

TALKING ABOUT TRANSPLANTATION

Living Donation

Information you need to know

UNOSSM

UNITED NETWORK FOR ORGAN SHARING

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United Network for Organ Sharing (UNOS) is a private non-profit 501(c)(3) 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.

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More than 120,000 people are listed for an organ transplant nationwide. Many face a lengthy wait for an available organ. To spare an individual patient a long and uncertain wait, relatives, loved ones, friends, and even individuals who wish to remain anonymous may serve as living donors. About 6,000 transplants each year are made possible by living donors.

If you are considering living donation, it is critical to gather as much information as you can from various sources. This brochure gives you basic information about living donation. Although it focuses primarily on living kidney donation, it also includes special considerations for potential living liver donors.

Who can be a living donor?

Living donors should be in good overall physical and mental health and older than 18 years of age. Some medical conditions could prevent you from being a living donor. Medical conditions that may prevent a living kidney donation may include uncontrolled high blood pressure, diabetes, cancer, HIV, hepatitis, acute infections, or a psychiatric condition requiring treatment. Since some donor health conditions could harm a transplant recipient, it is important that you share all information about your physical and mental health.

You must be fully informed of the known risks involved with donating and complete a full medical and psychosocial evaluation. Your decision to donate should be completely voluntary and free of pressure or guilt.

How do you start the process?

If you know a person you would like to help through living donation, talk to him or her and the transplant program where the person is listed. If you would like to be a non-directed living donor, contact a transplant center of your choice to find out if they have this type of donation program. Visit <http://optn.transplant.hrsa.gov> (choose Members > Find a Member) for a complete list of transplant centers. You can also call the United Network for Organ Sharing (UNOS) patient services line at 1-888-894-6361 for help.

When you contact transplant center staff, they will typically ask for your consent to begin a basic medical screening. With your consent, the transplant center staff will ask you questions about your medical history to find out if you have any conditions that would keep you from being a donor. This initial screening is typically followed by a blood test to see if you are compatible with the intended transplant candidate. If you are not compatible with that person, you may have other options to donate. These options, described in more detail below, include paired exchange, blood type incompatible donation or positive crossmatch donation.

Transplant centers are required to provide an Independent Donor Advocate (IDA) or IDA team for all potential donors. Your IDA should not be part of the potential transplant recipient's medical team. The IDA will assist you during the donation process. IDA responsibilities include, but are not limited to the following:

- Promoting the best interests of the potential living donor
- Advocating for the rights of the potential donor
- Assisting the potential donor in getting and understanding information regarding the:
 - 1) Consent process
 - 2) Evaluation process
 - 3) Surgical procedure
 - 4) Medical and psychosocial risks
 - 5) Importance of post-donation follow-up

The IDA can address any question you have. Please always be completely honest with the IDA and other transplant center staff about your feelings, concerns, and fears about being a donor.

Types of living donor transplants

The kidney is the most commonly transplanted organ from a living donor. One entire kidney is removed and transplanted. Living liver donation, where a segment of the donor's liver is transplanted, occurs less often, and the donor is usually related to the recipient. Also, in rare cases, a segment of organs such as lung, intestine or pancreas can be transplanted from a living donor.

In a **directed donation**, the donor names the specific person to receive the transplant. This is the most common type of living donation. The donor may be:

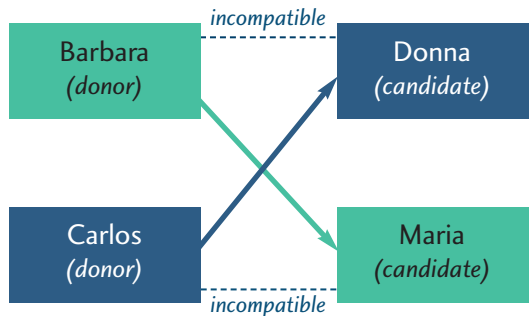
- a biological relative, such as a parent, brother, sister, or adult child,
- a biologically unrelated person who has a personal or social connection with the transplant candidate, such as a spouse or significant other, a friend or a coworker, or
- a biologically unrelated person who has heard about the transplant candidate's need.

In a **non-directed donation**, the donor does not name the specific person to get the transplant. The match is arranged based on medical compatibility with a patient in need. Some non-directed donors choose never to meet their recipient. In other cases, the donor and recipient may meet at some time, if they both agree, and if the transplant center policy permits it.

