

TALKING ABOUT TRANSPLANTATION



# *Living Donation*

*Information you need to know*

UNITED NETWORK FOR ORGAN SHARING





## UNITED NETWORK FOR ORGAN SHARING

United Network for Organ Sharing (UNOS) is the non-profit organization that operates the Organ Procurement and Transplantation Network (OPTN) under contract with the federal government. For more information about UNOS, living donation, and organ transplantation, please call 1-888-894-6361 or visit [www.transplantliving.org](http://www.transplantliving.org).

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*In response to the shortage of organs for transplantation, relatives, loved ones, friends, and even individuals who wish to remain anonymous may serve as living donors for the more than 100,000 people on the national organ transplant waiting list. During each of the past five years, more than 6,200 transplants were made possible by living donors.*

*A living donor can save and/or greatly improve the quality of life of a transplant candidate. However, donating an organ is a personal decision that should only be made after you are fully informed about the possible risks and benefits. This brochure gives you basic information about living donation. It is critical to gather as much additional information as you can.*

## **Types of living donor transplants**

### *Organ types*

- Kidney (entire organ)
- Liver (segment)
- Lung (lobe)
- Intestine (portion)
- Pancreas (portion)

### *Relationship with transplant candidate*

#### **Directed donation:**

- Biologically-related donors are blood relatives, such as parents, brothers/sisters, and adult children.
- Unrelated donors can include people who have some type of social connection with a transplant candidate, such as a spouse or significant other, friend, or coworker. Other unrelated donors may be acquaintances or even strangers who have learned about a transplant candidate.

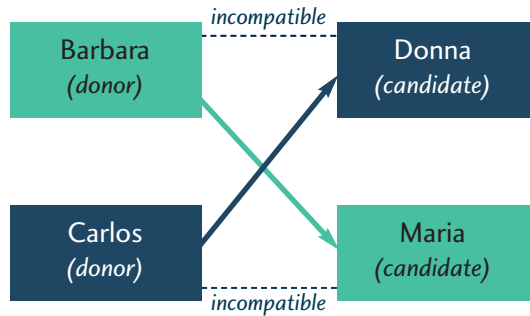
#### **Non-directed donation:**

- These individuals donate to an anonymous candidate on the national waiting list. Some of these donors may eventually meet the transplant recipients, but only if both parties agree.

## Matching donors and transplant candidates

- **Paired donation or paired exchange** involves two pairs of potential living kidney donors and transplant candidates who are not compatible. The two candidates “trade” donors so that each candidate receives a kidney from a compatible donor. For example, in Figure 1, Barbara wants to donate to her sister Donna, but they are not compatible. Carlos wants to donate to his wife Maria, but they are also not compatible. By “trading” donors so that Carlos matches Donna and Barbara matches Maria, two transplants are made possible. In some cases, this type of exchange has involved multiple living kidney donor/transplant candidate pairs.

Figure 1



- **Kidney donor waiting list exchange** occurs when a living donor who is incompatible with the intended transplant candidate donates to an anonymous candidate on the waitlist so the intended candidate can be given higher priority on the waitlist.
- **Blood type incompatible donation** occurs when a transplant candidate receives a kidney from a living donor with an incompatible blood type. To decrease the risk of rejection of the donated organ, candidates receive specialized medical treatment before and after the transplant.
- **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 against the donor’s cells, causing loss of the transplant. Specialized medical treatment is provided to the candidate to prevent rejection.

Certain living donation options may not be available at all transplant centers. Contact transplant centers directly for information on specific programs. You can also visit the Transplant Living Web site at [www.transplantliving.org](http://www.transplantliving.org) (choose Living Donation> First Steps).

## Who can be a living donor?

Living donors should be in good overall physical and mental health and free from uncontrolled high blood pressure, diabetes, cancer, HIV/AIDS, hepatitis, and organ diseases. Most living donors are older than 18 years of age and compatible with the intended transplant candidate. Since some donor health conditions can prevent the donation and transplant from being successful, it is important that you share all information about your physical and mental health.

You must be fully informed of the risks involved and complete a full medical and psychosocial evaluation. Your decision to serve as a donor should be completely voluntary and free of pressure or guilt. A living donor cannot be paid for the donated organ because it is illegal under the National Organ Transplant Act of 1984. However, living donors may receive reimbursement for certain expenses related to the donation process. Talk to a social worker or financial coordinator at the transplant center for more information.

