



Third Quarter 2018

NATCO empowers transplant professionals to achieve their highest potential. NATCO leads the donation and transplant communities by uniting our members, advancing education, and promoting research and advocacy.

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MEMBERSHIP

Procurement and transplant professionals who are committed to the advancement of organ, eye, and tissue donation and transplantation join together to improve outcomes and share best practices.

NATCO promotes and enhances relationships between donation and transplantation. Members improve their skills and competencies through sharing knowledge and best practices.

Membership runs from January 1st through December 31st of each year.

Click [HERE](#) to join or for more information.

MEMBER BENEFITS

NETWORKING: donation and transplant professionals collaborate to enhance professional development.

EDUCATION: geared specifically to donation and transplant professionals to provide the best patient, donor and family care.

CERTIFICATION: achieve and maintain current certification requirements

RESEARCH & SCIENTIFIC INFORMATION: through NATCO's *Progress in Transplantation* and website. Journal includes CE credit in each issue.

IN THE PRESIDENT'S WORDS

Dear NATCO Members,
It's hard to believe that a month has passed since the Annual meeting in Indianapolis. I hope that all of you who attended had a great time and left feeling energized with new ideas that you will use in your daily work.

A huge thank you to Indiana Donor Network for putting on one fabulous night at The Speedway, I am sure it will go down as one of the best offsite venues that NATCO planned for the attendees.

As we move forward with our planning for the 2019 Annual meeting to be held July 31st-August 2nd in beautiful Seattle-Bellevue, Washington, our goal will be to, once again, provide a quality educational experience for everyone.



Those of you who attended may remember my call to action for the rest of 2018 and 2019. In short, it was about building castles and bridges. No matter how big or small, make sure those bridges are inviting to everyone you work with. The other part of my call to action was a quote from Jim Kelly, the famed NFL quarterback, at this year's ESPY awards. "Make a difference today for someone who is fighting for their tomorrow", strong words from a strong individual. However those words should resonate with all of us in what we do every day.

My question is: How will you put those words into action and how big will your castles be?

We often hear so much about value, how it is measured, what does it mean and the impact it potentially has on all of us. NATCO has always played a valuable role in the donation and transplant community. Our top rated educational offerings, such as the Introductory Course for new procurement and transplant professionals, the CCTC review course and the Advanced Donor Management course are a few examples of how exceptional NATCO is. Our commitment to being the best is our highest priority because the value of NATCO is all of you, the members.

Thinking forward to the Annual meeting in 2019, I want to encourage all of you to share your knowledge and the value of what you have done or have undertaken. You can do this by submitting case studies and abstracts. Your work matters and we want you to share it.

In closing, I want all of you to know how proud I am of the work that all of you do on a daily basis; by helping families through difficult times and walking them through the donation process or watching a recipient regain their health because of their successful transplant. I am honored to be your NATCO President. Should you wish to contact me, my email is tsnyder24@icloud.com

All my best, your NATCO President
Timothy J. Snyder

COMMUNITY UPDATE

Workplace Partnership for Life

ADVOCACY: helping to advance public policy.

EDUCATION OPPORTUNITIES

Introductory Course for New Transplant and Procurement Professionals
[For More Information](#)

CCTC Review Courses
[For More Information](#)

WEBINARS:

[For More Information](#)

ONLINE LEARNING:

Online version of the Introductory Course for Transplant Professionals
[For More Information](#)

Fundamental Critical Care Support (FCCS) Self-directed Online Course
[For More Information](#)

Clinician's Guide to Donation and Transplantation
[For More Information](#)



Let life bloom.

During the Annual Meeting, NATCO proudly recognized the top 3 achievement winners in each of the Platinum, Gold, Silver, and Bronze levels as designated by HRSA in their 2018 National Hospital Organ Donation Campaign. At this time we would like to acknowledge the outstanding achievement of all the hospitals across the country for encouraging hospital staff and community members to enroll in their state registry as organ, eye, and tissue donors.

