VALUES IN ACTION

2013 ANNUAL REPORT



VALUES IN ACTION

2013 was a year of new beginnings. Most important, we renewed the contract to continue functioning as the national Organ Procurement and Transplantation Network (OPTN). For almost three decades we have been working collaboratively with donation and transplant professionals throughout the country—facilitating more than half a million organ transplants—to save and enhance lives. Throughout this report, we will highlight examples of national system improvements—improvements that will impact how scarce organs are allocated and help save the most lives possible while maximizing patient safety.

The current OPTN contract also entrusts us with developing policies for the newest frontier in transplantation—vascular composite allografts (VCAs)—most commonly known for hand and face transplants. Federal regulations for VCAs become effective in July 2014, and we have created a committee to begin preparing.

Equally important for UNOS is how we do our work, so this year we've renewed our commitment to professionalism by formally articulating our core values: stewardship, unity, trust, excellence and accountability. These are the values that guide not only the interactions of the 300+ UNOS staff members in Richmond, but also our interactions with the thousands of members of the transplant community throughout the nation. We have chosen our values as the theme for this year's annual report because they form the foundation for all of our collective work in serving those who depend on us.

With the renewal of the OPTN contract, we have renewed our commitment to promote long, healthy and productive lives for people with organ failure—by putting our values in action each and every day.

Kenneth A. Andreoni, M.D.President
United Network for Organ Sharing

Cernet Muleani

Brian M. ShepardChief Executive Officer
United Network for Organ Sharing

STEWARDSHIP

We act on behalf of those we serve to manage the resources and gifts entrusted to us, especially the gift of life.

UNOS is a steward of the gift of life every time our computer system matches an organ to a patient on the waiting list. Each organ allocation is governed by evidence-based policies proposed by UNOS committees and approved by the board. UNOS committees use all available medical research and data to develop policies that make the most of donated organs and save as many lives as possible.

Examples of stewardship actions in 2013 include:

- Board approval of a comprehensive revision to kidney allocation policy aimed at improving outcomes for transplant recipients, increasing the years recipients may have a functioning transplant and increasing utilization of available kidneys. The policy revisions may also reduce the need for repeat transplants and create more opportunities for first transplants.
- Implementation of broader geographic liver sharing aimed at reducing waiting list deaths among the sickest patients.
- Rapid development of innovative technology aimed at reducing labeling and delivery errors for organs transported from one part of the country to another. Through a U.S. Department of Health and Human Services innovation project, prototype technology involving bar-coding and mobile handheld devices will help prevent organ misdirection and wastage.
- In July 2013, the U.S. Department of Health and Human Services announced that vascular composite allografts (VCAs), including hand and face transplants, will be added to the definition of transplantable organs, effective July 3, 2014. With the renewal of the OPTN contract, the federal government directed UNOS to develop policies and guidelines for VCAs. We created a new committee of 18 people with experience in VCAs—including some of the leading pioneers in hand and face transplants and a double-hand transplant recipient—to develop recommendations to present to the board of directors.

Samantha Boling, lung candidate

Samantha needs a lung transplant to survive and has been waiting since January 2011. She says it feels "kind of like being trapped and you're waiting for a call to freedom." She dreams of the day she can travel. For now she's on a journey to "a happy soul."



Photo by Rudy Harris Photography Courtesy of LifeCenter Organ Donor Network

UNITY

We work collaboratively and respectfully, guided by consensus-building, sharing responsibility, time and abilities.

"Working together. Saving lives." is more than a slogan for UNOS. A large community of medical professionals and people personally touched by organ donation works collaboratively to allocate scarce organs responsibly and advance the field of transplantation.

UNOS staff in Richmond work with thousands of transplant and procurement professionals throughout the country—hundreds of whom volunteer on our board and committees. Along with patient representatives and other professional organizations, we develop policies by consensus and integrate many disciplines to make transplants possible.

