. Most recipients report feeling much better just after transplant. Others take longer to feel better, move around, and manage their care. Remember that you now have a functioning organ, which gives you a new lease on life.

We do not defeat death with a transplant; rather, we gain an extension of life. So the real question becomes, 'What are we going to do with the days, months, and hopefully years of extended life?'...the same question even the non-transplanted face in their own lives.

– Heart recipient

### Going Home

There is no set time when people go home after transplant. These factors can affect how soon you will be able to go home:

- The organ that you received; recovery for each organ is different
- Your overall health status and ability to take care of yourself
- Your lab results
- Other chronic health problems
- Availability of support at home

After you are discharged from the hospital, here are a few things to expect.

### Medications

Immunosuppressants, or anti-rejection medications, "hide" your new transplanted organ from your body's immune system to protect it from being attacked and destroyed. Take these and other medications just as your doctor prescribes. Talk to your transplant team before making any changes. You will take immunosuppressants for the lifetime of your transplanted organ. Visit [www.transplantliving.org](http://www.transplantliving.org) (click on After the Transplant > Medications) for more information.

You also will take other medications to help the immunosuppressants to do their job, or to control side effects. You may need medications for other chronic health problems. In the beginning it seems like you are taking lots and lots of medications, but this likely will change as you recover.

### Doctors Visits and Wellness Appointments

In the first few months after transplant, you will visit with your transplant team frequently to be sure that your new organ is functioning well and to help you develop good health habits. A big part of keeping your new organ healthy means keeping your body as healthy as possible. Keeping all wellness appointments will help you meet this goal.

- Keep up with other check-ups—dental, gender specific, eye exams.
- Monitor your blood pressure, weight, and cholesterol.
- Get all recommended health screenings on schedule.

### Get Moving

Every person is different. The amount and type of activity you can handle after your transplant depends on your age and health. The goal is still to get moving. For one person, “moving” may mean sitting up in a chair. For another, it might mean walking several times a day.

If moving is challenging, your transplant team may prescribe physical rehabilitation to get you started in the safest manner possible. Rehabilitation may be done at home or at an outpatient facility. Sometimes a stay in a rehab facility is necessary. Don't be alarmed if you need rehab. It is one resource your transplant team uses to get you back to a more normal life. Once you have found your “new normal,” keep exercising so that you stay as fit as possible.

**First we make  
our habits;  
then our habits  
make us.**

*– Charles C. Noble*

### Lifestyle Changes

You may be able to return to activities that you gave up because of your illness. Many people return to playing sports, gardening, or hiking. Remember, don't start or resume any activity without getting approval from your transplant doctor first.

After transplant you may need to change your diet. You may need to drink more water. You'll need to get laboratory tests done frequently. If you are a kidney recipient, you won't go to dialysis anymore. This is a good time to curb cigarette or alcohol use.

### Back to Work or School

Many people go back to their jobs or classes, or even start new careers based on insights gained during their transplant journey. Vocational rehabilitation helps people who have been out of the workforce because of a disability get assistance that allows them to go back to work. Ask your transplant social worker about vocational rehabilitation services in your state.

**What lies behind us  
and what lies before  
us are small matters  
compared to what  
lies within us.**

*– Ralph Waldo Emerson*

### **Physical Changes and Challenges**

It is common to have at least one episode of rejection, when your body attacks the newly transplanted organ. “Rejection” is a very scary word, but it doesn’t always mean you are losing your transplanted organ. Your transplant team knows how to manage rejection with medication. After treatment, most people live normally with their transplanted organ.

Other complications may require re-hospitalization. Going back into the hospital allows you to be properly monitored and treated so that you can get healthy quickly.

Many transplant patients experience annoying short-term side effects from the anti-rejection medications—hair growth, acne, mood swings, and weight gain, to name a few. Symptoms diminish as the initial high dose of medications is tapered down in the early months after transplant. Talk with your transplant team about your concerns.

### **Relationship Changes**

While you were ill, family members and friends may have managed many things for you or helped you with your care. After your transplant, you may be able to handle more of these issues on your own. As you change and feel better, everyone will have to adapt their thoughts and behaviors to a new you.

Before your transplant, sexual activity may have been out of the question. Now that you feel better, you may be ready to reconsider. Talk to your transplant team before resuming sexual activity. Open communication will be important to maintaining good relationships.

