



UNITED NETWORK FOR ORGAN SHARING

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2012

UNITED NETWORK
FOR ORGAN SHARING
ANNUAL REPORT



FOCUS

IN 2012, UNOS' ORGAN CENTER ASSISTED WITH THE PLACEMENT OF

11,739
ORGANS.

UNOS' ORGAN CENTER ALSO HELPED ARRANGE TRANSPORTATION FOR 2,160 ORGANS.

In 2012, UNOS staff traveled

341,460 MILES

to attend OPTN/UNOS board, committee and regional meetings.



The UNet Help Desk handled

15,364 CALLS

from members in 2012.

509 NAMES



are featured on the Wall of Names

IN THE NATIONAL DONOR MEMORIAL AT UNOS.

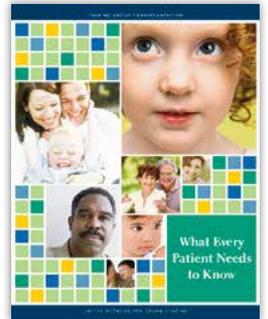
MORE THAN 1/2 MILLION ORGAN TRANSPLANTS

have been performed in the U.S. since UNOS began record keeping in 1987.

81%

of candidates on the waiting list are waiting for a life-saving kidney.

7,743



REQUESTS FOR RESOURCES AND INFORMATION FULFILLED

28,053 FROM 14,015

LIFE-SAVING ORGAN TRANSPLANTS

FROM

DONORS (LIVING AND DECEASED)

Letter from Leadership:

In July, we celebrated the 30th anniversary of the UNOS Organ Center, sometimes referred to as the “heart” of our organization because that is where the lifesaving matches between transplant candidates and donated organs take place. In the past three decades, Organ Center staff have handled more than 128,000 organ placements.

During that time, UNOS has grown from a handful of individuals primarily focused on matching organs to an organization of more than 300 professionals with expertise in policy development and compliance, research, information technology, organ placement, communications, professional education, patient services, finance, human resources and other disciplines necessary to manage our nation’s transplant network.

While celebrating the Organ Center milestone, we’ve been working on a number of improvements to better position the organization—and our nation’s transplant system—for the future.

As always, our main focus is on patients, with emphasis on developing policies to facilitate more transplants, more safely. We’ve also sharpened our focus on serving our membership through such efforts as enhanced professional education offerings, clearly written policies and bylaws, improved delivery of important information, and enhancements to our IT infrastructure and systems.

Our focus on organizational improvement this year included the development of new strategic plans for UNOS and the OPTN, with input from our board of directors as well as senior leadership.

2012 also saw the retirement of Walter K. Graham, UNOS’ executive director for 25 years. We thank him for his leadership in guiding UNOS through decades of growth and change, and most of all, for his unwavering commitment to serving the thousands of transplant patients who depend on UNOS.

As we enter 2013 and prepare for the future, patients, and their well being, will continue to be our primary focus.



John P. Roberts, M.D.
President
United Network for Organ Sharing



Brian M. Shepard
Acting Chief Executive Officer
United Network for Organ Sharing

ON THE COVER: *The liver transplant 2-year-old Temperance Geneman received in November, 2012, makes it easier for her to walk now that her belly isn’t swollen. She’s trying new foods, eating more and sleeping better. Temperance’s mom Krisa remembers thinking, “It was hard to know that someone had to go through what I had been dreading for two years, but I was also so excited that the day had finally come.”*

Photo/UW Health

To view this annual report online, scan the quick response (QR) code to the left or visit www.unos.org > about us. To download a free QR code reader, visit www.scanlife.com from your smartphone.

FOCUS

Focus on

In 2012, there were 28,053 life-saving organ transplants from 14,015 donors (living and deceased), while 117,040 people were on the waiting list on Dec. 31. Because the demand for organs continues to exceed supply, one of our top goals is to increase the number of transplants. Another is to increase access to transplants.

2012 EFFORTS TO HELP MEET THESE GOALS INCLUDED:

Kidney Paired Donation Pilot Program (KPDPP)

The national KPDPP added more participating centers, lined up successful transplants, revised operational guidelines for greater equity and efficiency, and made its resources more widely accessible. By year-end, 128 kidney transplant programs were participating in the program.

The KPD program increased its match runs to once a week, increasing opportunities for finding suitable kidneys for candidates who have willing, but incompatible, donors.

The method of assigning waiting time points for KPD candidates was revised to assure that they are assigned consistently. KPD waiting time now begins when a candidate is added to the system and accrues daily.