## How do you start the process?

Contact the transplant center where the intended transplant candidate is being followed. If you would like to be a non-directed living donor, contact transplant centers directly to find out if they have this type of donation program. Visit the Transplant Living Web site at [www.transplantliving.org](http://www.transplantliving.org) (choose *Community > Member Directory*) for a complete list of transplant centers. You can also call the UNOS patient services line at 1-888-894-6361 for help.

When you contact transplant center staff, they will ask you questions about your medical history to find out if you have any conditions that would keep you from being a donor. You will complete a blood test to see if you are compatible with the intended transplant candidate. The transplant staff will answer your medical questions and tell you about the possible risks and benefits involved in being a donor. During this time, it is important for you to get as much information as possible from the center and other sources, such as those listed at the end of this brochure.

## Next steps

If you remain interested in being a donor after your first contact with the transplant center, the staff will begin their evaluation process. You will need to give them all information that they request. The transplant staff will ask about your financial situation and talk about who can give you physical help and emotional support throughout the donation process. Involving your loved ones in the educational part of the evaluation process can be helpful. They can learn about the donation surgery and recovery process and support you in your decision.

You will be asked to fully describe your reasons for thinking about donation and how it might affect your lifestyle (such as employment and family relationships). You will be given a complete physical and psychosocial evaluation and numerous medical tests to minimize any risk to your health and safety. The results of your evaluation should be kept confidential. The transplant candidate cannot access your personal information.

**The length of time it takes to complete the evaluation process can vary. If the candidate’s transplant center is far away, you may be able to complete *some* tests at a hospital or lab near your home.**

Here are examples of some of the tests you may be asked to complete as part of the evaluation:

**1. Blood test:** to check blood type compatibility between you and the transplant candidate.

- **Blood Type Compatibility Chart**

Donor’s Blood Type	Transplant Candidate’s Blood Type
O	O
A or O	A
B or O	B
A, B, AB or O	AB

*Note: The Rh factor (+ or -) in blood type is not important in compatibility.*



- **Tissue Typing:** this blood test checks the tissue compatibility between you and the transplant candidate.
- **Crossmatching:** this blood test determines how the transplant candidate will react to your organ. A “positive” crossmatch means that your organ is incompatible with the candidate. A “negative” crossmatch means that your organ is compatible with the candidate.
- **Antibody Screen:** when a foreign substance (antigen) enters a person’s body, a protein substance (antibody) is created in response to that antigen. (Blood from transfusions and viruses are examples of antigens.) Results of this test will show if the transplant candidate has antibodies in his/her body that would react to your antigens.
- **Blood tests to screen for transmissible diseases:** these tests determine if you have HIV/AIDS, hepatitis, cancer, and other transmissible diseases.

**2. Urine Tests:** a 24-hour urine sample is collected to look at your kidney function.

**3. Chest X-Ray and electrocardiogram (EKG):** these tests screen for heart and lung disease. Depending upon your age and medical history, other heart and lung tests may be needed.

**4. Radiologic testing:** these tests help physicians view the organ you want to donate, including its blood vessel supply. They can include a CAT scan, MRI, and arteriogram.

**5. Psychosocial and/or psychological evaluation:** this tool assesses your mental health, whether you feel pressure from others to donate, your ability to understand information and make an informed decision, and your daily life circumstances (such as the possible impact on your job, whether you would have any help while recovering from donation, and your family’s views about the donation).

**6. Gynecological examination:** female donors may receive a gynecological examination.

**7. Cancer screening:** these tests may include a colonoscopy, mammogram, prostate exam, and skin cancer screening. Your transplant team will determine your individual needs.



## Making an informed decision

Each transplant center must have a written living donor informed consent process. The OPTN/UNOS Living Donor Committee developed a resource that can help centers in developing their consent process. You can review it at [www.transplantliving.org](http://www.transplantliving.org) (choose *Living Donation >Informed Consent*). The informed consent process should help you understand all aspects of the donation process, including the risks and benefits. You should also talk about alternative procedures or types of treatment that are available to the transplant candidate, including dialysis or a transplant from a deceased donor.

