

TALKING ABOUT TRANSPLANTATION

UNOS

# Facts and Figures

UNITED NETWORK FOR ORGAN SHARING



# United Network for Organ Sharing

The United Network for Organ Sharing (UNOS) coordinates the nation's organ transplant system, providing vital services to meet the needs of men, women and children awaiting lifesaving organ transplants. Based in Richmond, Va., UNOS is a private, nonprofit membership organization.

UNOS members encompass every transplant hospital, tissue matching laboratory and organ procurement organization in the United States, as well as voluntary health and professional societies, ethicists, transplant patients and organ donor advocates.

## UNOS at work

UNOS assists the transplant community and the patients it serves in a number of ways:

- increasing public awareness of the critical need for donated organs and tissues
- maintaining the national organ transplant waiting list
- coordinating the matching and distribution of donated organs
- collecting and reporting data on transplant recipients, donors and outcomes
- serving as a forum to create and define organ sharing policies that maximize the use of donated organs
- establishing transplant physician and surgeon training and experience criteria for UNOS membership
- producing professional education tools
- providing extensive information about organ transplantation to patients, the public and the transplant community

Nearly 25,000 men, women and children receive life-saving organ transplants each year.

## Funding

UNOS is a private, nonprofit scientific and educational organization. About six percent of UNOS' funding is derived directly from its federal contract. The rest of its operating budget comes from computer registration fees paid by members, charitable contributions and project grants from foundations and corporations.



### UNOS Web site

The UNOS Web site ([www.unos.org](http://www.unos.org)), first launched in March 1995, provides a wealth of transplant data, informational resources and news about UNOS and the process of organ donation and transplantation. The site is used by many people with an interest in transplantation, including the following:

- transplant patients and their families
- donor family members
- medical professionals
- news media
- potential living donors
- students

More than 300,000 organ transplants have been performed in the U.S. since UNOS began keeping records in 1987.

### Use of technology

To work effectively, UNOS must collect and provide highly detailed, instantly accessible information. At the same time, it must maintain a high level of security to protect the confidential medical records of individual patients and donors. As a result, UNOS develops and uses sophisticated technology that emphasizes accessibility and reliability.

UNet<sup>SM</sup> is UNOS' computer-based network for allocating donated organs and managing transplant data. Every organ sharing institution is electronically linked in a secure, real-time environment over the Internet so that donated organs can be placed as quickly as possible. While UNet<sup>SM</sup> utilizes the Internet for common accessibility to UNOS members, it employs highly secure encryption and password access to protect confidential medical data.

### Utilizing data

About 20 full-time researchers and statisticians continually analyze and report data on transplant recipients, donors, outcomes and trends.

- Transplant professionals use the data to develop policies and practices to improve the likelihood of a successful donation or transplant.
- Public health researchers use the data to identify trends that will shape the future of the field.
- Patients and their families can assess their treatment options.
- The news media and the general public gain a greater understanding of the transplant system's achievements, as well as its ongoing challenge to meet the needs of people awaiting transplants.

# UNOS and the history of transplantation

## Development of organ transplantation

In 1954, the 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 were begun in the 1980s.

Until the early 1980s, the potential of 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.

## UNOS' beginnings

UNOS originated in 1977 as an initiative of the South-Eastern Organ Procurement Foundation (SEOPF). SEOPF was the first organization to develop a computerized system to use medical information to match organ donors with transplant candidates.

SEOPF began the Kidney Center in 1982, with staff working around the clock to regionally place available organs. This operation evolved into the UNOS Organ Center.

UNOS was formally incorporated as an independent, non-profit organization in 1984 to meet the growing demand for transplants nationwide.