The board of directors approved including “bridge” donors in KPD chains arranged through the program. The policy will allow these donors, with their consent, to be matched at a later time with a new chain of KPD transplants. The board also approved incorporating some of the OPTN KPD operational guidelines into policy, with which participating programs must comply.

Kidney Donor Profile Index

In 2012, 16,487 people received a kidney transplant. 95,022 candidates were on the waiting list on Dec. 31, 2012.

Given the imbalance of supply and demand of kidneys for transplant, we are using a new quality metric to safely reduce the number of deceased donor kidneys that are discarded: the Kidney Donor Profile Index. KDPI measures the potential longevity of a kidney relative to other kidneys. Including this score with each donor offer can help clinicians make more informed choices and eventually lead to higher deceased donor kidney utilization.

UNOS' kidney paired donation work is partially funded by the OPTN contract and in part by private sponsors.

\$1.17
MILLION

was contributed in 2012, by generous sponsors to support kidney paired donation implementation. See page 24.

AS OF DECEMBER 31, 2012



128

transplant centers had signed up for the
Kidney Paired Donation Pilot Program

(KPDPP).

As a young active dad and soldier, **Keith McCarter** thought nothing of it when he began to feel bad. It turned that he had congestive heart failure, which led to the need for a Ventricular Assist Device (VAD) to keep him alive. Keith and his wife Jessica are both Operation Iraqi Freedom veterans. As Keith waits for a heart transplant, they are thankful for the moments they share.

Photo/UW Health



PATIENTS

Broader access for liver transplant candidates

In June, revisions to liver allocation policy were approved to ensure broader access to organs for candidates in urgent need of liver transplantation.

Lung allocation

The board approved changes to the calculation of the lung allocation score (LAS), which is the primary factor in prioritizing organ offers for lung transplant candidates. The updated LAS is expected to improve the balance of priority for all groups of candidates.

UNOS toll-free patient services line

Our toll-free patient services line now offers interpreters in more than 170 languages for callers with limited English skills who have questions about transplantation.

Relaunch of Transplant Living website

Our interactive patient website, Transplant Living, became the anchor of the “Transplant Living patient education program,” which encompasses the English and Spanish versions of the website, a monthly e-newsletter, support and assistance by phone and e-mail, as well as a variety of printed educational materials. In 2012, the Transplant Living website attracted more than 321,000 visits.

253,006

people visited www.transplantliving.org and www.transplantesyvida.org.



UNOS' TRANSPLANT LIVING PATIENT EDUCATION PROGRAM IS MADE POSSIBLE BY THESE GENEROUS SPONSORS:

- Novartis**
- Astellas**
- Bristol-Myers Squibb**
- Genentech**
- Teva Pharmaceuticals**

TRANSPLANT LIVING received

20,763 VOTES

during the month of April to decide the site's favorite story during the "Stories of Hope" contest.

170

Our toll-free patient services line, (888) 894-6361, offers interpreters in more than 170 languages for callers with limited English skills who have questions about transplantation.



6th

In 2012 we published our 6th brochure available in Spanish, *Programa piloto de intercambio de donates de rinon de las OPTN*.

To view all our 30+ print resources, visit our online store at <http://store.unos.org/>.

30⁺

Born with biliary atresia, which she defines as a “fancy term for liver failure,” **Jill Nolen** had two liver transplants by the age of 11 months. Jill’s transplant allowed her to pursue her love of sports. Growing up she did it all—gymnastics, softball and dance to name a few. As she enters her mid-twenties with a new college degree, Jill is living life to the fullest.



PATIENTS



Rachael Wong serves as a patient representative on the OPTN/UNOS kidney transplantation committee and vice chair of the Legacy of Life Hawaii board of directors. Rachael makes time for this and other important volunteer work to fit into her busy schedule as vice president and COO of the Healthcare Association of Hawaii. A kidney transplant 10 years ago not only saved her life, but allows Rachael to make a positive impact in the transplant and wider healthcare communities.

Focus on

In our most recent membership survey, we learned that members were pleased with the services UNOS provides. 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.

WE RESPONDED TO MEMBER FEEDBACK WITH THE FOLLOWING PROJECTS IN 2012:

OPO metrics and performance improvement

We monitor member performance and identify opportunities for improvement. Historically, these efforts focused on transplant program performance. Now a process has been initiated with approval from the organ procurement organization (OPO) committee and transplant community for using accepted metrics to monitor OPO performance and then provide resources to improve.