Matching donors and transplant candidates

Paired donation or paired exchange involves two pairs of living kidney donors and transplant candidates who do not have matching blood types. The two candidates "trade" donors so that each candidate receives a kidney from a donor with a compatible blood type. For example, in figure 1, Barbara wants to donate to her sister Donna, but they do not have matching blood types. Carlos wants to donate to his wife Maria, but they are also not compatible. By "swapping" donors so that Carlos matches Donna and Barbara matches Maria, two transplants are made possible. This type of exchange often involves multiple living kidney donor/transplant candidate pairs.

Figure 1



Blood type incompatible donation occurs when a transplant candidate receives a kidney from a living donor with a non-matching blood type. To decrease the risk of rejection of the donated organ, candidates receive specialized medical treatment before and after the transplant. This may include removing the transplant candidate's spleen during the transplant.

Positive crossmatch donation involves a living donor and a transplant candidate who do not match because the candidate has certain antibodies (a protein substance) that will immediately react against the donor's cells and cause the transplant to fail. Specialized medical treatment (plasmapheresis) is provided to prevent rejection. This type of donation is usually only considered when no other living donors match.

Certain living donation options are not available at all transplant centers.

Contact transplant centers directly for information on specific programs.

Next steps

If you have contacted the transplant center and remain interested in being a donor, the staff will begin the psychosocial and medical evaluation process. This serves two purposes: to protect you and to help ensure success of the transplant.

You will need to answer all the questions that are asked. This includes questions about any history of "high risk" behaviors. 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. You will be asked to fully describe your reasons for wanting to donate and how it might affect your lifestyle (such as employment and family relationships). 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.

Here are examples of some of the tests potential donors will undergo as part of their evaluation:

1. 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.

2. Blood test: this is done 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 after your blood type (for example, being A positive or O negative) is not important in matching.

- **Tissue Typing:** this blood test checks the tissue match between six codes on the transplant candidate's and your white blood cells. The more matches that are found, the better the chance is that the transplant may be successful long-term.
- **Crossmatching:** this blood test determines how the transplant candidate will react to your organ. A "positive" crossmatch means that your organ will not match the candidate. A "negative" crossmatch means that your organ is compatible with the candidate.
- **Blood tests to screen for transmissible diseases:** these tests determine if you have HIV, hepatitis, cancer, or other diseases. Some positive test results may need to be reported to local, state, or federal health authorities for public health reasons.

3. Urine testing: a 24-hour urine sample is collected to look at your kidney function.

4. 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.

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

6. Gynecological examination: female donors may need to receive a gynecological examination.

7. Cancer screening: age and risk appropriate screening which may include a colonoscopy, prostate exam, mammogram, and skin cancer screening.

The results of your evaluation will be kept confidential under the Health Insurance Portability and Accountability Act of 1996 (HIPAA). 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.

Making an informed decision

The informed consent process should help you understand all aspects of the donation process, including the risks and benefits. This will include a discussion about alternative procedures or types of treatments that are available to the transplant candidate, including dialysis or transplant from a deceased donor. Your consent to become a donor is 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 will be kept confidential.

Talk in detail with your loved ones, such as family members and close friends. Before making a final decision, talk with other people who have been living donors. Consider contacting your transplant center, and organizations and Web sites listed at the end of this brochure, to learn more about what it's like to be a living donor. Fully consider how donation may affect 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

The short-term risk of living donation involves risks associated with anesthesia and major surgery. 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 little national systematic long-term data collection on the long-term risks associated with living organ donation. Based upon limited information that is currently available, overall risks are considered to be low. Risks differ among donors and according to the type of organ you donate.

Possible long-term risks of kidney donation may include high blood pressure (hypertension); reduced kidney function, which may be measured by large amounts of protein in the urine; hernia; organ impairment or failure that may lead to the need for dialysis or transplantation; or even death.

Possible risks of liver donation include wound infections, hernia; abdominal bleeding; bile leakage; intestinal problems including blockages and tears; organ impairment or failure that could require additional treatments, surgery, or liver transplantation; or 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 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 include the use of medications with risks and side effects. Ask your center for most up-to-date information available on the risks associated with living donation.



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 trying to improve 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 they could not enjoy while ill.

A living donation makes it possible to schedule the transplant at a convenient time for the donor and recipient. Better genetic matches between living donors and candidates may decrease the risk of organ rejection. In addition, kidneys from living donors usually work immediately.

Many kidney donor operations are now done with laparoscopic surgery. This form of surgery is less invasive than other procedures and involves smaller incisions. As a result, it can help to minimize recovery time for the donor.