## National Organ Transplant Act

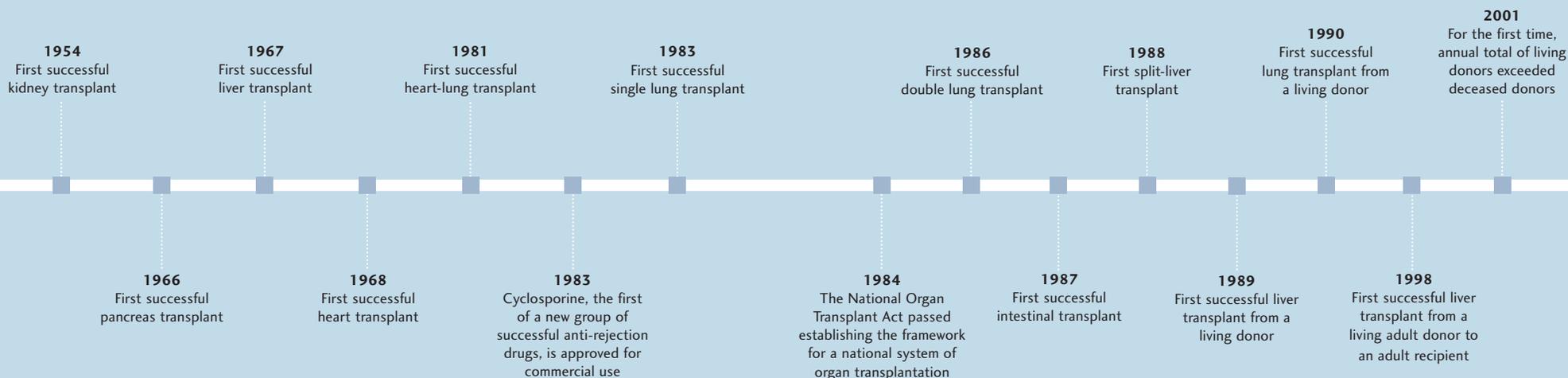
Also in 1984, Congress passed the National Organ Transplant Act, which prohibited the sale of human organs and called for a national Organ Procurement and Transplantation Network (OPTN) to facilitate organ recovery and placement. The act assigned the task of developing equitable organ distribution policies to the OPTN.

## UNOS and the OPTN

UNOS was first awarded the national OPTN contract in 1986 by the U.S. Department of Health and Human Services. It continues as the only organization ever to operate the OPTN.

In this capacity, UNOS has served as the forum by which the entire U.S. transplant community and the public continually improve the nation's transplant system.

## U.S. MILESTONES IN TRANSPLANTATION



## Developing transplant policy

### Board and committees

A 40-member board of directors makes policy decisions. Board members represent the diversity of professions and viewpoints within the field of organ transplantation.

To aid in its deliberations, the board receives input from nearly 20 permanent and ad hoc committees. These committees address a variety of specific perspectives and interests, including the following:

- patient and donor family issues
- medical issues specific to the various transplantable organs
- needs and concerns of ethnic minorities and children needing transplants
- technical aspects of organ recovery and matching
- ethical principles
- collection and reporting of scientific data

### OPTN/UNOS Committees

Communications Committee  
Data Advisory Committee  
Ethics Committee  
Executive Committee  
Finance Committee  
Histocompatibility Committee  
Kidney and Pancreas Transplantation Committee  
Liver and Intestinal Organ Transplantation Committee  
Membership and Professional Standards Committee  
Minority Affairs Committee  
Organ Availability Committee  
Organ Procurement Organization Committee  
Patient Affairs Committee  
Pediatric Transplantation Committee  
Thoracic Organ Transplantation Committee  
Transplant Administrators Committee