OPTN/CMS crosswalk

Transplant hospitals are surveyed by both UNOS and CMS for compliance with federal and OPTN requirements. In response to concerns from the transplant community about differing and sometimes overlapping processes and rules, UNOS, HRSA and CMS representatives worked together to find a solution.

We developed a crosswalk tool that compares and contrasts review methods used by each entity. This is a resource document to help programs review requirements and prepare for site visits. To explain how to use the crosswalk document most efficiently, CMS, UNOS and HRSA sponsored a webinar for all interested transplant professionals.

Transplant Pro website

UNOS revamped its online archive of important information for the transplant community. The new resource for transplant professionals, Transplant Pro, offers professionals easy and timely access to critical information on transplant policy, patient safety, educational webinars and more.

A consensus conference on transplant program quality and measurement

In February, UNOS and the contractor for the Scientific Registry for Transplant Recipients coordinated a consensus conference on transplant program quality and measurement. Participants discussed the methods used in measuring solid-organ transplant program performance and made recommendations for improvements to those methods.

OPTN bylaws rewritten in plain language

We rewrote the OPTN bylaws for greater readability and more logical organization of content, and they are now available on the OPTN website, <http://optn.transplant.hrsa.gov>.

IMPROVEMENT

IT programming

For several years, UNOS has been working on a major overhaul of its information technology (IT) infrastructure, making it necessary to postpone programming required to implement some board-approved actions, including allocation policy revisions. Last fall, we reviewed our IT project plan to determine what improvements we could make. We reworked our project planning, and resumed programming some previously approved policy changes.

Examples of policy changes to be programmed in 2013 include:

- National sharing for liver-intestines – to provide broader access for those awaiting a combined liver-intestine transplant.
- Share 15 national – Livers from adult deceased donors will be offered to status 1A or 1B candidates or those who have a MELD or PELD of 15 or higher before being offered to any candidates of lesser urgency.
- Regional share 35 – Livers from adult deceased donors will be offered to candidates with a MELD or PELD score of 35 or higher at the local and regional level before being offered to candidates with lower scores.
- New HCC imaging criteria – includes more rigorous imaging criteria to establish the diagnosis of hepatocellular carcinoma (HCC).
- Update CPRA calculation to include C locus antibody, update HLA frequencies, and create a mechanism for CPRA default to distinguish between a value of zero and a null value.
- Revise lung allocation score (LAS) – Incorporate bilirubin into the calculation of the LAS score; include variables and coefficients in the underlying survival models.
- Update the LAS calculator in WaitlistSM reports – including LAS missing/expired and critical and expected data. The LAS will be programmed so that it can never be zero, so a transplant candidate will never be completely screened off the match run just because of his/her LAS.

At the same time, we are working to deliver an infrastructure for UNOS IT systems that is stable, robust, reliable, flexible and scalable.



Our member website, Transplant Pro, launched Oct. 18, 2012. By Dec. 31, it had received

14,599 VISITS
& 5,550
TOTAL E-NEWSLETTER SUBSCRIPTIONS.

THE UNET HELP DESK STAFF SPENT

3,649,998
seconds on the phone assisting members.

3,677 INDIVIDUALS PARTICIPATED IN
10 UNOS
EDUCATIONAL WEBINARS IN 2012
ON TOPICS INCLUDING PATIENT SAFETY,
KPD AND THE OPTN/CMS CROSSWALK.



Liver recipient **Rick Nisleit**, pictured here with his oldest daughter and living donor Amanda Jensen, placed second in Transplant Living's "Stories of Hope" video contest in November. Thirty years after a motorcycle accident and subsequent blood transfusion, Rick found out that he had contracted Hepatitis C as a result. It led to liver cancer. Amanda's selfless gift saved her father's life and allowed him to walk her down the aisle.

IMPROVEMENT



Nefeterius McPherson won *Transplant Living's* "Stories of Hope" contest with a video honoring her liver donor, 12-year-old Taitlyn Shae Hughes from West Virginia. Now Nefeterius (a Texas native) loves West Virginia University football as much as Taitlyn did—enough to wear Taitlyn's WVU football shirt (a gift from Taitlyn's mom) to the game when the team played at the University of Texas.

Focus on

The board of directors met in February and focused entirely on UNOS corporate matters. They redefined UNOS' corporate purpose and established key corporate goals.

UNOS' CORPORATE PURPOSE

is to be **THE OPTN CONTRACTOR**, a **MEMBER SERVICES** organization, and, ultimately, the **WORLD LEADER** in **TRANSPLANTATION** services.

The board recognized a need to enhance corporate governance and increase board involvement in oversight of the corporation, to help UNOS remain a strong non-profit corporation capable of fulfilling the OPTN contract requirements at a high level of performance. As a result, three new committees of the board were formed. All three consist of board members and outside expert advisors.