Each transplant center must also have written protocols for all phases of the living donation process. As part of these protocols, you should be assigned an independent donor advocate (IDA) who is ideally not part of the transplant patient's medical team. This staff member advocates for your needs, rights, and interests and helps you understand the informed consent, evaluation, surgery, and follow-up processes.

Ask the IDA and any other staff at the transplant center any questions you have. It is important to be completely honest about your feelings, concerns, and fears about being a donor. Your decision to become a donor must be completely voluntary. You should never feel pressured to become a donor. You have the right to delay or stop the donation process at **any** time. The reasons behind your decision should be kept confidential.

Talk in detail with your loved ones, such as family members and close friends. Talk with other people who have been living donors. Consider contacting your transplant center and relevant organizations and Web sites listed at the end of this brochure before making a final decision. Fully consider how donation may impact your physical and emotional health, as well as your family life, financial situation, and current and future health and life insurance status.

### Medical and psychological risks

Living donation involves anesthesia and major surgery and their associated risks. Surgical complications can include pain, infection, blood loss (requiring transfusions), blood clots, allergic reactions to anesthesia, pneumonia, injury to surrounding tissue or other organs, and even death.

Please note that there has been no national systematic long-term data collection on the risks associated with living organ donation. Based upon limited information that is currently available, overall risks are considered to be low. Risks can differ among donors. Risks can also differ according to the type of organ you donate.



Some possible risks of kidney donation may include high blood pressure (hypertension); large amounts of protein in the urine; hernia; organ impairment or failure that leads to the need for dialysis or transplantation; and even death.

Some possible risks of liver donation include wound infections; hernia, abdominal bleeding; bile leakage; narrowing of the bile duct; intestinal problems including blockages and tears; organ impairment or failure that leads to the need for transplantation; and even death. There may be other medical risks for each type of organ donation surgery since there are limited data about long-term complications and since each donor's surgery and recovery experience is unique.

Negative psychological symptoms are possible during the healing process and even years after the donation. Your donated organ may not function in the recipient after it is transplanted. You and/or the transplant recipient may have medical problems from the surgery. Scarring or other aspects of the donation process could possibly contribute to problems with body image. You may have feelings of regret, resentment, or anger. You may have symptoms of anxiety or depression. Treatment for these conditions can be lengthy, costly, and could possibly include the use of medications with risks and side effects.

## **Positive aspects of living donation**

The gift of an organ can save the life of a transplant candidate. The experience of providing this special gift to a person in need can serve as a very positive aspect of the donation. Some donors have reported positive emotional experiences, including feeling good about improving another person's life. Transplants can greatly improve recipients' health and quality of life, allowing them to return to normal activities. They can spend more time with family and friends, do more physical activities, and pursue interests and hobbies.

A living donor makes it possible to schedule the transplant at a time that is convenient for the donor and the transplant candidate. Better genetic matches between living donors and recipients may decrease the risk of organ rejection. In addition, kidneys from living donors usually work immediately in recipients in comparison to kidneys from deceased donors. The newer, laparoscopic kidney donation surgery is less invasive and involves smaller incisions. This type of surgery can help to decrease recovery time for the donor.

A living donor also removes a candidate from the national transplant waiting list, which currently includes more than 100,000 people. Based upon 2008 OPTN data, about 11% of kidney candidates added to the waiting list in 2007 received a kidney within one year. About a third of candidates added to the waiting list in 2003 received a kidney within five years. More than 20% of both liver and lung transplant candidates have been waiting for more than five years. In 2008, more than 4,500 kidney transplant candidates and more than 1,400 liver transplant candidates died while waiting on the list.

## Data on living donation

Reviewing national and local transplant center data may affect your decision to become a donor; however, there are limited long-term data available on how living donors do over time. Based upon OPTN data from 1999 through 2008, of the 3,313 individuals who were living liver donors, at least five\* have been listed for a liver transplant due to complications related to the donation surgery. Of the 60,644 individuals who were living kidney donors from 1999 through 2008, at least seven\* have been listed for a kidney transplant. However, the medical problems that caused these kidney donors to be listed for transplant may or may not be connected to the donation.