### Ad Hoc Committees

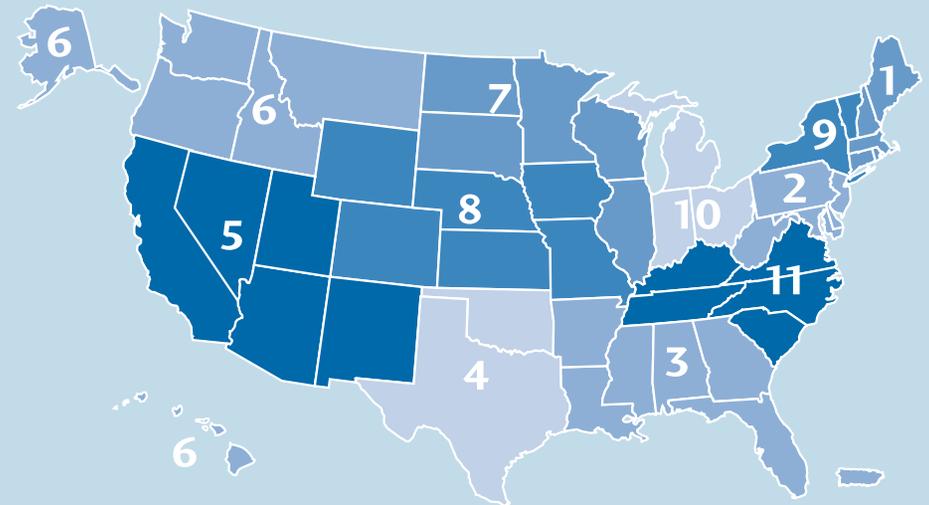
Ad Hoc International Relations Committee  
Ad Hoc Living Donor Committee  
Ad Hoc Transplant Coordinator Committee  
Ad Hoc Operations Committee

### Regions

UNOS has established 11 geographic regions for administrative purposes. Each region is assigned a UNOS staff administrator to assist in coordinating regional activities.

To ensure geographic representation, each region is represented on the board of directors and on each permanent standing committee.

### UNOS REGIONAL MAP



## Policy development process

UNOS strives to achieve consensus in policy development. The field of organ transplantation depends on the cooperation of many people and organizations, and it is vital to ensure that the perspectives of all interested parties are heard and addressed.

Each committee typically meets one to two times prior to each biannual board of directors meeting. Based on current discussion and data analysis, the committee may draft a new or revised policy to address a particular issue.

UNOS publishes all substantial policy proposals for public comment by other committees, the various UNOS regions and interested persons or organizations. The sponsoring committee will consider all comments received before it makes a final recommendation to the board. The board then considers policy proposals in light of the input received.

While the UNOS board approves OPTN policies for voluntary application, these policies are subject to review and approval by the U.S. Department of Health and Human Services before they can become binding under federal regulation. The UNOS board also acts independently on issues that are not within the responsibilities of the OPTN.

## An evolving forum

Continuing advances in the science and practice of organ transplantation require ongoing refinement of policy. To ensure the best possible solutions for patients awaiting transplantation, the policy development process is

- **inclusive**—encouraging participation by interested persons and organizations;
- **responsive**—assessing and modifying policies to remain current with the field;
- **equitable**—helping to ensure that all patients have an equal chance of receiving a suitable organ; and
- **evidence based**—making decisions based on extensive and valid scientific data and analysis.

In a single year, more than 10,000 volunteers within and beyond the transplant community devote thousands of hours to UNOS' life-critical mission.

## Prioritizing patients for transplantation

Each organ type has its own individual distribution policy, reflecting the unique medical considerations of each type of transplant. However, certain general factors apply to all organ allocation policies:

- Patients who are close biological matches with a particular donor offer (including blood type, body size and/or tissue typing match) are given priority. Closer matching tends to result in better longterm survival after transplantation.
- For heart, liver and intestinal organs, patients whose medical status is most urgent receive priority over those whose medical status is not as urgent.
- When possible, organs are offered first to patients locally, then to a larger region, then nationally. This is done to minimize organ preservation time, which is associated with better transplant survival. However, there are exceptions to this sequence for particularly well-matched organ offers and for the most urgent category of liver patients.
- The policies strive to ensure equivalent access for patients who might be at a disadvantage because of the progression of their disease or their ability to receive suitable organ offers. For example, most policies afford children special priority because of the medical risks they face while awaiting transplant.
- Waiting time is used to break ties between patients who are similar in other respects. Patients who have waited longer at their current medical status receive priority over those who have waited less time.