Congratulations on this important achievement!

For the complete list of hospitals who excelled during this campaign, please visit <https://www.organdonor.gov/sites/default/files/awareness/files/recognitionlist2018.pdf>



HOSPITAL CAMPAIGN TOOLKIT

For more information on how to participate in the upcoming campaign, please visit: <https://www.organdonor.gov/awareness/workplace/hospital.html>

IN THE SPOTLIGHT

Caring for Transplant Patients after Hurricane Maria
By: Marissa Barnes

When Hurricane Maria ripped through Puerto Rico on September 20, 2017, it was a Category 4 storm with winds of 155 mph. Rooftops collapsed, trees toppled; massive floods and power outages ravaged the island. There are approximately 2500 transplant patients living in Puerto Rico, and the lack of electricity, transportation and communication made it difficult to care for these patients. One of the main concerns was making sure patients had access to immunosuppressive drugs.



Immediately after the disaster, the transplant team at Auxilio Mutuo Hospital in Puerto Rico reached out to their colleagues at the American Society of Transplant Surgeons (ASTS) for donations of immunosuppressive drugs. The ASTS helped to secure the needed medications and by October 4th, the supply to Puerto Rico began to normalize. Companies such as Encompass RX, Total Care RX, Genentech, Astellas and Novartis joined with ASTS to assist with these at-risk patients. They donated immunosuppressive drugs as well as other medications.

In addition, the Puerto Rican government created a health coalition to determine the best ways to provide access to medical services. Because communication was impaired, the group turned to radio to inform the transplant population on how to best access the medications. Another problem was getting patients on the kidney transplant wait list to the hospital for dialysis. A Federal Emergency Management Agency Nurse Practitioner worked from a central location on the island to identify transplant patients in need of medical evaluation or medications, and coordinated transportation to the hospital for treatment.

Two weeks after the hurricane the hospital began receiving organ offers again and between September 20 and October 20 eight transplants were done. Soon after the hurricane, LifeLink of Puerto Rico, the OPO for the island, continued to evaluate hundreds of organ donors, even under the most challenging of conditions.

Editor's Note: As a community we can find inspiration in the determination and perseverance that the transplant and OPO teams demonstrated in facing this disaster. More recently, another area of our community faced challenges brought about by hurricane Florence. To all those who were impacted by Florence, please know that the transplant and donation community is here to support you in any way we can.

Vascular Composite Allograft Transplants at the Cleveland Clinic
by:
Debra Priebe RN, BSN, CCTC, ANM, Kidney and Pancreas Transplant,
VCA (Face/Hand) Transplant Coordinator

The Cleveland Clinic Reconstructive Transplant Team completed its third and most complex face transplant on a 21 year old young woman whose transplant journey was highlighted in the September 2018 issue of National Geographic. Katie Stubblefield became the youngest face transplant recipient in the world when she underwent a full face transplant in May 2017.

The face transplant team worked tirelessly for 31 hours straight beginning with recovering the delicate skin, nerves, muscle, bone and teeth from the donor, and ultimately transplanting the graft onto Katie's damaged facial structures. Katie's procedure, along with the second face transplant recipient done at Cleveland Clinic, was funded by a Department of Defense grant which aimed to examine the feasibility of facial transplants.

In December 2018, the Cleveland Clinic will celebrate the 10 year anniversary of its first face transplant, which was the first procedure of its kind done in the United States. Connie Culp was the fourth person in the world to receive a face transplant, and is currently the longest surviving face transplant recipient in the world. The transplant team hopes to begin evaluating patients for hand/upper limb transplantation in early 2019.