*\*this total only captures data on transplant candidates who are known to the OPTN/UNOS to be previous donors.*

Below are additional national data from the OPTN:

### Graft (transplanted kidney) Survival Rates for Living Donor Kidney Transplants Performed 2003-2007

Recipients of Living Donor Kidney Transplants		
Number of years after the transplant	Survival rate of the transplanted kidney for adult recipients*	Survival rate of the transplanted kidney for pediatric recipients*
1	95.6%	95.2%
3	89.0%	88.8%
5	80.3%	81.0%

*\*Percentage of transplants in which the transplanted kidney is still working at the end of the listed period of time (e.g. 1 year; 3 years, etc.)*

Based on OPTN data as of July 24, 2009. Data subject to change based on future data submission or correction.

# Graft (transplanted liver) Survival Rates for Living Donor Liver Transplants Performed 2003-2007

Recipients of Living Donor Liver Transplants		
Number of years after the transplant	Survival rate of the transplanted liver for adult recipients*	Survival rate of the transplanted liver for pediatric recipients*
1	84.0%	87.7%
3	76.6%	88.3%
5	70.5%	79.9%

*\*Percentage of transplants in which the transplanted liver is still working at the end of the listed period of time (e.g. 1 year, 3 years, etc.)*

Based on OPTN data as of July 24, 2009. Data subject to change based on future data submission or correction.

You can find more national data and local transplant center data at <http://optn.transplant.hrsa.gov> (choose Data > View Data Reports) and [www.ustransplant.org](http://www.ustransplant.org). If you need help with these resources, please call the UNOS patient services line at 1-888-894-6361.

Since June 2006, UNOS has provided a patient safety system for transplant centers to report medical problems experienced by living donors. Centers must report any living donor deaths, as well as instances in which a donor’s native organ (remaining kidney or other organ of which a portion was donated) fails to function, within 72 hours of becoming aware of this information. Transplant centers must report these incidents for two years after the donation surgery occurs.

Talk with your transplant center about their living donor follow-up procedures and ask about data they have collected, such as:

- the number of living donor surgeries performed at the center
- the percentage of successfully submitted two-year living donor follow up reports
- the number of living donors who have had medical problems, including any incidents reported to the UNOS patient safety system
- transplant recipient and graft/organ survival rates
- Medicare outcome requirements that the center has not met (such as meeting certain recipient and graft/organ survival rate expectations)

## Financial and Insurance Factors to Consider

The transplant recipient's insurance will cover your general expenses as a donor, such as the evaluation, surgery, and limited follow-up tests and medical appointments. However, the recipient's insurance may not cover follow-up services for you if medical problems occur from the donation. Your own insurance may not cover these expenses either. The recipient's insurance coverage usually does not include transportation, lodging, long distance phone calls, childcare, or lost wages.

You should talk about any financial concerns with the transplant center staff. They may have resources available for you. Also, consider contacting the National Living Donor Assistance Center at (703) 414-1600 or <http://www.livingdonorassistance.org>. This service may be able to provide financial help for travel, lodging, meals, and other non-medical expenses connected with your evaluation, surgery, and follow-up services (within 90 days after the donation).

Transplant centers must turn in follow-up forms on living donors for two years after the donation surgery. It is important to ask your transplant team about payment for follow-up care. The center and the recipient's insurance may not cover these costs.

Some transplant candidates have Medicare, which may provide coverage for donors who have donation-related complications. For more information, contact Medicare by phone at 1-800-MEDICARE or at [www.medicare.gov](http://www.medicare.gov). (TTY users can call 1-877-486-2048.) Talk with your transplant center about medical and disability insurance that provides coverage for problems that may occur from the donation. Some centers may provide these services free of charge, while others may offer them for purchase.

Some donors have reported difficulty in getting, affording, or keeping health, disability, or life insurance. It is important that you talk with your own insurance carriers before making a decision about being a living donor. Your premiums could increase. If you do not have health insurance, serving as a donor could be considered a pre-existing condition if you apply for insurance later.

If you work, talk with your employer about any existing leave policies before committing to living donation. Also, fully think about the financial impact on your family, especially if you and/or whoever serves as your caregiver during the donation recovery process may face lost wages.



# Recovery from Surgery

Your IDA and transplant center staff members are a good source for medical information about the living donor surgery and recovery process. Please talk with these professionals to understand what to expect, although the surgery and recovery process can differ among living donors. Consider talking with other donors and contacting the organizations listed at the end of this brochure for more information.