The UNOS computer system is programmed to consider each of these issues automatically when matching donor organs to patients awaiting a transplant. Therefore, the patients ranked highest will be those who have both the greatest need and greatest likelihood for a successful transplant.

## Matching organs with patients in need

### The organ offer process

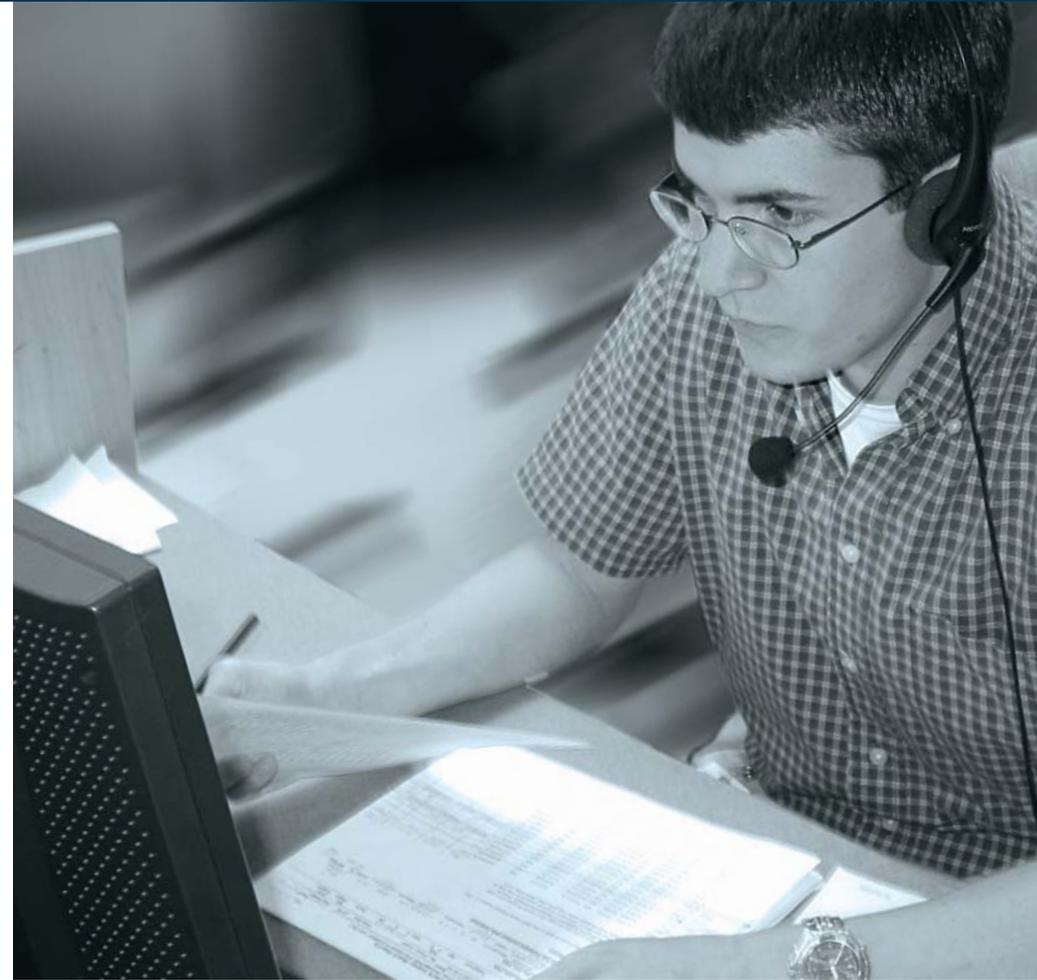
When a deceased organ donor is identified, a transplant coordinator from an organ procurement organization enters medical information about the donor into the UNOS computer system.