"How a Transplanted Face Transformed a Young Woman's Life" can be accessed at:
<https://www.nationalgeographic.com/magazine/2018/09/face-transplant-katie-stubblefield-story-identity-surgery-science/>

ADVANCING PUBLIC POLICY
By: Wade Delk

I hope everyone had an enjoyable summer. We are now approaching the mid-term elections in November. These are traditionally times when political positioning goes into overdrive as new candidates and incumbents seek to leverage what they have, or plan to do to seek support from the voters. Before we discuss a few federal bills, I want to alert you to a bill in California that as of this writing has been sent by the Legislature to the Governor's desk.

California SB1156, has the potential to change the way dialysis payments are made to patients. The bill requires third party groups to confirm that the patients they are working with are not eligible for Medicaid. The reason for this bill is the thought that Medicaid eligible patients are being steered toward enrollment in private insurance plans that reimburse at a higher rate than the



government. The argument against this is that it will cause financial burdens and limit a patient's access to care. The Governor has until the end of September to act on the bill. There are similar proposed bills in other states to confront this issue.

At the Federal level, in July, Representative Cartwright (D-PA) introduced legislation, HR 6448, Organ Donation Clarification Act of 2018. This is similar to what has been proposed in the past, seeking to increase organ donation. The legislation would remove barriers donors face, and would create a pilot program to test the effectiveness of non-cash incentives to increase the supply of available organs for donation. This legislation, like others over the years, seeks to revisit what The National Organ Transplant Act (NOTA) defines as "valuable consideration" which is currently prohibited. The bill attempts to provide clarification of payments that are reimbursement and not valuable consideration, and will measure the success of the program through five year pilot projects (which would need to be approved by the Secretary of HHS). There are currently 15 co-sponsors.

Another bill introduced in July was H.R. 6517, Fairness in Liver Allocation Act of 2018. This one came from Representative Engel (D-NY). This bill seeks to reform the criteria for liver allocation so that it is not based on the donor's residence. It directs the Organ Procurement and Transplantation Network (OPTN) to make these reforms by December 31, 2018 (somewhat of an unreasonable timeline that would likely be adjusted), and if not, gives that authority to the Secretary of HHS. The implementation date regardless of whether it is OPTN or HRSA establishing the criteria would be June 30, 2019.

The Centers for Medicare and Medicaid Services recently released a proposed rule on End Stage Renal Disease Prospective Payment System. This rule focuses on the importance of dialysis facility referrals of patients for transplants, as they are in a position to, where appropriate, promote transplantation as an alternative to dialysis. Encouraging transplantation by educating those that would likely benefit, even if the entities are required to, is likely in the best interest of the patient.

NATCO and others in the transplant community have been working for many years to see that those who donate an organ are covered under the Family Medical Leave Act (FMLA). We were pleased to see that on August 30, The Department of Labor released a legal opinion affirming this.

As a reminder the Living Donor Protection Act (H.R. 1270), which we have long supported, now has 72 co-sponsors. If you have not already, please contact your Representative asking for their support.

-Wade

OPTN/UNOS



OPTN/UNOS Transplant Coordinators Committee
By: Kimberly Uccellini, MS, MPH

The OPTN/UNOS Transplant Coordinators Committee (TCC) would like to keep you informed of our ongoing activities and projects.

The TCC Learning Series is a series of educational offerings that share lessons learned, improve professional practices and ultimately hope to increase the number of transplants. The series is aimed at both OPO and transplant centers and allows transplant professionals to learn strategies that are being utilized in the community to address common issues and barriers to transplant.

The following education offerings are available via UNOS Connect under the TCC Learning Series for 2018:

1. 1. UNetsm Reports - Leveraging UNet reports - Released in January
2. 2. PHS Increased Risk - How to talk to patients about increased risk donors - Released in April
3. 3. Donor Management - Impact of donor management on transplant - Released in August
4. 4. Explaining the Waitlist - Helping coordinators educate patients on the process of organ allocation -

TBD (anticipated fall 2018)

OPTN Public Comment Period Open from August 3 - October 5

Your questions and comments are important to the OPTN. Please take time to review the OPTN proposals that are currently out for public comment at <https://optn.transplant.hrsa.gov/governance/public-comment/>.