As a kidney donor, you can generally expect to stay in the hospital for three to seven days after surgery. Most kidney donors return to normal activities after four to six weeks, depending on the physical demands of your daily living and work tasks. You may not be able to drive for up to two weeks. You may have lifting restrictions for at least six weeks.

As a liver donor, you may stay in the hospital up to a week, or longer in some cases. The liver typically regenerates in two months. Most liver donors return to work and normal activities in two months, although some may need more time.

Every transplant center is required to have a written protocol for the living donor follow-up process. As mentioned previously, centers must report living donor follow-up data for two years. Talk with your IDA and other staff at the transplant center about their follow-up procedures. Ask for detailed information about office visits, laboratory tests, and other possible requirements following the donation surgery. Attend all appointments to make sure that you are recovering appropriately. The information collected during the follow-up process is critical to help future potential living donors to make informed decisions.

Think about how the donation process may affect your daily activities. Who will serve as your caregiver and support you during your recovery, especially if you have to travel a long distance for the surgery? How much time off will you need from work? How will this affect your caregiving responsibilities such as childcare or caring for an elderly relative?



## Where Can You Get More Information?

### The Organ Procurement & Transplantation Network & United Network for Organ Sharing

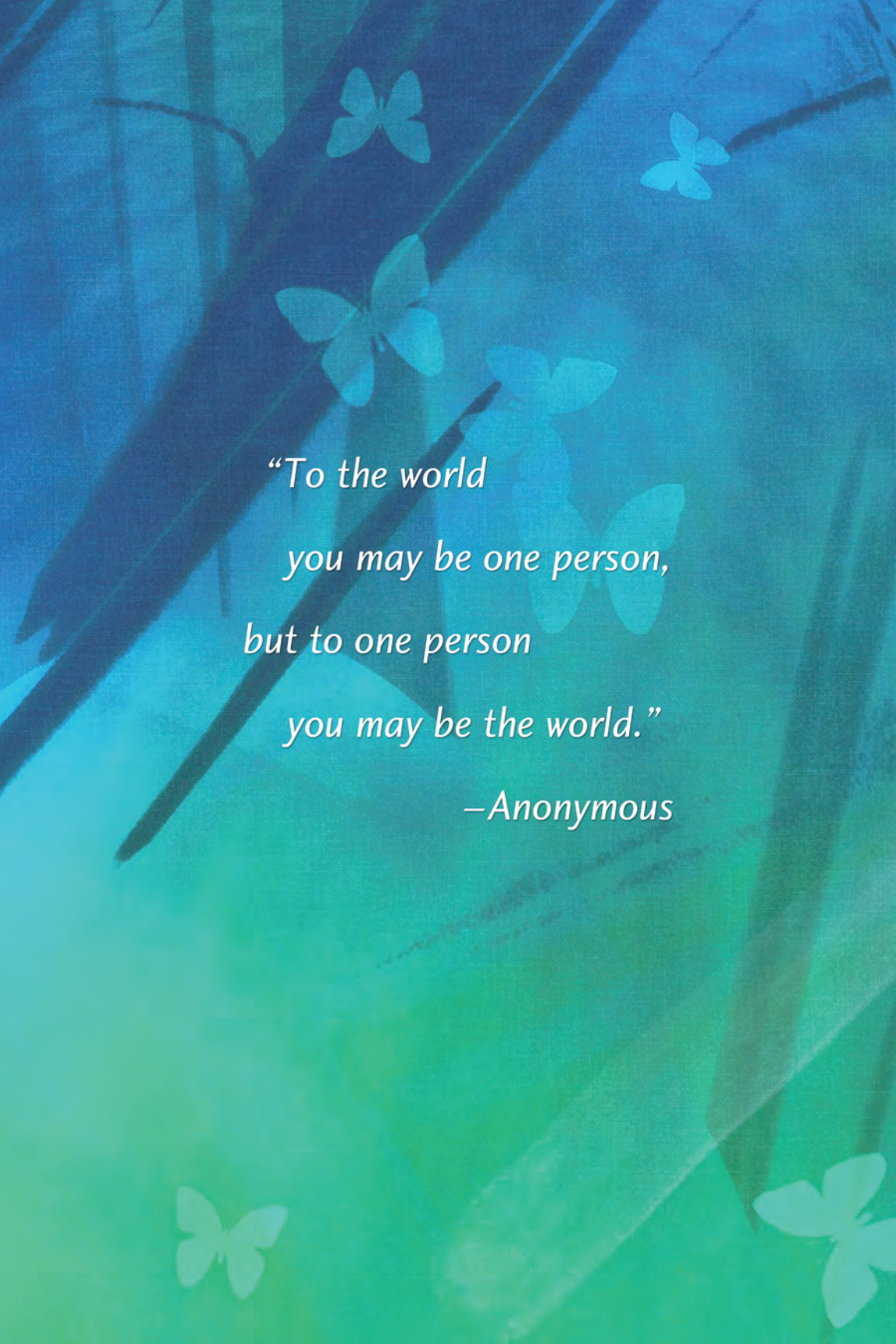
The Organ Procurement and Transplantation Network was established under the National Organ Transplant Act of 1984. Since 1986, the United Network for Organ Sharing, a non-profit, scientific, and educational organization, has administered the OPTN under federal contract to the Department of Health and Human Services, Health Resources and Services Administration. You can learn more about the role, mission, and responsibilities of the OPTN and UNOS at <http://optn.transplant.hrsa.gov> (choose About OPTN) and [www.unos.org](http://www.unos.org) (choose Who We Are).