- The corporate affairs committee oversees and directs UNOS corporate matters and reports to UNOS' board of directors.
- The corporate finance committee oversees UNOS corporate financial matters.
- The IT advisory committee provides oversight and advice about UNOS' IT efforts and is charged with making recommendations regarding immediate and longer-term planning to support UNOS IT operations.

The corporate affairs committee developed a new strategic plan for UNOS.

At the same time the OPTN/UNOS executive committee (including HRSA representatives) worked with UNOS leadership to develop a strategic plan for the OPTN to help guide the network for the next several years.

OPTN STRATEGIC PLAN GOALS

- 1 Increase the **NUMBER** of transplants.
- 2 Increase **ACCESS** to transplants.
- 3 **IMPROVE SURVIVAL** for patients with end stage organ failure.
- 4 Promote transplant **PATIENT SAFETY**.
- 5 Promote **LIVING DONOR SAFETY**.
- 6 Promote the **EFFICIENT MANAGEMENT** of the OPTN.

For more information on the OPTN strategic plan visit <http://optn.transplant.hrsa.gov>.

PLANNING

Focus on

Safety continues to be a top priority, with special emphasis on preventing disease transmission and enhancing safety for living donors. In 2012, UNOS undertook the following initiatives:

Enhanced living donation policies

Policies were enacted to improve consistency in the medical and psychosocial evaluation and informed consent processes for living kidney donors and to improve the quality of clinical information reported on post-transplant outcomes.

The new policies specify minimum required tests and procedures for the medical and psychosocial evaluation of potential living kidney donors, as well as minimum requirements for informed consent for donation.

We will provide resources to transplant programs to help our members successfully implement the new living donor policies.

Recognizing infections

The ad hoc disease transmission advisory committee developed guidance documents to:

- help organ procurement organizations and transplant centers assess potential donors who have meningoencephalitis
- identify risk factors for Mycobacterium tuberculosis during the evaluation of potential living kidney donors

Important changes in vessel policy

To reduce the risk of accidental disease transmission, policies concerning storage, use and disposal of vessels were updated. All extra vessels that are hepatitis C antibody positive and hepatitis B surface antigen positive must be destroyed.

In November, the board approved a policy that requires transplant hospitals to report the use or disposal of extra vessels within seven calendar days.

IN 2012, THERE WERE NEARLY
5,900
LIVING DONOR
KIDNEY AND LIVER TRANSPLANTS.

In 2012, **6,256** people received
a liver transplant; however, as of Dec. 31
15,925
people were on the waiting list for a liver.

2/5ths of living kidney donors in 2012
were **NOT RELATED OR
MARRIED** to their recipients.



Jeanne Anne Love, shown here with husband Jared, received a new heart on New Year's Eve 1994. "A new year, a new heart, a new life! I was able to go to college, and after graduation, my heart brought me back to the hospital where I was transplanted. I am now working in cardiothoracic research where I belong."

SAFETY



Before his double-lung transplant, cystic fibrosis patient **Miller Brackett** often had to stop singing during stage productions due to cough and voice loss. Now, ready to begin college, Miller recently moved from Chicago to New York to pursue his dreams as a performer.

Photo/UW Health

Focus on

With UNOS and members alike placing increased emphasis on patient safety and member performance, UNOS refined the focus of the services offered to UNOS members. In addition to providing printed resources, staff created interactive educational programs on a wide range of transplant-related topics and OPTN policies.

- Thousands of UNOS members registered for distance-based learning programs, which usually offered continuing education credits. Topics included: patient safety; disease transmission; kidney allocation; extra vessel reporting; the OPTN/CMS crosswalk; HIPAA; packaging and labeling of organs and living kidney donor programs.
- A “toolkit” of resources was posted on <http://transplantpro.org> > professional resources to help OPOs and transplant centers encourage information sharing between recipients and donor families.
- UNOS staff members authored and presented several studies at the American Transplant Congress. They were primary authors of eight papers on OPTN policy impacts, patient safety and other current transplantation topics.

CONTINUING education points for transplant coordinators awarded from UNOS trainings for members.

687

10,000

pieces of printed materials, such as policy brochures and patient booklets, were distributed throughout the year.



15,000

PEOPLE FOLLOW UNOS ON FACEBOOK, TWITTER, YOUTUBE AND OTHER SOCIAL MEDIA.



UNOS STAFF RESPONDED TO

3,694

queries from patients, friends, family members, potential donors and medical professionals.