A living donor also removes a candidate from the national transplant waiting list. Based on OPTN data as of June 2012, most people waiting for a deceased donor kidney transplant will wait at least three years. Half of all liver candidates will wait longer than two and a half years.

Data on living donation

Reviewing national and 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 2014, of the 4,689 living liver donors, at least seven have been listed for a liver transplant. Of the 95,987 individuals who were living kidney donors from 1999 through 2014, at least 46 have been listed for a kidney transplant. However, the medical problems that caused these donors to be listed for transplant 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.*

You can find more national data and local transplant center data on the OPTN Web site at <http://optn.transplant.hrsa.gov/> (choose Data > View Data Reports) and the site of the Scientific Registry of Transplant Recipients at <http://srtr.transplant.hrsa.gov>. 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 for two years after the donation surgery. Although major adverse events are rare, centers must report to UNOS if any of the following events happen within two years of the donation surgery:

- living donor death
- loss of a function in a donor's remaining kidney or other organ of which a portion was donated
- any organ that could not be transplanted or is not used for original planned recipient

Talk with your transplant center about their living donor follow-up procedures and ask about data they have collected. They are often able to provide you useful information such as:

- the number of living donor surgeries performed at the center,
- the percentage of living donors who receive two years of required follow-up,
- the number of living donors who have had medical problems, including any incidents reported to the UNOS patient safety system,
- transplant recipient and transplanted organ survival rates and
- any Medicare outcome requirements that the center has not met (such as meeting expectations relating to number of transplants done and recipient and organ survival rates).

Financial and insurance factors to consider

The transplant recipient's insurance will cover your medical expenses as a donor, such as the evaluation, surgery, and limited follow-up tests and medical appointments. However, the recipient's insurance may or 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. A living donor cannot be paid for the donation 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.

You should talk about any financial concerns with the transplant center social worker or financial coordinator. They may have resources available for you. Contact the National Living Donor Assistance Center at (703) 414-1600 or 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 send follow-up data to UNOS 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.

Most 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. (TTY users can call 1-877-486-2048.) Talk with your transplant center about medical and disability insurance that covers problems that may occur from the donation. Some centers may provide these policies 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 carrier before making a decision about being a living donor. Your premiums could increase. Serving as a donor could impact your ability to obtain health or life insurance in the future.

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

Recovery from surgery

Please talk with your Independent Donor Advocate (IDA) and other transplant center staff about the surgery and recovery process, which differs 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 resume normal activities after four to six weeks, depending on the physical demands of their 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. Many donors have reported experiencing fatigue for varied periods of time.

As a liver donor, you may stay in the hospital up to a week, or longer in some cases. The liver typically regrows to normal size 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 report living donor follow-up data at six months, 12 months and 24 months post donation. Talk with the staff at the transplant center about

their follow-up procedures. Ask for detailed information about follow-up office visits, laboratory tests, and other possible requirements, and who will pay for follow-up. Attend all follow-up appointments to make sure that you are recovering appropriately. What we learn about donor outcomes can help future potential living donors 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 care giving responsibilities such as childcare or caring for an elderly relative?

Where can you get more information?

Organ Procurement and Transplantation Network/United Network for Organ Sharing

The Organ Procurement and Transplantation Network (OPTN) was established under the National Organ Transplant Act of 1984. Since 1986, United Network for Organ Sharing (UNOS), a non-profit, scientific, and educational organization, has operated 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/> and www.unos.org.