### **Take It All In**

It may be difficult to absorb all that has happened. If you received an organ from a deceased donor, you may feel sad or guilty because someone else died so that you could have a chance at a healthier life. Take advantage of emotional and spiritual supports to help you understand how you feel about your transplant.

### **Communicate with Your Donor or Donor Family**

When you are ready, you may want to express your feelings to or about your donor. If you received your organ from an unknown deceased donor, you could write a letter to the donor family. Your transplant team can help get your letter or other communication to a living donor or donor family.



### Pay It Forward

Your transplant is an awesome gift. You can never truly repay your donor, but you can honor the sacrifice that was made:

- Take good care of yourself and your new organ.
  - Take your medications.
  - Exercise.
  - Keep up with wellness checks.
- Get involved in promoting organ and tissue donation in your community so that someone else can receive the same wonderful gift.

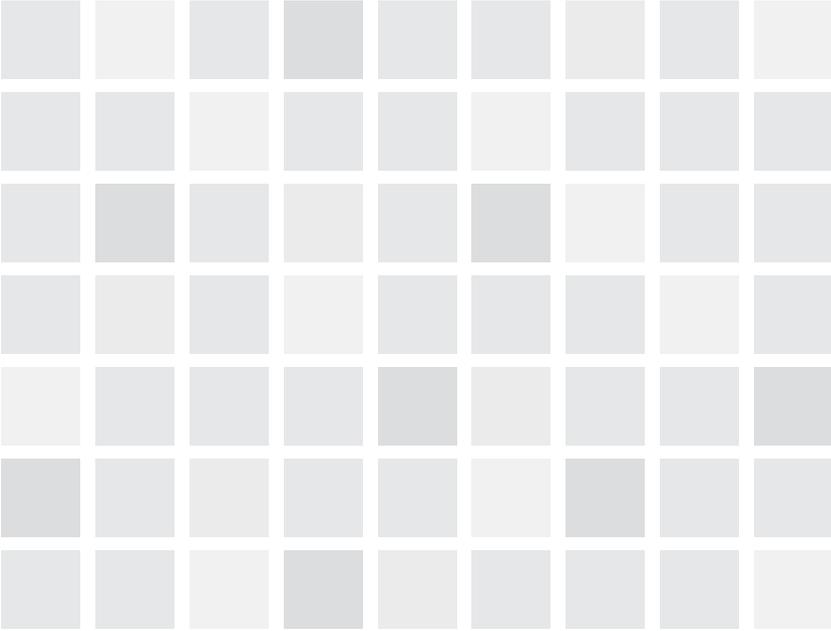
See Section 6, Promoting Organ and Tissue Donation in Your Community, for more information about volunteering.

**We must be  
the change we  
wish to see in  
the world.**

*– Mahatma Gandhi*



## SECTION 6



# Promoting Organ and Tissue Donation in Your Community

As you know, the organ shortage is the reason why patients must wait for transplants. You can help promote organ and tissue donation by urging others to become an organ donor, inform their families, and sign onto their state's donor registry.

Most states have a donor registry that allows people to record their decisions to become organ, tissue, and eye donors after death. In nearly every state, these decisions become binding after death. Encouraging others to document their donation decisions will help to ensure that their wishes are honored and that lives will be saved through their gifts—maybe even your own life.

In 2006, about 60 million Americans were registered to be donors. That number increased to 100 million in 2011 because people like you encouraged others to document their wishes. You can actively promote donation in your community by contacting your local OPO. Most OPOs have volunteer programs that provide speaker training so that you can learn how to tell your story. OPO staff will help connect you with the right opportunities for your comfort level, such as working at health fair booths or speaking to civic groups. To locate your local OPO, call UNOS patient services at (888) 894-6361 or visit <http://optn.transplant.hrsa.org> (select Members>Member Directory).

The next section provides some facts to help you promote organ and tissue donation.