Recorded webinars about the public comment proposals are available here: <https://transplantpro.org/education/public-comment-webinars/>.

Call for OPTN Committee Nominations

The OPTN needs experienced and knowledgeable people to fill available positions on OPTN/UNOS committees. Volunteers who serve on OPTN/UNOS committees make

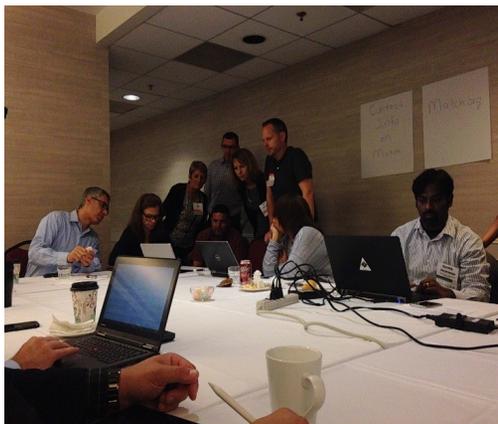


By: Anne Paschke, UNOS

UNOS wants your opinion! Learn about the proposed geographic frameworks currently out for public comment and tell us which one you think would work best for all organs and why. Also let us know what you think about the pancreas, pediatric and HLA public comment proposals.

Make sure you and your patients are ready for the changes to adult heart allocation policy coming this fall. There are courses on UNOS Connect to prepare OPOs and centers. Log in through UNet or, if you don't have UNet access, go to <https://UNOSConnect.unos.org>. We also created a [slide set](#) you can download and use to help your patients understand the changes as well as a patient-centered Q&A.

Did you ever want to look deep inside UNOS and the OPTN to find out about how policies made? Would you like to know about all the resources available to you? Now is your chance. A full-day [UNOS Primer](#) will be held on October 9, 2018 in Minneapolis, in conjunction with the Transplant Quality Institute (TQI).



Your ideas and participation in the UNOS Innovation Event at NATCO's 43rd Annual Meeting made it a success. Here are

crucial decisions that shape the national transplant network's ability to serve transplant patients, living donors, family members of deceased donors, and professionals involved in organ donation and transplantation. The term of service begins on July 1st of each year.

To indicate interest in serving on a committee, complete our online bio form at <https://optn.transplant.hrsa.gov/members/get-involved/>. Note that you can indicate interest in multiple committees and positions on the form. Prior to submitting the bio form, we recommend that you review the below information regarding committee terms and expectations for each role.

Deadlines for submitting bio forms

- If interested in a regional representative position, submit bio form by October 19, 2018.
- If interested in at-large positions, submit the bio form by November 30, 2018.
- If you submitted a bio form earlier this year or in 2017 and did not receive a committee appointment, our staff will be in touch with you to confirm your continued interest and get any updated information needed.

the statuses of the improvement projects UNOS development teams worked on at the conference:

- Donor ID Search on Organ Offer Reports and Sharing Custom Reports in Waitlist are awaiting final testing and will be released by October 2018
- TransNet Living Donor Organs needs additional development and will be released by the beginning of 2019

Our goal is to continuously improve our systems and make them easier to use. Please send your improvement ideas to tara.taylor@unos.org.

DONATE LIFE AMERICA

By: Lida Pieterman, Communications and Outreach Coordinator, Donate Life America

DLA Welcomes New NATCO Liaison - Tammy Wright, RN, BSN, CCTC

We are excited to announce that Tammy Wright will be serving as the new NATCO Liaison to the DLA Advisory Council. As the Lead Living Donor and Exchange Coordinator for Sharp Kidney and Pancreas Transplant in San Diego, California, Tammy is responsible for educating and evaluating living donors. She has worked in the field of transplant since 1993 and is on the National Kidney Registry Operations Committee and Medical Board. Welcome, Tammy, and thank you outgoing NATCO Liaison, Dianne LaPointe Rudow.