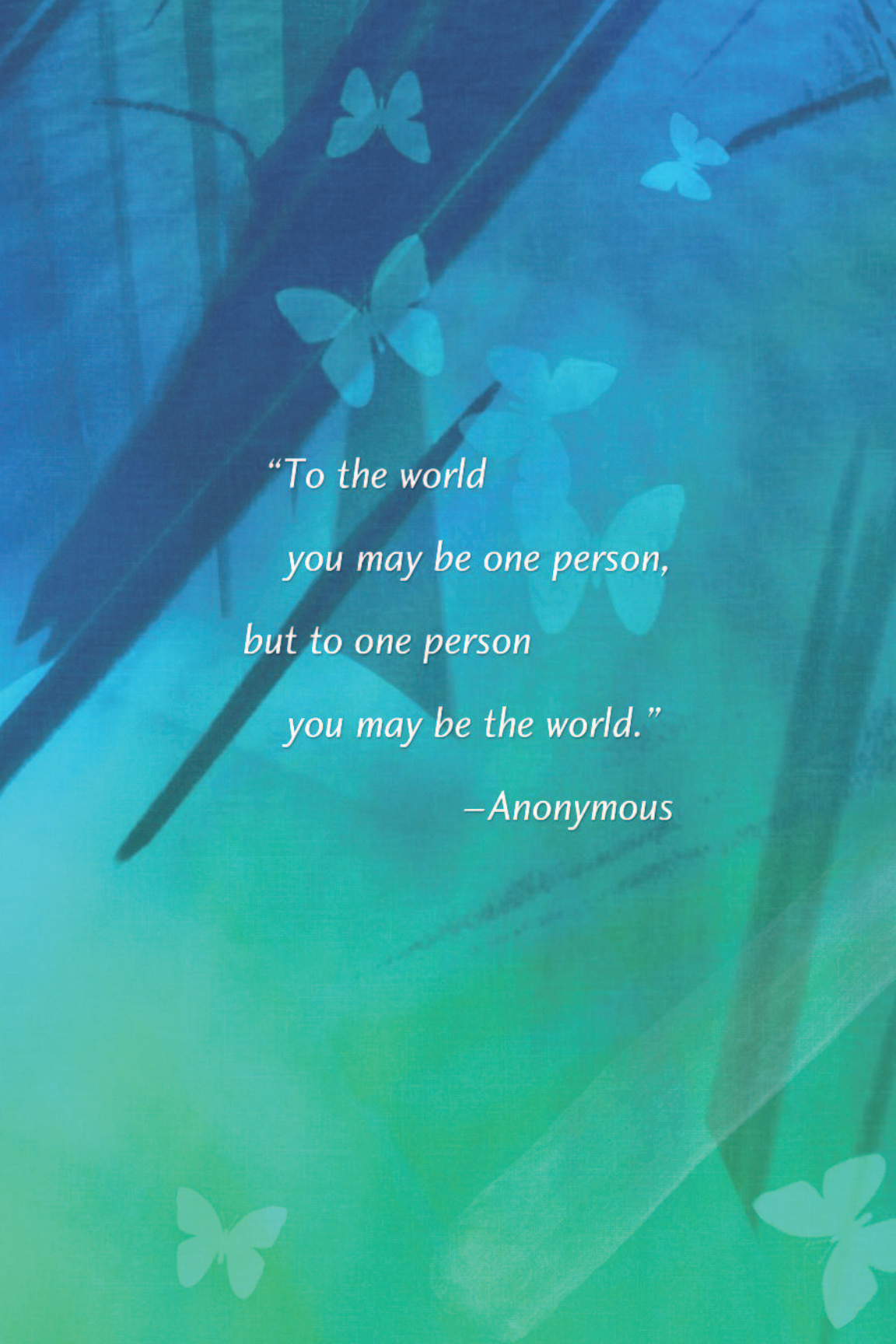
UNOS offers a toll-free patient services line to help living donors, transplant candidates, recipients, and family members/friends understand donation and transplantation policies and data. You can also call this number to talk about concerns or problems. The toll-free patient services line number is 1-888-894-6361. UNOS also has a Web site for living donors and transplant candidates: www.transplantliving.org. You can access educational material 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. You can access policies that impact living donors and transplant candidates at <http://optn.transplant.hrsa.gov/> (**choose Governance > Policies, then select Living Donation**). You can also send your feedback on current policy proposals by participating in the public comment process at <http://optn.transplant.hrsa.gov/> (**choose Governance > Public Comment**).



Additional resources

- **American Liver Foundation:** 1-800-465-4837, www.liverfoundation.org
- **American Lung Association:** 1-800-586-4872, www.lungusa.org
- **Centers for Medicare and Medicaid Services:** 1-800-MEDICARE (1-800-633-4227)
TTY: 877-486-2048, www.cms.hhs.gov
- **Living Donors Online:** www.livingdonorsonline.org
- **National Institutes for Health:** 1-301-496-4000, TTY: 1-301-402-9612, <http://www.nih.gov>
Kidney and Urologic Diseases 1-800-891-5390
Digestive diseases 1-800-891-5389
- **National Heart Lung, and Blood Institute:** 1-301-592-8573
- **National Kidney Foundation:** 1-800-622-9010, www.livingdonors.org
- **National Living Donor Assistance Center:** 1-703-414-1600 or 1-888-870-5002
<http://www.livingdonorassistance.org/>
- **U.S. Government information on organ and tissue donation and transplantation:**
<http://organdonor.gov/about/livedonation.html>



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

–Anonymous

*Our 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.*



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