**Giving  
liberates the  
soul of  
the giver.**

*– Maya Angelou*



## Donation Facts and Figures

- People of all ages and medical histories are potential donors. As medical science advances, donation opportunities change. Your medical condition at the time of death will determine what organs and tissue can be donated.
  - Donated organs—heart, pancreas, kidneys, liver, lungs and intestines—save lives. Tissue is needed to replace bone, tendons, and ligaments lost to trauma or cancer and other diseases. 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. Even hands and faces can be transplanted to improve the lives of those in need.
  - All major religions either support organ and tissue donation as an unselfish act of charity or leave the decision to the individual. Some even go so far as to say it is a “sin” not to donate organs when possible.
  - There is no cost to the deceased donor’s family or estate for organ and tissue donation. The donor family pays only for medical care before death and funeral expenses.
  - It is illegal to buy or sell organs and tissue in the United States.
  - It is possible to donate life as a living kidney donor or as a partial liver, lung, pancreas, or intestine donor. For more information visit [www.transplantliving.org](http://www.transplantliving.org).
  - Each year since 2004, more than 7,000 deceased donors make more than 20,000 organ transplants possible. In addition, there are more than 6,000 transplants each year from living donors. There are about 30,000 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. More than 112,000 men, women, and children currently await life-saving organ transplants. Sadly, an average of 18 people die each day because of a lack of available organs.
  - Each organ and tissue donor can save and enhance the lives of up to 50 people.

**To find your state’s online registry link, go to Donate Life America’s map at <http://donatelife.net/register-now/>.**

## The Organ and Tissue Donation Process

- Organ and tissue donation becomes an option only after all life-saving efforts have been made and death has been declared. Donation does not interfere with medical care.
- Consent for donation is confirmed by either verifying the person’s enrollment on a state registry or obtaining written consent from the family. The donor’s family is asked to participate in the process by providing a medical history.
- A surgical procedure is used to recover donated organs and tissue. The body is always treated with great care and respect.
- Donation will not delay or change funeral arrangements, and will not interfere with an open-casket funeral viewing.

### Who Receives Donated Organs and Tissue

Organs are matched based on medical information such as blood type, body size, and tissue type through a national computer system operated by UNOS. Tissue is distributed based on patient need, availability, and medical criteria.

### Tell Your Story

In advocating organ and tissue donation, here are four points to get across:

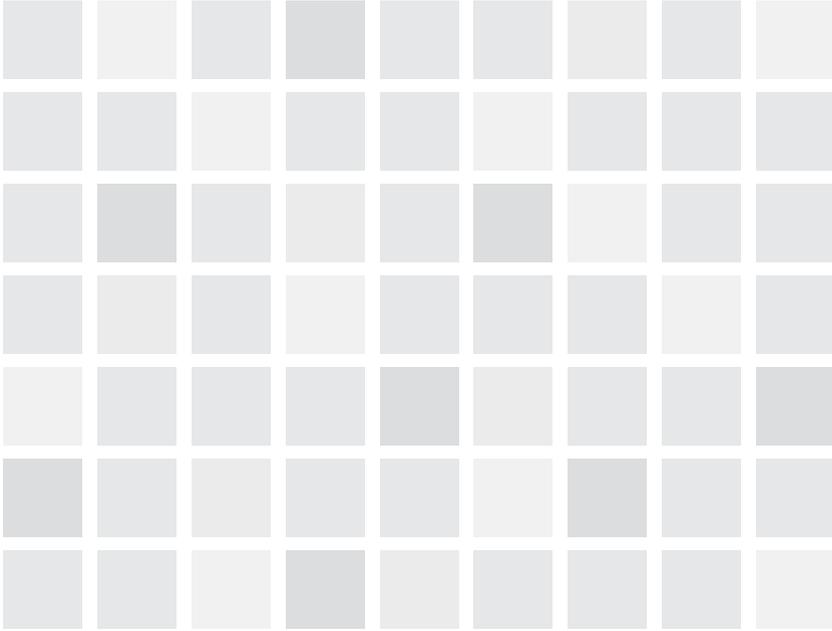
1. Transplantation works! Your own story is proof.
2. Encourage people to make their own decisions about donation.
3. Encourage them to take action and sign up with their state's donor registry.
4. Ask them to tell their family and friends, and to find out their wishes about organ donation. (Although registration is legally binding, telling family members is still a good idea.)

**Giving is better  
than receiving,  
because giving  
starts the  
receiving process.**

*– Jim Rohn*



## SECTION 7



## Glossary

For more terms, see  
<http://optn.transplant.hrsa.gov>  
 (click on Resources>Glossary)

### Adherence

See “Compliance.”