New Donate Life Lapel Pins



Also, we are happy to announce that the five new Donate Life lapel pins styles are now available for purchase on the Donate Life Public Store, DonationMerchandise.com. They can also be ordered in bulk through Members.DonationMerchandise.com. Get yours today!

NATCO Meeting Recap

Thank you to all who stopped by DLA's exhibit at the NATCO conference last month and attended our presentations: The What and Why of the National Donate Life Registry, and DLA Registry Analysis Gap Update. If you missed The What and Why of the National Donate Life Registry, here some key highlights:

- More than four million people are currently registered in the National Donate Life Registry
- The National Donate Life Registry launched in 2015 in response to the need for a national, easy, secure and mobile friendly registration opportunity that would allow for future national opportunities and partnerships
- The key elements to legal authorization as set forth in the UAGA are met by the National Donate Life Registry
- The Registry captures an electronically signed record legally authorizing donation, the document of gift is accessible to recovery organizations 24/7 and the document of gift can be revoked or augmented at any time by the registrant
- Donation and transplantation community professionals can search through access managed by OPOs
- Most states have a single-search process (a simultaneous search of both the state and National Donate Life Registry)
- Data dashboard access is available for state data and associated campaign pages
- Date and de-identified demographic filters include: age, gender, zip code (zip code reports by request)
- As of August 2018, 800 campaign pages have been created (three-quarters of these are organization pages)

Additional information about this presentation, along with slides from the DLA Registry Gap Analysis Update session discussing DLA's ongoing work to understand the gap between those who register as organ donors and those who support organ donation in order to better inform and target outreach activities can be accessed on DLACommunity.net.

Donor Registration Survey

Do you ask about donor registration status when listing candidates and meeting with their families? If so, do you have any best practices that you can share? DLA is always looking for replicable examples that can be used by others in the Donate Life

Community.

[Please take a moment to complete this brief survey.](#) We will share the survey results in the Q4 edition of In Touch. The deadline to provide feedback is Friday, October 19. Thank you for your help!

NUTRITION

By: Becca Wallschlaeger, MS RDN; Dan Pieloch MS RD CPHQ, Linda Ulerich, RD

NATCO's 7th Annual Transplant Nutrition Conference Recap

Transplant Dietitians from all across the country gathered at the 7th Annual Transplant Nutrition Conference in Indianapolis August 8-9, 2018. From its grassroots beginning in 2011, this conference continues to set the standard for transplant nutrition education by providing state-of-the-art information on the science and practice of transplant nutrition to solid organ transplant dietitians and other transplant professionals. This 2-day Transplant Nutrition Conference offered 15 hours of CPEUs in accordance with the Commission on Dietetic Registration and is the only conference offered specifically for Transplant Dietitians. The conference continues to be appropriate for both the entry level and the advanced practice transplant dietitian and provides content to maintain required competency in transplant nutrition. Roughly a third of dietitians who attended were new to the transplant nutrition field.

Twenty-seven transplant nutrition related presentations were given at this year's event. Some highlights included presentations on the implementation and impact of dietitian driven frailty assessments on transplant candidates & recipients, improving organ transplant outcomes with prehab & rehab nutrition, and a "Transplant Nutrition 101" talk on everything transplant dietitians need to know. Another key highlight was an ethics presentation provided by renowned transplant surgeon Dr. Nicolas Onaca on "Transplant Tourism."

A separate breakout session for pediatric dietitians, several smaller round table presentations, research posters, and a speed networking session were all incorporated into this year's conference to help optimize the educational experience for those practicing with different transplant populations.

NATCO's 2019 Transplant Nutrition Conference is already being planned and will take place in Bellevue, WA July 31st-August 1st. Please share with your Transplant Leadership and Transplant Dietitian(s)!

