

Building for the **FUTURE**



UNITED NETWORK FOR ORGAN SHARING
2011 ANNUAL REPORT

The Future

UNFOLDS



Anonymous living kidney donor John Mastro (left) later met his recipient, 12-year-old Jose Castaneda.

Twenty-five years ago, UNOS signed the first of seven contracts with the federal government to establish and run the national Organ Procurement and Transplantation Network (OPTN). But before there was an OPTN or any talk of a federal contract, there was a cadre of transplant professionals who shared a vision for widening the pool of potential organ matches and bringing more transplants to more patients in need. The leadership of the American Society of Transplant Surgeons and the SouthEastern Organ Procurement Foundation joined together to address that need. Their solution was UNOS.

UNOS created the infrastructure, developed OPTN policies, and built a national organ donation and transplantation network—thousands of individuals dedicated to saving lives through this fascinating science. More than half a million people have received an organ transplant since those first days.

UNOS' growth over the years mirrors the momentum of organ transplantation in the United States—the growing population of candidates, recipients and living donors; the innovations and research that drive improvement; and the education of the professionals who must apply new knowledge to their transplant practices.

As UNOS observed this silver anniversary of operating the OPTN in 2011, we realized how far we have come, but we also recognize the ongoing need to better serve transplant patients.

A great question we continually ask: how do we build a better transplant system for the future?

Like everything in the transplant world, we know there is not just one, simple answer, but several, interconnected solutions. From professional and patient education, to innovative technology, to programs and services that ensure patients have the greatest possible access to transplants and the strongest safety net, we know that we can and must do more.

So we rolled up our sleeves and started looking at blueprints. This report gives you a glimpse at our plans, our work in progress, and of course, our accomplishments, which would not be possible without the cooperation and dedication of thousands in the transplant community.

In a future filled with uncertainty and opportunity, one thing never changes: our deep commitment to serving those who depend on us.



Interested in seeing more stories about recipients and patients like the ones featured in this annual report? Go to transplantliving.org, our online community

for transplant candidates and patients, or scan this QR code using your smartphone or tablet browser.

John R. Lake, M.D., President

Walter K. Graham, Executive Director



UNOS envisions an interactive learning center to enhance current education offerings for transplant professionals.

Work in PROGRESS

As UNOS looks to the future, we know that demand for life-saving organ transplants will remain strong. Hypertension, heart disease, obesity and diabetes have reached epidemic proportions in America, gravely harming aging and underserved populations. These conditions contribute to the long list of patients in need of transplants and an increased burden on the U.S. medical system overall.

How do we improve the efficiency and effectiveness of our nation's transplantation network and increase patient safety?

Education and research are two important ways to make a major impact on our core mission, to advance organ transplantation.

UNOS Distance Learning Network

For 27 years, UNOS has provided education and training programs to transplant professionals; we have now expanded to include online distance learning and new onsite workshops and symposia, aimed at elevating knowledge and promoting efficiency and patient safety at all 242 transplant hospitals and 58 organ procurement organizations (OPOs) in the United States.

Center for Transplant System Excellence

UNOS' research and innovation think-tank develops new ideas to foster large-scale, system-wide health and policy solutions to improve transplantation and address the needs of Americans facing end-stage organ failure, as well as several global initiatives.

Tii Informatix: Software, Clinical Trial and Analytic Services

Tii Informatix, an independent business unit of UNOS, provides customized software development and analytic services to U.S. and international organizations in the transplant industry. Tii proceeds directly support the UNOS mission. In 2011, Tii developed a web-based donor management portal for OneLegacy, a donation after cardiac death donor registry for the ISHLT, renewed the INTERMACS registry contract for another five years with the University of Alabama, Birmingham, and launched the OPOConnects™ enterprise collaborative portal platform to the OPO community.

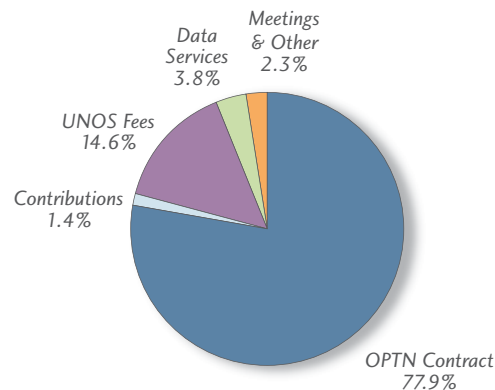
2011 Financial Facts

UNOS' primary mission is to perform the OPTN contract. Total OPTN funding represents 77.9% of UNOS revenues. The OPTN is a cost-sharing contract in which the federal government contributed 12.6% of funds in 2011. The remaining 22.1% of revenues provide for resources needed to support the mission and the financial health of the organization.