UNOS offers a toll-free patient services line to help living donors, transplant candidates, recipients, and family members/friends understand donation and transplantation policies and data. You can also call this number to talk about concerns or problems, such as a possible policy violation. The toll-free patient services line number is 1-888-894-6361. UNOS also has a Web site for living donors and candidates: [www.transplantliving.org](http://www.transplantliving.org). You can access educational material and transplant center contact information by visiting the Web site or calling the patient services number.

The Department of Health and Human Services directed the OPTN to develop living donor guidelines and policies in 2006. The OPTN/UNOS Living Donor Committee is addressing this important task. You can access policies that impact living donors and transplant candidates at <http://optn.transplant.hrsa.gov> (choose Policy Management>Policies). You can also send your feedback on current policy proposals by participating in the public comment process at <http://optn.transplant.hrsa.gov> (choose Policy Management>Public Comment).

### Additional Resources

- **American Liver Foundation:** 1-800-465-4837, [www.liverfoundation.org](http://www.liverfoundation.org)
- **American Lung Association:** 1-800-LUNGUSA (586-4872), [www.lungusa.org](http://www.lungusa.org)
- **American Society of Transplant Surgeons:** 1-703-414-7870, [www.astso.org](http://www.astso.org)
- **American Society of Transplantation:** 1-856-439-9986, [www.a-s-t.org](http://www.a-s-t.org)
- **Centers for Medicare and Medicaid Services:** 1-800-MEDICARE (1-800-633-4227) TTY: 877-486-2048, [www.cms.hhs.gov](http://www.cms.hhs.gov)
- **Living Organ Donor Advocate Program:** [www.lodap.com](http://www.lodap.com)
- **NATCO, The Organization for Transplant Professionals:** 1-913-895-4612, [www.natco1.org](http://www.natco1.org)
- **National Institutes for Health:** 1-301-496-4000, TTY: 1-301-402-9612, [www.nih.gov](http://www.nih.gov)  
Kidney and Urologic Diseases: 1-800-891-5390, Digestive diseases: 1-800-891-5389, Lung diseases: 1-301-592-8573
- **National Kidney Foundation:** 1-800-622-9010, [www.kidney.org](http://www.kidney.org); [www.livingdonors.org](http://www.livingdonors.org)
- **National Living Donor Assistance Center:** 1-703-414-1600, [www.livingdonorassistance.org](http://www.livingdonorassistance.org)
- **Organ Procurement and Transplantation Network:** <http://optn.transplant.hrsa.gov>
- **Scientific Registry of Transplant Recipients:** [www.ustransplant.org](http://www.ustransplant.org)
- **Transplant Living Web site:** [www.transplantliving.org](http://www.transplantliving.org)
- **United Network for Organ Sharing:** 1-888-894-6361, [www.unos.org](http://www.unos.org)
- **U.S. Government Information on Organ and Tissue Donation and Transplantation:** <http://organdonor.gov/donation/typesofdonation.htm>



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

*—Anonymous*

*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.*