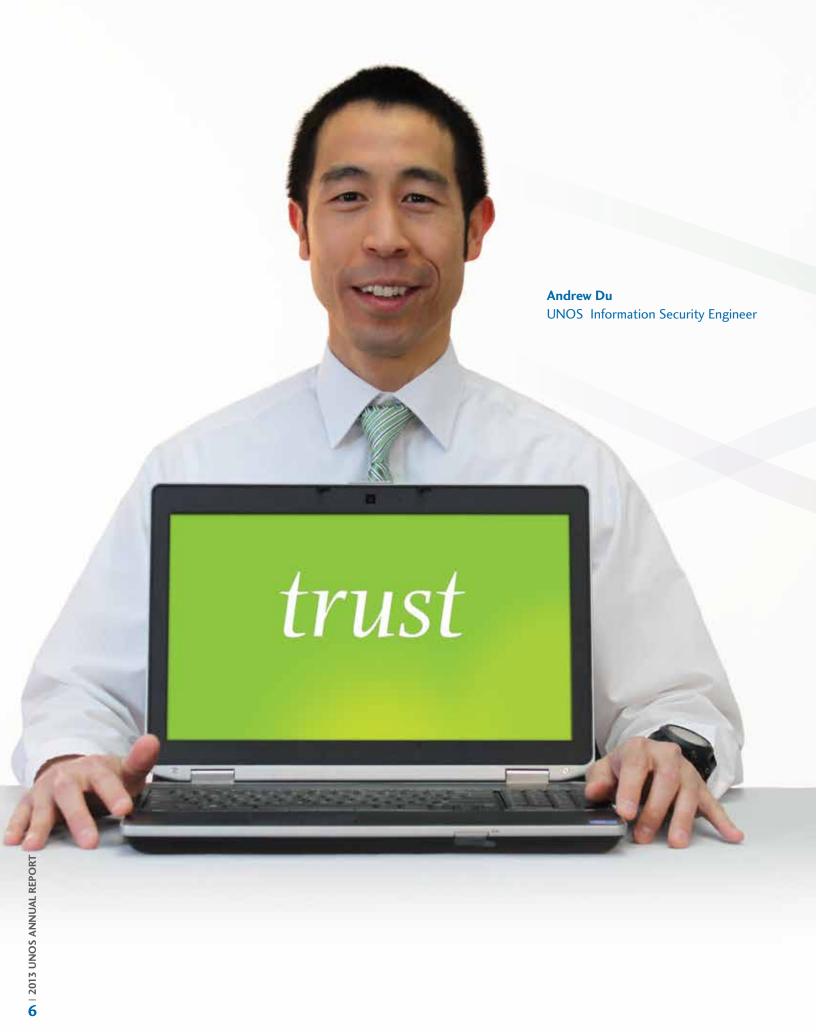
Some of the many ways we worked together in 2013:

- The number of transplant hospitals participating in our national kidney paired donation (KPD) pilot program grew to 134, making more transplants possible for patients who are difficult to match with donors. In 2013, our KPD program arranged 52 transplants. The KPD program is truly a collaborative effort: it is funded in part by the OPTN contract and by private sponsors.
- In early 2013, KPD participation guidelines became OPTN policy, strengthening coherence among participating transplant hospitals and improving safety for the living donors. Other enhancements involved the inclusion of bridge donors, increasing the number of donors paired to each candidate and eliminating the chain cap on non-directed donor chains. The national KPD program is poised for growth in coming years.
- UNOS' TII Informatix business unit developed and manages a web-based data entry and analysis system that allows organ procurement organizations (OPOs) in Region 5 to collaborate with each other and reach common goals. Aimed at increasing the number of donors and transplantable organs, Region 5's highly successful Donor Management Goal portal has been opened up to OPOs in other regions. TII is exploring the possibility of developing electronic medical record interfaces to further reduce duplicate data entry and to make the portal more attractive to new participants.

Hallie Twomey, donor mom/non-directed kidney donor

By donating her kidney to a stranger on December 19, Hallie Twomey kicked off a transplant chain arranged by our KPD pilot program. Her generosity enabled three people to receive kidney transplants. Hallie already had personal connections to organ donation and transplantation: her father was a heart recipient and her son (pictured here) was a donor.





TRUST

We demonstrate integrity and reliability through consistency, openness and honesty.

Every transplant starts with a donor. People will agree to donate only if they trust the system to provide a fair chance of getting an organ and to protect patients and living donors. For this key reason and others, our policy-making process is transparent and communicated clearly to our constituents, including the general public.