The OPTN represents 67.2% of expenses for the organization. OPTN-related expenses (10.1%) are indirect costs related to the OPTN contract.

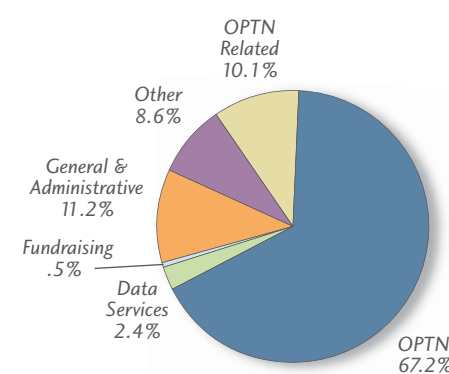
REVENUES

OPTN Contract	\$33,039,241
Contributions	573,150
UNOS Fees	6,195,422
Data Services	1,625,779
Meetings & Other	972,023
Total	\$42,405,615



EXPENSES

OPTN	\$28,724,576
Data Services	1,057,514
Fundraising	213,265
General & Administrative	4,778,736
OPTN-Related	4,314,665
Other	3,673,780
Total	\$42,762,536



Change in Net Assets (\$356,921)



For a full financial snapshot, view the results of our annual financial audit conducted by independent certified public accountants. It can be found by going to unos.org > About Us > Governance > Financials or by scanning this QR code.

1,000

More than 1,000 transplant professionals participated in UNOS-sponsored Web training on health privacy issues. We also offered sessions on liver policy, ABO verification, kidney paired donation, patient notification and more.

24+

Experts in 24+ fields contribute to Center for Transplant System Excellence projects, including a \$1.7 million study to determine future trends of potential U.S. deceased organ donors.

150+

We hosted three UNOS Primer workshops, comprehensive training seminars onsite in Richmond to educate 150+ transplant professionals on the workings of UNOS and the national transplant system.

6

UNOS research department staff co-authored six studies published in the *American Journal of Transplantation*.

8

UNOS staff presented eight studies at the 2011 American Transplant Congress.

81

UNOS Meeting Partners, with 81 years of combined experience, expanded its conference and travel planning services to the transplant community.

47

Last June, we purchased The Jackson Center in the historic Jackson Ward district of downtown Richmond, Virginia, near UNOS headquarters. We're retrofitting the building to house 47 employees and offer new programs.

Heart recipient and donation advocate Rick Hunsicker celebrated his 60th birthday with a sky-diving expedition.



Shari Kurzrok-Schnall, a liver transplant recipient and patient affairs committee member, and husband Robby welcomed daughter Alexis in 2011.



STRUCTURE *for* Patient Safety

FOUNDATION *for* Technology Improvement

Technology is central to running our nation's complex transplant system. To ensure we have the necessary capacity to support current and future needs, UNOS is implementing Chrysalis, a multi-year IT infrastructure overhaul with three main components:

- architecture: building a new, modular technology framework
- membership system rewrite: upgrading the information network for 25,000 individuals who comprise the OPTN membership
- waitlist system rewrite: updating the nationwide system of more than 113,000 people awaiting transplants

With Chrysalis, UNOS aims to shore up the nation's transplant system infrastructure, with:

- scalable, flexible and secure systems, aligned with current industry standards
- a modular approach, making it easier to implement new OPTN policies and revise current ones
- a system that is quicker to code and test, and that reduces code conflicts
- a framework for future data interchanges and other improvements

This complex project must link a number of detailed computer applications, but it is worth the time and effort to create a more efficient, effective national transplant system for the hundreds of thousands of people who rely on it.

In 2011, we built the architecture for the new waitlist, membership and allocation analysis applications and the hardware underlying them. The modular design will enable simultaneous policy changes to be programmed. In the new allocation analysis system alone, we expect to reap great efficiencies. By automating 70% of testing processes, we hope to significantly improve system speed and performance, and to reduce the chance for error in analyzing the 22,000+ allocations that occur each year.



The U.S. transplant system is unique in medicine, thanks to UNOS members and the vast number of dedicated individuals who cooperate to make it work. In this system, collaboration is a key structural component. Transplant centers, organ procurement organizations (OPOs) and histocompatibility labs serve on the front lines; board and committee members and UNOS staff advise and support them, working with federal officials to operate a national system that is ever safer, stronger and more secure. It takes rigorous planning, coordination and expertise at all levels to maintain a solid system for patients and living donors.

Putting Patient Safety First

In 2011, UNOS sharpened its patient safety focus. We initiated continuous on-call coverage to monitor our patient safety portal and 1-800 member reporting line, and we began a process to handle time-sensitive patient safety issues in a way that helps members create corrective action responses more quickly. UNOS also began facilitating OPO peer visits to provide more focused assistance to organ donation professionals.