### Allocation

The process of determining how organs are distributed. Allocation includes the system of policies and guidelines that ensure that organs are distributed in an equitable, ethical, and medically sound manner.

### Allocation Policies

Rules established by the OPTN to guide and regulate organ allocation and distribution in the U.S.

### Allograft

An organ or tissue transplanted from one individual to another of the same species (for example, a kidney transplanted from one human to another human).

### Antibody

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

### Antigen

See Histocompatibility Antigen.

### 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.

### Body Mass Index

A measure of body size, calculated as weight in kilograms divided by height in meters squared.

### Blood Type

A blood type (also called a “blood group”) is a classification of blood based on the presence or absence of inherited antigenic substances on the surface of red blood cells (RBCs).

### Blood Type Incompatible Exchanges

Allows candidates to receive a kidney from a living donor who has an incompatible blood type. To prevent immediate rejection of the kidney, recipients undergo plasmapheresis treatments before and after the transplant to remove harmful antibodies from the blood. The surgeon also removes the spleen at the time of transplant.

### Brain Death

Irreversible and permanent cessation of all brain function. Artificial support systems may temporarily maintain body functions such as heartbeat and respiration for a few days, but not permanently. Most deceased donor organs are taken from brain-dead donors.

### Cardiomyopathy

A disease of the heart muscle itself that may result from inadequate blood flow, genetic diseases, toxic or inflammatory injury, or excessive workload on the heart.

### Calculated Panel Reactive Antibody (CPRA)

A number to describe the chance that a random organ donor would not be compatible with the intended recipient (patient) due to antibodies against the potential donor’s HLA antigens. A low CPRA number means that more donors are likely to be compatible and a high CPRA means that it may be very difficult to find a compatible donor. For example, we may know (through antibody testing) that an individual is “sensitized” to the human antigen A3; therefore, that person would likely suffer a rejection episode if they received an organ from a donor who had that antigen. Because we know that 22% of donors have the antigen A3, that person would theoretically be incompatible with 22% of the available organ offers or have a CPRA value of 22.

### Chronic Obstructive Pulmonary Disease (COPD)

A slowly progressive disease of the airways that is characterized by a gradual loss of lung function.

## Cirrhosis

A disease of the liver in which normal, healthy tissue is replaced with nonfunctioning fibrous scar tissue, and healthy, functioning liver cells are lost. It is the end stage of chronic liver damage that can occur because of alcohol abuse, malnutrition, viral infections, blockages in blood or bile flow, genetic diseases, toxins, or other, unknown causes.

## Cold Ischemia Time

The amount of time an organ spends being preserved after recovery from the donor.

## Compliance (also called Adherence)

The ability of a patient to follow (adhere, comply with) medical advice, especially as it relates to taking medications after transplant.

## Crossmatch

A complex blood test that is performed prior to a transplant to determine if the donor organ is compatible with the intended recipient. A positive crossmatch means that there was a reaction when the blood of the donor was mixed with that of the recipient; therefore, the organ should not be placed with that patient. A negative crossmatch means there is no reaction between donor and recipient, and it is probably safe to proceed with the transplant.

## Directed Donation

The donation of an organ to a specifically-identified recipient. Instructions are given by a donor or donor family member.

## Donate Life America

A nonprofit group of health care professionals, transplant patients, and voluntary health care and transplant organizations. Donate Life America works to increase public awareness of the organ shortage and promote donation of organs and tissues.

## Donation After Circulatory Death (DCD)

Donation after circulatory death is the recovery of organs after the circulation has ceased. DCD occurs when a patient's care is futile, and the patient is to be removed from all medical life-sustaining measures/supports.

## Durable Medical Power of Attorney

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

## End-Stage Organ Disease

A disease that leads to the permanent failure of an organ. Examples are end-stage renal disease and end-stage liver disease.

## Expanded-Criteria Donors

“Less traditional” donors who are 60 or older or who are between 50 and 59 with at least two of the following conditions:

- history of high blood pressure
- creatinine level >1.5 mg/dL (a creatinine test measures how well a kidney is functioning; normal range is 0.8 to 1.4 mg/dL)
- cause of death from a cerebrovascular accident (stroke or aneurysm)

## Functional Status

A way of measuring the effects that lung disease may have on a person's ability to perform routine daily tasks. Functional status is used in the Lung Allocation Score.

## Graft

A transplanted organ or tissue.