- We open our committee and board meetings to the public. This year we began offering a call-in option so people around the country will be able to listen.
 Summaries of meeting discussions are available on our website.
- Patients trust the transplant hospitals that provide their medical care. For this reason, we clarified the policy that requires patients to be notified when their center is not actively accepting organ offers.
- While transplantation by its nature can never be risk free, we strive to make it as safe as possible, especially for living donors. This year, we strengthened living kidney donor policies by including specific requirements for the independent donor advocate assigned to every living donor.

- The board of directors approved a rewrite of OPTN policies in plain language, which makes policies easier for professionals, patients and the general public to understand.
- The public must trust that their wish to become a donor will be honored when medically possible. After receiving input from the ethics committee and others, the board voted unanimously to improve requirements for developing protocols for donation upon circulatory death (DCD). Organ procurement organizations must address key medical and ethical issues in the individual DCD protocols they develop with donor hospitals.



The Phillips, donor family

David and Christina Phillips were proud to honor the wishes of their 15-year-old son, David III, after he was tragically killed in a car accident. Days before, David saw his siblings pick up donation material at a fair and said he would sign up to be a donor when he got his driver's license. He died wearing the green Donate Life bracelet he picked up that day.



EXCELLENCE

We achieve high quality through measurement, evaluation and continuous improvement of our standards, processes and effectiveness.

In our most recent membership survey, we learned that members were pleased with the services UNOS provides, and they also suggested some improvements: deliver consolidated communications via e-mail; write policies in easy-to-understand language; and collaborate with Centers for Medicare and Medicaid Services (CMS) and other regulatory agencies to reduce overlap.

Highlights of 2013 efforts:

- A UNOS Organ Center performance improvement project reduced discrepancies in donor data before attempting to place an organ. The result has been improved accuracy, reduced placement errors and reduced organ placement time.
- We analyzed the way our surveyors reviewed transplant programs and OPOs to make site surveys more relevant to the day-to-day activities of our members. This project involved an online survey of transplant and OPO administrative leadership, interviews with key stakeholder representatives, a formal mapping of current processes and a systematic review of the literature on best audit practices.
- We increased the number and quality of our professional education offerings, some of which award continuing education credits. Webinars and online instruction in 2013 covered such topics as revisions to the policy covering liver transplant candidates with hepatocellular carcinoma, toxoplasma testing, changes in the kidney allocation system, kidney paired donation and living donation.
- The website of our comprehensive patient information program, Transplant Living, again garnered an award for excellence in an international communications competition. Funded entirely by charitable contributions, www.transplantliving.org received nearly 289,000 visits in 2013, as it helped patients and their families navigate through the transplant process.



Whittney Edwards, kidney recipient

What DeAndre Robinson and Whittney Edwards have in common has nothing to do with elementary school, sports or other activities that kids commonly do. Their families met while they were receiving dialysis treatments. Extraordinarily, they received kidney transplants on the same day from the same donor.



DeAndre Robinson, kidney recipient

Photos by Dero Sanford/Courtesy of Arkansas Regional Organ Recovery Agency

Cynthia Coleman UNOS Survey Services Manager



Photo by Ralph Lauer/Courtesy of LifeGift

ACCOUNTABILITY

We take ownership of our actions and fulfill our commitments to our stakeholders and each other.

Transplantation both demands and provides more public accountability than any other field of medicine. Policies are developed with public input. Data is collected on every organ donation and transplant. And, statistics are available online, from the national level down to the individual transplant center.

UNOS helps the transplant community fulfill its commitments to stakeholders—especially patients and donor families—in a number of ways. To name just a few:

- The UNOS and OPTN strategic plans guide the actions of our staff and board of directors. In 2013, we developed key organizational metrics for monitoring our collective performance, as well as departmental metrics to be used in developing performance improvement goals.
- To assist members in accountability, we created resources and checklists this year to help living donor recovery hospitals develop their own site-specific tools for ensuring compliance with new living donor policies.
- We updated the "Crosswalk Guide to OPTN and CMS Reviews of Transplant Programs." The guide summarizes what surveyors from each organization review on their site visits and allows transplant program administrators to see where the requirements overlap.
- This year our member website, Transplant Pro, turned one. We take seriously our responsibility for keeping members updated on requirements and how UNOS can be of assistance. Our monthly e-newsletter keeps members informed about policy developments, patient safety issues and educational opportunities.
- This fall we sent living kidney donor programs a report of their donor follow-up rates. This information helps programs assess how they can achieve the required minimum follow-up thresholds for data reporting established in OPTN policy.