ABSTRACTS

By: Linda Ohler, MSN, RN, CCTC, FAAN

[A Multi-Center Case-Control Study of the Effect of Acute Rejection and Cytomegalovirus Infection on Pneumocystis Pneumonia \(PCP\) in Solid Organ Transplant Recipients](#)

Pneumocystis pneumonia (PCP) is associated with morbidity and mortality in solid organ transplant (SOT) recipients. In this case-control study, we determined the association between post-transplant PCP and 3 variables: cytomegalovirus infection, allograft rejection and prophylaxis.



[Excluding patients from transplant due to social support: Results from a national survey of transplant providers](#)

Social support is used to determine transplant eligibility despite lack of an evidence base and vague regulatory guidance. It is unknown how many patients are disqualified from transplantation due to inadequate support, and whether providers feel confident using these subjective criteria to determine eligibility. Transplant providers (n = 551) from 202 centers estimated that, on average, 9.6% (standard deviation = 9.4) of patients evaluated in the prior year were excluded due to inadequate support. This varied significantly by United Network for Organ Sharing region (7.6%-12.2%), and by center (21.7% among top quartile). Significantly more providers used social support in listing decisions than believed it ought to be used (86.3% vs 67.6%). Nearly 25% believed that using social support in listing determinations was unfair or were unsure; 67.3% felt it disproportionately impacted patients of low socioeconomic status. Overall, 42.4% were only somewhat or not at all confident using social support to determine transplant suitability. Compared to surgical/medical transplant providers, psychosocial providers had 2.13 greater odds of supporting the criteria (P = .03). Furthermore, 69.2% supported revised guidelines for use of social support in listing decisions. Social support criteria should be reconsidered in light of the limited evidence, potential for disparities, practice variation, low provider confidence, and desire for revised guidelines.

[Mood, body image, fear of kidney failure, life satisfaction, and decisional stability following living kidney donation: Findings from the KDOC study.](#)

Prior studies demonstrate that most living kidney donors (LKD) report no adverse psychosocial outcomes; however, changes in psychosocial functioning at the individual donor level have not been routinely captured. We studied psychosocial outcomes pre-donation and at 1, 6, 12, and 24 months post-donation in 193 LKDs and 20 healthy controls (HCs). There was minimal to no mood disturbance, body image concerns, fear of kidney failure, or life dissatisfaction, indicating no incremental changes in these outcomes over time and no significant differences between LKDs and HCs. The incidence of any new-onset adverse outcomes post-donation was as follows: mood disturbance (16%), fear of kidney failure (21%), body image concerns (13%), and life dissatisfaction (10%). Multivariable analyses demonstrated that LKDs with more mood disturbance symptoms, higher anxiety about future kidney health, low body image, and low life satisfaction prior to surgery were at highest risk of these same outcomes post-donation. It is important to note that some LKDs showed improvement in psychosocial functioning from pre- to post-donation. Findings support the balanced presentation of psychosocial risks to potential donors as well as the development of a donor registry to capture psychosocial outcomes beyond the mandatory 2-year follow-up period in the United States.

Citing Literature

ABOUT OUR SPONSOR

Organ Recovery Systems, is the global market-leading provider of organ preservation products. We are committed to advancing organ preservation by developing innovative medical technologies to preserve organs. Based in Chicago, with regional offices in Brussels and São Paulo, we currently support over 225 transplant programs in 34 countries with our

proprietary LifePort® Kidney Transporter and organ preservation solutions.

LifePort Liver Transporter is in process of regulatory reviews. PILOT™, (Preservation to Improve Liver Outcomes in Transplantation), is a prospective randomized multi-center trial comparing LifePort Liver Transporter system with Vasosol®, to static cold storage. Patient enrollment is scheduled to begin during the second half of 2017. We are dedicated to furthering the field of transplantation through pre-clinical and clinical research



www.organ-recovery.com

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