## Graft Survival

The length of time an organ functions successfully after being transplanted.

## Histocompatibility Antigens

Markers found on cells in the body that are unique to each individual. Also known as human leukocyte antigens (HLAs), these markers are inherited from one's parents. A person's immune system uses HLA markers to differentiate self from non-self. Any cell displaying a person's HLA type belongs to that person and therefore is not an invader. Any cell displaying some other HLA type is foreign or “non-self” and is identified as an invader. This will set off a chain of events that could result in the rejection of any cells or tissue bearing those markers. Therefore, it is important to test a transplant candidate to identify their unique HLA type.

## Histocompatibility Test

Testing to identify a patient's human leukocyte antigens (HLA) is often referred to as "tissue typing." Tissue typing is routinely performed for donors and transplant candidates to match the donor with the most suitable recipients and help decrease the likelihood of rejecting the transplanted organ. See "Human Leukocyte Antigen (HLA) System."

## Human Leukocyte Antigen (HLA)

See Histocompatibility Antigens.

## Human Leukocyte Antigen (HLA) Mismatch

An HLA mismatch is said to exist between a potential donor and recipient if the donor has a least one HLA antigen that is not shared with the recipient.

## Human Leukocyte Antigen (HLA) System

The complex of genes that includes those that make the HLA antigen proteins and other genes that regulate inflammatory responses to infections, cancer and foreign (non-self) tissues.

## Immune Response

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

## Immunosuppression

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

## Implanted Cardioverter Defibrillators (ICDs)

Pacemaker-like devices that continuously monitor the heart's rhythm and deliver life-saving shocks if a dangerous heart rhythm is detected.

## Informed Consent

The process of reaching an agreement based on a full understanding of what will take place. Informed consent involves information sharing as well as the ability to understand and freely make a choice.

## Kidney Paired Donation (KPD)

Program to assist incompatible recipients and their living donors to find a complementary, incompatible recipient/donor pair, with the end result of swapping kidneys from the first donor to the second recipient, and vice versa.

## Left Ventricular Assist Device (LVAD)

A mechanical device implanted into a patient with left heart failure that assists the left ventricle to provide blood circulation.

## Lung Allocation Score

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

## Match

Compatibility between the donor and the recipient. The more appropriate the match, the greater the chance of a successful transplant.

## Match Run

A computerized ranking of transplant candidates based on donor and candidate medical compatibility and criteria defined in OPTN allocation policies.

## Match System

The computerized algorithm used to prioritize patients waiting for organs. It eliminates potential recipients whose size or blood type is incompatible with that of a donor and then ranks those remaining potential recipients according to the ranking system approved by the OPTN Board.

## Mismatch

In kidney transplantation, a mismatch indicates the donor has at least one HLA antigen that is not present in the recipient.

## Model for End-Stage Liver Disease (MELD)/Pediatric End-Stage Liver Disease (PELD) Score

A numerical scale ranging from six (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 laboratory test results.

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 MELD scores.

## Multiple Listing

Being on the waiting list for the same organ at more than one transplant center.

## National Organ Transplant Act (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 and Tissue Procurement

Recovery of organs and tissues for transplantation.

## Organ Preservation

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

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

Organ Preservation Times:

- **Heart:** 4 – 6 hours
- **Liver:** 8 – 12 hours
- **Kidney:** 24 – 28 hours
- **Heart-lung:** 4 – 6 hours
- **Lung:** 4 – 6 hours
- **Pancreas:** 12 – 18 hours

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

## Organ Procurement Organization (OPO)

The organization 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 58 OPOs around the country, and all are UNOS members.

## Organ Procurement Organization (OPO) Donation Service Area

Each OPO provides its services to the transplant programs in its area. An OPO's donation 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.

## Plasmapheresis

The removal, treatment, and the return of blood plasma from the blood circulating in the body. During plasmapheresis, blood is initially taken out of the body through a needle or previously implanted catheter. Plasma is then removed from the blood by a cell separator. After plasma separation, the blood cells are returned to the person undergoing treatment, while the plasma (which contains antibodies that may cause organ rejection), is first treated and then returned to the patient.