The system then matches the donor's medical characteristics with the medical information of candidates awaiting a transplant. The computer generates a ranked list of patients for each organ recovered from the donor.

The transplant team of the first person on the match run is offered the organ needed. Often the top-ranked patient may not get the organ for one of several reasons, including the following:

- he or she cannot be located or cannot reach the hospital in time for a transplant
- he or she is temporarily too sick to receive a transplant
- the medical team believes the organ would not benefit the candidate due to the donor's age or medical condition
- medical tests performed after the initial offer show the candidate's immune system would likely reject the organ

If an offer is turned down for one transplant candidate, the organ is offered to the next candidate on the match run. These offers continue until the organ is placed or until no potential recipient can be located in time for a successful transplant.



Every day the UNOS Organ Center handles 350 requests from transplant organizations for organ placement assistance, waiting list additions and modifications, policy information and organ transportation assistance.

### UNOS Organ Center

The UNOS Organ Center places many organs and also helps members with running computer matches, arranging transport for organs, updating patient records and providing information about organ sharing policies.

The Organ Center is staffed 24 hours a day, seven days a week, 365 days a year. If a catastrophe prevents use of the current facilities, operations can be switched in minutes to a fully equipped disaster recovery site.

## Addressing the donor shortage

### Increasing organ availability

Transplantation has saved and enhanced the lives of more than 300,000 people in the United States. It is the leading form of treatment for many forms of end-stage organ failure.

With this success, however, has come increasing demand for donated organs. Today more than 82,000 people are awaiting transplants nationwide. Sadly, about 17 patients die every day while awaiting an organ—one person every 85 minutes.

Living donation (transplanting all or part of an organ from a living person) has increased dramatically in the last few years, helping increase the number of transplants performed. In addition, UNOS has enacted a number of policies to encourage more efficient use of available organs, such as “splitting” livers from deceased donors to allow two recipients to be transplanted.

The only long-term solution to the organ shortage, however, is for more people to agree to become organ donors. UNOS works closely with medical professionals to increase their understanding and support of the organ donation process.

In late 2001, the UNOS board of directors set a goal to reach 50 million people directly, encouraging them to become donors. UNOS also works closely with the U.S. Department of Health and Human Services (HHS) and national organizations such as the Coalition on Donation to foster the public’s knowledge and commitment regarding organ donation.

UNOS staff will gladly address any questions you may have about organ donation and transplantation.

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[askunos@unos.org](mailto:askunos@unos.org)

### How you can help

You can help save and enhance lives by making the decision to become an organ donor. You can designate your donation decision on your driver’s license or on a donor card you keep with you (see attached flap).

An increasing number of states have adopted legislation making it illegal for a family member to override an individual’s documented decision to donate. Even so, it is important to share your decision with your loved ones. Sharing your decision will help them ensure they are carrying out your wishes. Many donor family members say they are greatly comforted in knowing that the generosity of their loved one has helped others to live longer and better lives.

There are many other ways you can help promote organ donation. The Workplace Partnership for Life, a campaign initiated by HHS Secretary Tommy Thompson and the transplant community, calls on corporations, businesses and organizations of all sizes to share information about organ donation with their employees and promote the opportunity to donate life. Through this program, UNOS is teaming with HHS Secretary Tommy Thompson to reach a larger base of people.

### How can your company and UNOS promote organ donation in the workplace?

- Hire a “star-power” speaker to address your organization through our National Speaker’s Bureau.
- Distribute brochures with vital transplant information to your employees.
- Place our public service announcement on your company’s intranet or e-mail it directly to employees.

For more information about how to start an awareness program in your business, school, place of worship, civic or other organization, call (804) 782-4800 or e-mail [askunos@unos.org](mailto:askunos@unos.org).

*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.*



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