Ruben Salinas, liver recipient

After nearly a year of battling liver cancer—with radiation, chemotherapy, and a series of surgeries, Ruben Salinas' only hope for survival was a liver transplant. He had nearly lost hope of seeing his children grow up when the call came. Now he makes a point of enjoying the simple things in life—like working in his vegetable garden and spending time with his family.



2014 AND BEYOND

In 2014, UNOS will celebrate the 30th anniversary of our incorporation as the nonprofit organization serving as the national Organ Procurement and Transplantation Network. It will be a year of moving forward, not looking back. By mid-year, we will be well under way with preparations in implementing the new kidney allocation system. We will officially assume full responsibility for vascular composite allograft policy development. And we will tackle tough issues, such as geographic disparities in organ allocation.

To successfully meet these and other challenges, we will continue focusing on institutional, departmental and personal performance improvement. We will seek new ways of improving UNOS' effectiveness and the quality of our service to the transplant community and the patients who depend upon us. We will make sure that whatever we do, we do well, and always with an emphasis on our core values of stewardship, unity, trust, excellence and accountability.





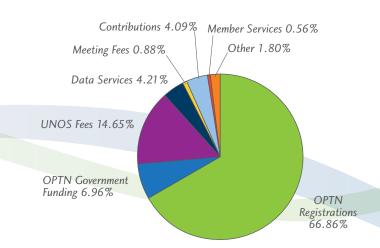
FINANCIALS

UNOS' primary mission is to perform the OPTN contract.

The OPTN is a cost-sharing and cost-reimbursement contract in which the federal government contributed \$3,208,420 in federal appropriations and the transplant community contributed approximately \$30,805,558 of the \$34,013,978 program in fiscal year 2013.

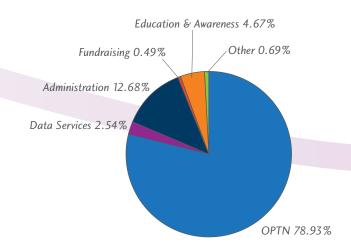
OPTN funding represents 73.8% of UNOS revenues. The remaining 26.2% of revenues comprised member fees, data services, meeting registration fees and charitable contributions. These additional revenues provide resources needed to support the OPTN contract and the financial health of the organization.

Revenues (fiscal year 2013)*	
OPTN Registrations	\$30,805,558
OPTN Government Funding	3,208,420
UNOS Fees	6,751,874
Data Services	1,939,684
Meeting Fees	403,594
Contributions	1,882,865
Member Services	256,313
Other	827,410
Total	\$46,075,718



Expenses (fiscal year 2013)*	
OPTN	\$34,013,978
Data Services	1,093,320
Administration	5,465,737
Fundraising	211,221
Education & Awareness	2,012,012
Other	298,160
Total	\$43,094,428

Change in Net Assets \$2,981,290



*UNOS operates on a fiscal year of October 1 through September 30.



To view the results of our annual financial audit conducted by independent certified public accountants, go to www.unos.org > about us > governance > financials.

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The UNOS Foundation is responsible for securing support of UNOS' mission through charitable gifts, educational grants and sponsorships. Activities in 2013 focused on fundraising for the kidney paired donation automation project, Transplant Living patient education program, National Donor Memorial, renovations to UNOS' second location and a learning management system.

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For more information about planned giving, visit http://support.unos.org/.

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UNOS gratefully thanks these sponsors for their generous support of the KPD automation project:

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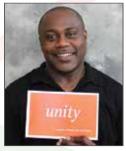




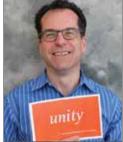
















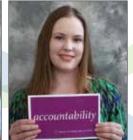




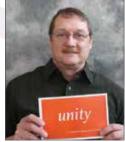












































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To advance organ availability and transplantation by uniting and supporting its communities for the benefit of patients through education, technology and policy development.

UNOS Vision:

To promote long, healthy and productive lives for persons with organ failure by promoting maximized organ supply, effective and safe care, and equitable organ allocation and access to transplantation.