8

UNOS STAFF WERE FIRST AUTHORS ON 8 AND CO-AUTHORS ON 4 STUDIES FOR THE 2012 AMERICAN TRANSPLANT CONGRESS.

4

EDUCATION

Focus on the

As 2012 drew to a close, HRSA issued its pre-solicitation notice for the continued operation of the next OPTN contract. Among the stated objectives: “support the continued improvement of national organ allocation policies to maximize the benefit of transplantation to those with end-stage organ failure.”

UNOS has held the contract for 26 years and looks forward to submitting a bid for its renewal. The main goal of our corporate strategic plan is “to be the OPTN contractor.” While preparing and submitting the bid for this contract, we will continue working on the goals we’ve developed this year for the OPTN and UNOS, which call for continuous improvement in OPTN and corporate operations and enhancements of services provided to our membership.

Above all, we will continue to focus on the thousands of patients and their families who depend on us to develop the policies that will maximize the benefits of transplantation for them.

UNOS HAS OPERATED THE OPTN SINCE
9/30/86.

CANDIDATES WAITING
*for life-saving transplants
as of December 31, 2012:*

117,040

1,700

CANDIDATES ON THE WAITING LIST
ARE UNDER
THE AGE OF **18**

In 2012, UNOS’ Organ Center placement activity averaged

31.18 **ORGANS
PER DAY**

which was also an **ALL-TIME ANNUAL RECORD.**

454

**VOLUNTEERS
SERVE ON OUR
BOARD, COMMITTEES
AND WORK GROUPS.**



Within a year, both **Zion** and **Zhania Coleman** received life-saving heart transplants. Zhania is now able to take dance and swim lessons, something her family never thought she would be able to do. And Zion? He's playing baseball — one of his favorite sports. Their mom says that experiencing the gift of life twice taught their family to love and cherish each moment because so few are fortunate enough to get a second chance at life.

Photo/Rudy Harris
Courtesy of LifeCenter

FUTURE

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 \$2,500,000 in federal appropriations and the transplant community contributed approximately \$35,441,000 of the \$37,940,000 program in fiscal year 2012.

OPTN funding represents 78.5% of UNOS revenues. The remaining 21.5% 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.

Tii Informatix

Through our for-profit subsidiary, Tii Informatix, UNOS generates revenue to support corporate operations. Tii provides software development, clinical registry support and data analytic services to the healthcare and transplant services market.

- In 2012, Tii expanded its software development business to the OPO market with “OPOConnectsSM,” a web-based business networking platform that strengthens communication and collaboration between transplant centers, OPOs and other business partners with robust document storage in a secure, hosted environment.
- The Interagency Registry for Mechanically Assisted Circulatory Support (INTERMACSTM) was expanded to include a pediatric component that focuses on pediatric patients who receive mechanical circulatory support device therapy. INTERMACS is administered by the University of Alabama at Birmingham.
- Tii also rolled out two new prospective clinical registries in 2012, sponsored by the International Society for Heart and Lung Transplantation. The international registry for mechanically assisted circulatory support tracks patients with mechanical circulatory support devices. The Donation after Cardiac Death (DCD) Donor Registry seeks to quantify the prevalence and outcomes of DCD lung transplants at participating institutions.
- Tii grew its data analytic services business by adding a number of new pharmaceutical clients interested in outcomes research and immunosuppressive use trends. Tii is also participating in the Health and Human Services sponsored Tissue and Organ Donor Epidemiology Study as a data consultant to Research Triangle Institute.

UNOS Meeting Partners

In addition to coordinating all of UNOS' committee and board meetings, UNOS Meeting Partners provides travel and conference planning services to external clients, to help generate additional revenue for the organization. In 2012, UNOS Meeting Partners signed agreements with two new clients: Society for Transplant Social Workers and the National Marrow Donor Program.

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UNOS Foundation

The UNOS Foundation is responsible for securing support of UNOS' mission through charitable gifts, educational grants and sponsorships. Activities in 2012 focused on fundraising for the Kidney Paired Donation automation project, Transplant Living patient education program, National Donor Memorial and renovations to UNOS' second location, the Jackson Center.

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Clark Beck has lived with a transplanted kidney for almost half his life! It has allowed him to have two careers; volunteer for donation awareness and other good causes; and see his children graduate from high school and go on to college, get married and have children of their own. The grandfather of three teenagers, Clark is still active in sports, including the Transplant Games.



Our Mission:

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

Our Core Values:

Stewardship

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

Unity

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

Trust

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

Excellence

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

Accountability

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



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