## Positive Crossmatch

The intended recipient already has antibodies to the donor organ, meaning that if a transplant were to take place, the organ would most likely be rejected. There are treatments available that can reduce the number of antibodies within a transplant candidate and thus reduce the strength of a rejection response. These treatments are referred to as “desensitizing” and include drugs, plasmapheresis and a combination of the two. These treatments are very expensive, are very hard physically on the potential recipient, and are still considered experimental. Therefore, surgeons will usually perform positive crossmatch live-donor kidney transplants after a desensitizing treatment only if there are no other live donors with a negative crossmatch.

## Rejection

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

## Required Request

Hospitals must inform the local Organ Procurement Organization (OPO) of potentially suitable donors. The OPO then works with hospital staff to inform families 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.

## Retransplantation

Sometimes, because of organ rejection or transplant failure, 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.

## Right Ventricular Assist Device (RVAD)

A mechanism implanted into a patient with heart failure that maintains right ventricular blood circulation, which is circulation from the heart through the lungs.

## Sensitization

Patients are said to be sensitized when they have developed antibodies in their blood to specific HLA antigens. This can happen due to pregnancy, blood transfusions, or previous rejection of an organ transplant. Sensitization is measured by CPRA. For example, if a candidate has developed a specific antibody to the HLA antigen A2, that person is said to be “sensitized” to the A2 antigen. If a donor organ that displayed the A2 antigen were placed in that candidate, there may be an immediate rejection response (a hyperacute response) which would lead to the rejection of the transplanted organ. We know that 47% of all donors have the A2 antigen; so that person has a CPRA of 47%. That person may have to wait a long time to find a compatible donor.

## Split Liver

A split liver transplant occurs when the donor liver is divided into two segments and then transplanted into two recipients, or one segment could be transplanted into a child for whom an entire adult liver would be too large.

## Standard-Criteria Donor

A donor who does not meet the criteria for donation after circulatory death (DCD) or extended-criteria donation (ECD).

## Status/Score

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

## Survival Rates

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

## Thoracic Organs

Organs located in the chest — specifically, the heart and lungs.

## Tissue

An organization of a great many similar cells that perform a special function. Examples of tissues that can be transplanted are bones, bone marrow, corneas, heart valves, ligaments, saphenous veins, and tendons.

## Tissue Type

An individual's combination of HLA antigens. Matching for tissue type is used in the allocation system for kidney and pancreas transplantation.

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

– Joshua J. Marine

## Tissue Typing

A blood test that helps evaluate how closely the tissues of the donor match those of the recipient.

## Total Artificial Heart

A mechanical pump used to replace the function of a damaged heart, either temporarily or as a permanent prosthesis.

## Transferring Wait Time

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

## Transplant Center

A hospital that performs transplants, including evaluating patients for transplant, registering patients on the national waiting list, performing transplant surgery, and providing care before and after transplant.

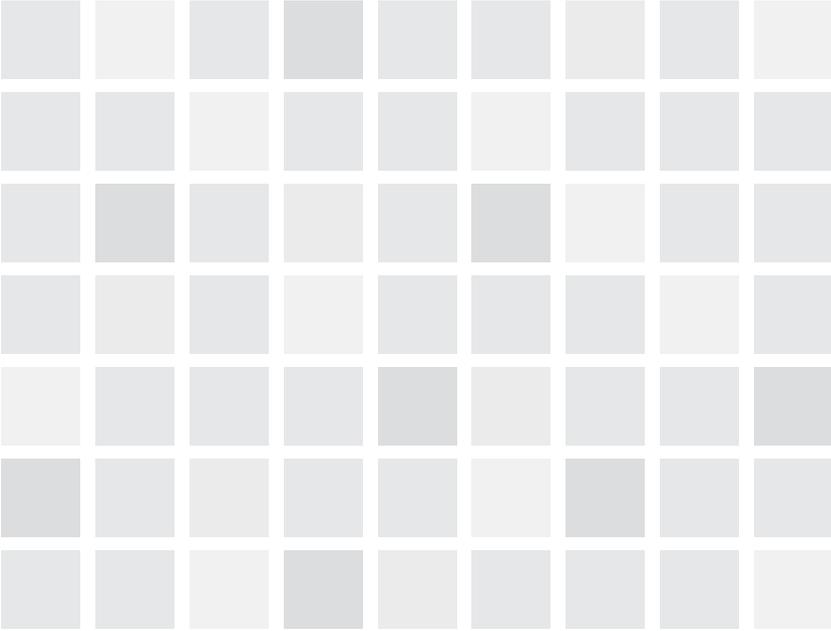
## Transplant Program

The organ-specific facility within a transplant center. A transplant center may have programs for the transplantation of hearts, lungs, liver, kidneys, pancreata, pancreas islets, and/or intestines.