Potential donor-derived disease transmission reporting continues to increase. In 2011, the ad hoc disease transmission advisory committee (DTAC) reviewed 181 cases of potential transmission. This is up 13% from 2010. The DTAC uses this information to guide educational efforts designed to minimize future risk and aid in patient care. Committee members strive to reduce donor-derived disease transmission by presenting at professional societies, publishing manuscripts, and producing the DTAC News, distributed in the UNOS member e-newsletter.

UNOS provides data that help member organizations make better decisions. Information gleaned from bimonthly OPO donor data quality monitoring reports and other sources helps ensure equitable organ allocation and patient safety.

Dwayne Straws, father of three, waited for more than a year for a kidney transplant. Fortunately, Dwayne's transplant occurred in November 2011. "I hope our story puts a human face to the need for organ donation," says his wife, Theresa.



Warner Granger received a kidney and his daughter Kim Lewis donated one as part of a paired-donation exchange.

EXPANSION *Plans*

Of the more than 113,000 individuals on the national organ transplant waiting list, the vast majority of them, around 80%, are waiting for kidneys. Living donation is one option, but what happens when the potential donor is not a biological match with the transplant candidate he or she wants to help?

Kidney Paired Donation

Kidney paired donation (KPD) facilitates matches among a larger pool of compatible donors and candidates. UNOS' national pilot program, involving 100 transplant centers, completed its first full year of operation in 2011, with 15 transplants accomplished and more potential matches identified for later transplants. We implemented new operational guidelines and installed an automated entry system to help programs enroll potential donors and candidates more efficiently. The KPD pilot is operated under the OPTN contract, with assistance from charitable contributions. Through these efforts, we hope to significantly increase the number of kidney transplants among living donors, which also impacts the number of candidates on the national waiting list.

Living Donor Follow Up

The OPTN contract has included oversight of living donor transplantation since 2004. Last year, the board of directors adopted rules to enhance reporting of living donor follow up. The transplant center performing the living donor organ recovery must now report donor follow up, to facilitate improved information gathering about these patients. In addition, the living donor committee developed a resource that provides best practices for collecting and submitting high quality data for living donor follow up. Transplant programs can use it to develop their own strategies.

Increases in KPD and other programs necessitate close attention to living donors, before, during and after transplant. UNOS provides detailed information to transplant centers on their living donor follow up annually. Assessments compare center-specific data for an individual program's one-year living donor follow up to the national median.



Liver recipient Jacob Smirl (center), age 9, cycled with his donor's dad in the U.S. transplant games. He is pictured here with his family.

BUILDING

Bridges



Kennedy Carter (right), a kidney recipient, started a charity to provide toys to hospitalized children.

Patients awaiting transplant, recipients and donor families all face more than their share of the unknown. But in this journey, there is one certainty that can bring comfort: no one walks alone. UNOS provides a variety of information and support materials to help patients navigate their way through the transplant experience, to give comfort to donor families, and to heighten awareness of organ donation and transplantation.

Making the Connection

A collaborative effort begun in 2011 should help improve and increase information sharing among deceased donor families, living donors and recipients. UNOS is part of a task force of transplant-related groups, and government and individual representatives that is finding simple and effective ways for transplant centers and OPOs to connect transplant recipients with their donor's family whenever possible. These connections provide great opportunities to comfort and heal.

Keeping it Simple

At the request of our membership, UNOS is in the midst of an effort to streamline the policies and bylaws that guide the operation of the national transplant system. Our plain language initiatives made significant progress in 2011. The rewritten bylaws were approved by the membership and professional standards committee and went out for public comment in December. Plans are to send the policy rewrite for public comment in 2012.

Opportunities to Share

Heart transplant recipient Debra O'Hearn found a unique way to share her experience and to honor her donor, a young woman named Emily. O'Hearn's "My Journey: Embracing Life," presented at The Gallery at UNOS in 2011, conveys her gratitude in pictures and words and serves to educate a wider audience about the importance of organ donation.



Countless others have expressed their gratitude and sentiments about the organ donors in their lives by posting tributes on UNOS' National Donor Memorial Web site, the virtual component of the 10,000-square-foot memorial garden at UNOS headquarters in Richmond, Virginia. Visit www.donormemorial.org or scan the QR code to the left with your smartphone.

Also in 2011...

The board of directors approved a plan to assess OPO performance, to introduce standards using a statistical model and clearly identify expectations.

Committees created, and the board of directors approved, guidance documents on several important patient safety issues, policies and procedures.