## 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 system 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.

## SECTION 8



## Resources

Go to [www.transplantliving.org](http://www.transplantliving.org) for more resources, or call UNOS patient services at (888) 894-6361.

### **Air Charity Network (Angel Flight)**

4620 Haygood Road, Suite 1  
Virginia Beach, VA 23455  
Phone: (800) 549-9980  
Web: <http://aircharitynetwork.org>  
Transports ambulatory patients using private pilots and aircraft, for transplant and follow-up appointments. Service is free-of-charge; patient must document medical and financial need.

### **American Kidney Fund**

6110 Executive Blvd., Suite 1010  
Rockville, MD 20852  
Phone: (800) 638-8299  
Web: [www.akfinc.org](http://www.akfinc.org)

### **American Liver Foundation**

39 Broadway, Suite 2700  
New York, NY 10006  
Phone: (800) GOLIVER [465-4837]  
Email: [webmail@liverfoundation.org](mailto:webmail@liverfoundation.org)  
Web: [www.liverfoundation.org](http://www.liverfoundation.org)

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

2501 COTA Drive  
Bloomington, IN 47403  
Phone: (800) 366-2682  
Web: [www.cota.org](http://www.cota.org)

### **Georgia Transplant Foundation (GTF)**

6600 Peachtree Dunwoody Road  
600 Embassy Row, Suite 250  
Atlanta, GA 30328  
Phone: (866) 428-9411  
Web: [www.gatransplant.org](http://www.gatransplant.org)  
Provides financial and educational assistance for those undergoing or waiting for a transplant.

### **Medicare Hotline**

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

### **Minority Organ Tissue Transplant Education Program**

2041 Georgia Avenue, NW  
Ambulatory Care Center, Suite 3100  
Washington, DC 20060  
Phone: (800) 393-2839; (202) 865-4888  
Web: [www.nationalmottep.org](http://www.nationalmottep.org)

### **National Living Donor Assistance Center (NLDAC)**

2461 S. Clark Street, Suite 640  
Arlington, VA 22202  
Phone: (888) 870-5002, (703) 414-1600  
Web: [www.livingdonorassistance.org](http://www.livingdonorassistance.org)

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

Phone: (201) 567-1542  
Web: [www.nosscr.org](http://www.nosscr.org)

### **National Transplant Assistance Fund**

150 N. Radnor Chester Road, Suite F-120  
Radnor, PA 19087  
Phone: (610) 727-0612, (800) 642-8399  
Web: [www.ntafund.org](http://www.ntafund.org)

### **National Foundation for Transplants**

5350 Popular Ave., Suite. 430  
Memphis, TN 38119  
Phone: (800) 489-3863, (901) 684-1697  
Email: [info@transplants.org](mailto:info@transplants.org)  
Web: [www.transplants.org](http://www.transplants.org)

### **Transplant Recipients International Organization (TRIO)**

Phone: (800) TRIO-386 ([800] 874-6386)  
Email: [info@trioweb.org](mailto:info@trioweb.org)  
Web: [www.trioweb.org](http://www.trioweb.org)



### Prescription Drug Assistance Programs

Patient assistance programs for prescribed immunosuppressive medications are available by contacting:

#### Abbott Patient Assistance Program

Phone: (800) 633-9110

Web: [www.abbottpatientassistancefoundation.org](http://www.abbottpatientassistancefoundation.org)

#### Astellas Reimbursement Services

9a.m. – 8.p.m ET

Phone: (800) 477-6472

Fax: (866) 317-6235

Web: [astellasreimbursement.com](http://astellasreimbursement.com)

#### Genentech Access to Care Program

Phone: (877) 757-6243

#### Novartis Transplant Reimbursement Information

Phone: (877) 952-1000

#### NeedyMeds

Web: [www.needy meds.org](http://www.needy meds.org)

Web-based list of prescription assistance programs

**The only thing that stands between a person and what they want from life is often the will to try it and the faith to believe it's possible.**

*– Rich DeVos (heart transplant recipient and founder of Amway)*