The board of directors approved pediatric liver committee recommendations to remove a requirement that children waiting for a liver transplant must be in a hospital ICU to be listed at a higher priority and to allow a higher priority status for children with non-metastatic hepatoblastoma.

UNOS began conducting onsite living donor program surveys and educating members about related policies and guidelines during these visits.

The operations and safety committee launched an electronic patient safety newsletter for transplant professionals to explain reporting and safety issues and to provide resources.

The patient affairs committee led a major rewrite of *What Every Patient Needs to Know*, a comprehensive printed transplant guide for patients.

More than 2,200 customers of the UNOS online store ordered more than 100,000 printed resources for patients and professionals.

The minority affairs committee and UNOS research staff published a study in the August 2011 *American Journal of Transplantation* on end-stage renal disease risks among prior living kidney donors.

UNOS presented the annual National Donor Memorial Award of Excellence to James Carter of Vermont, for his two decades of volunteer efforts to promote organ donation.

We created a one-page educational advertisement for NAACP's *The Crisis* magazine (circulation one million), focusing on minorities and kidney disease.

A Community of CONNECTIONS

The United States transplant system operates with an enormous amount of collaboration among dedicated individuals and organizations. These are some of the representative roles and connections of the people who work hard every day to save lives and support transplantation.

Donor Family
Karac, Jaira and Tyler Gordon



Deceased Donor
Jovante Woods



Donor Mom & Board Member
Mary Nachreiner



UNOS Organ Center Placement Specialist
Tim Ernst



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Nadine Rozier-Lawrence



UNOS Regional Administrator
Shannon Edwards

“I’m the person at UNOS who transplant professionals in regions 1,4 and 9 should contact when they have a question about policy or anything UNOS or OPTN-related.”

DONORS



Living Donor
Kimberly Alexander

“It was the right thing to do. I live my life by the Golden Rule—do unto others as you would have them do to you.”

CANDIDATES



RECIPIENTS

Kidney Recipient
Shamequia Cason

OPOs

Donor Family Advocate
Jeremy Ward

“Being a family advocate allows me to be present on one of the worst days of a family’s life and offer them comfort and hope in a dark time. To be able to see that flicker of hope in a mother’s eyes when she agrees to give such a profound gift, to save lives in spite of her own situation, is truly amazing.”

Organ Procurement Coordinator
Michelle Riggs



Histocompatibility Laboratories

HLA Laboratory Supervisor
Beth Wagner

“We play a significant role in the selection process for organ transplantation through HLA typing, antibody monitoring and crossmatching. Combined with post-transplant care, we hope to extend patients’ lives and improve the quality of the lives they live.”



KPD Living Donor
Reyna Hernandez

TRANSPLANT CENTERS



Transplant Physician
Pang-Yen Fan



Transplant Surgeon
Richard Perez



Heart Transplant Nurse Coordinator
Heather Jeager

Financial Coordinator
Amy Hackney

“As transplant financial coordinators, we help our patients and their families develop a financial strategy for transplant while maximizing reimbursement for our transplant centers.”



Social Workers
University of Maryland Medical Center

Transplant Administrator
Nancy Metzler

“Every day is different when you are a transplant administrator. In addition to the basics of any administrative role, we also get to see the incredible transformation transplant has on patients, work with an amazing team of transplant professionals, and ensure that our team meets or exceeds all guidelines established by UNOS.”



To read what other organizations across the country are doing, subscribe to the UNOS Update, our bi-monthly magazine that contains news and information of interest to the transplant community. For more information visit: unos.org > Donation & Transplantation > Professional Education > UNOS Update or scan the QR code to take you there directly.

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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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LOOKING *Forward*

Kimberly Alexander (left) and Erika Bomar are coworkers with a connection. Kimberly donated a kidney to Erika's husband, Damon.

As we enter 2012, we are preparing to bid on the next OPTN contract with the federal government. In doing so, we've taken stock of the growth of OPTN responsibilities in recent years, especially in areas such as policy monitoring and enforcement, oversight of living donation and disease transmission reporting. We anticipate the scope of the next contract to be even greater — with increased responsibilities for living donation, kidney paired donation, patient safety, and OPTN member education and training. There also may be new requirements, such as vascularized composite allograft transplants (e.g., limb and face transplants).

To help meet future challenges and become a more responsive organization, we spent some time examining our strengths and weaknesses, with an eye toward filling the gaps and adding expertise where needed. We also reviewed the fundamental structure of our corporate board and anticipate creating several new board committees to focus on corporate governance, finance, IT, and a new task for the executive committee to conduct OPTN strategic planning. This structure will help to make UNOS a stronger organization and one that truly anticipates the needs of members, on behalf of the patients they serve throughout the nation.



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