



# The latest news and information from NATCO

#### Third Quarter 2019

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 <u>HERE</u> to join or for more information.

#### MEMBER BENEFITS

NETWORKING: donation

## IN THE PRESIDENT'S WORDS

Dear NATCO Family,

As I write this letter it is hard to believe that just a few short weeks ago many of us were in Seattle-Bellevue at the 44<sup>th</sup> Annual NATCO Meeting. I hope that those of you who attended left the meeting energized and motivated to make a difference in the lives of donor and transplant patients and families.

My priorities this year include fostering the involvement, engagement and growth of all of you, the NATCO members. That means continuing to provide high quality educational offerings both at in-person meetings as well as through our webinars. I am eager to get started on building upon the past accomplishments of this organization and launching new programs.



A huge success in just one short month has been the formation of our organ specific committees. These committees will attend the local UNOS meetings and provide leadership for important events including the opportunity to participate in UNOS Public Comments. This is a perfect example of members being engaged in NATCO to make a difference. Thanks to all of the donation and transplant members that comprise these committees. I am looking forward to learning from and working with all of you.

One of the new programs we are launching in 2020 is the Emerging Leaders Program. All NATCO members are eligible to participate in this inaugural leadership course. Look for announcements to come out soon!

There is still time to register for the NATCO Introductory Course in Tempe, AZ. This meeting is an incredible opportunity for new professionals who have joined the donation or transplantation workforce to learn alongside your colleagues. NATCO has been successfully training new professionals for over 30 years, so come and join us.

There are many educational offerings for you to consider. Please check out our current list on our NATCO website. <u>www.natco1.org</u> Look for the one that is right for you!

We have so much to look forward to in the next year. I hope that you are all Saving

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.

**ADVOCACY:** helping to advance public policy.

EDUCATION OPPORTUNITIES

#### IMPORTANT PROGRAM CHANGE:

**Beyond the Basics of Authorization** Workshop, originally scheduled for Nov 6-8, 2019 is being postponed and reformatted for an offering in 2020. We apologize for this inconvenience. Based on valuable feedback from our membership, we feel this change will be most beneficial to our target audience. We look forward to bringing you this exciting new program in 2020.

Emerging Leaders Program

#### For More Information

Introductory Course for Transplant and Procurement Professionals

For More Information

**CCTC Review Courses** 

For More Information

### WEBINARS:

the Date for NATCO 2020! The dates for NATCO's 45<sup>th</sup> Annual Meeting are August 4-7<sup>th</sup>, 2020 in Kansas City. You should have all received the "Call for Presentations and Posters" that came out for this meeting. Share your expertise with fellow NATCO members.

I am so grateful for the opportunity to serve as your NATCO President. I look forward to getting to know more of our incredible NATCO membership. Together, we can make a difference in the lives of donor and transplant families. Please reach out to me with ideas or feedback. My email is <u>slerret@chw.org</u>.

Sincerely,

Stacee Lerret

### NATCO NEWS

# NATCO 44th Annual Meeting, Making a Difference

by Wendy Garrison, BSN, CPTC

NATCO certainly made a difference by bringing over 400 procurement, transplant, and nutrition professionals together at its annual 3-day action-packed meeting this year in Seattle Washington where the theme was "Make a Difference Today." With an agenda full of stimulating topics, key professionals from across the country came to speak on best practices, share case studies, and address hot topics in organ donation and transplantation.

After a delightful breakfast, Wednesday morning launched with a welcome from the NATCO President, Tim Snyder, detailing NATCO's successes over the past year followed by Chris Ramsey's personal story as a donor husband. He shared his tragic story recounting the loss of his beautiful giving wife and how choosing donation was paramount in his family's healing process. Our keynote speaker this year was our very own President Tim Snyder. Tim shared his recent experience of the most unimaginable loss of his son, Ryan, in December 2018 who, just like in life, continued helping others through tissue donation. Tim delivered a gripping narrative titled "Make a Difference Today with the Dash in Your Life" which focused on how we impact others with our choices and attitudes. If you missed it, here is a clip...



Live Your Dash

Other highlights of the day included a briefing on the future of Donate Life America by

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 Past President of OPTN, Sue Dunn. This year NATCO broke from the tradition of all day plenary for the opening day and instead included multiple breakout sessions for procurement and transplant. All attendees came back together for a riveting discussion on death led by the world-renowned Dr. Tom Nakagawa giving attendees a new perspective on determining death.

Top abstract and case studies were also announced on Wednesday. The top abstract award went to Brittany Lyons Advanced Practice Coordinator with Gift of Life for "Creating Brain Death Potential from the Donation after Circulatory Death Pool" and Yvonne Zacarese and Brian Papszycki with Live On NY received top case study award for "Teamwork Leads to DSA's Youngest Ever DCD." As the afternoon slid into evening, attendees readied themselves for the social event which included a trip to downtown Seattle for some sightseeing, cocktails, and delicious local fare.

Day 2 kicked off with all attendees back together for a captivating presentation by Tara Storch, mother and businesswoman, on how to "Outlive Yourself." Attendees divided for a morning and afternoon full of inspirational breakout sessions with the goal of equipping attendees with the tools they need to MAKE A DIFFERENCE in our community. A few of these key topics included a ground-breaking discussion on the use of donor-derived hepatitis C thoracic organs for transplant, collaborating with hospital partners to improve donation rates, and the use of serial bronchoscopies to improve lung donation outcomes.

Our final meeting day commenced with a lasting connect to purpose- a lung recipient recounting her journey and the impact transplant had on her life. Incoming President Stacee Lerett addressed the exciting future of NATCO and encouraged attendees to stay engaged in NATCO and attend the next meeting to be held in Kansas City, MO August 4-7 2020. The meeting wrapped with all attendees back together one last time to attend a topic affecting everyone in our industry- burnout. This session shed light on how to recognize and approach this sensitive subject leading to happy, healthy productive staff.

The 2019 Annual Meeting Planning Committee would like to thank President Tim Snyder for an amazing year along with Donna Dickt, Karen Libs, and Teresa Bristow for another successful meeting. Thank you to everyone who attended the meeting and we look forward to seeing you again next year in Kansas City!

# **Poster Presentation Highlights**

by Jennifer Reese, BSN, MSN, ANP-BC, APRN-CNP, CCTC

The Board of Directors at NATCO is proud to showcase some of our poster presentations/presenters from the 44th Annual Meeting in Bellevue, Washington last month. We will continue to showcase these throughout our quarterly newsletters to highlight these individuals. In this issue, we highlight the top 3 award winners:

#### 1st place award: Brittyne Dunn Hospital Donation Champions, the Unsung Heroes

In 2012, the OPO implemented a DSA wide Champion Training program to provide more efficient training and understanding of the donation process specifically related

to nurses in critical care areas and the emergency department. Hospital Development took the lead on preparing the training, promoting the new program and encouraging nurses to attend. The program was an 8 hour class, in which a representative from all pertinent departments in the OPO gave a presentation ranging from potential donors to aftercare programs. During the time the Champion Training program has been implemented, there has been over 800 hospital staff that have attended the training and are now wonderful donation resources in their units. After attending the program, the attendees are energized and excited to make a difference in their hospitals. We have found that the number of overall hospital variances and terminal extubations has significantly decreased. The percentage of both timely organ referrals and timely calls before terminal extubation/de-escalation in care rate increased from 84% in 2011 to 95% in 2018. This program was also beneficial to OPO staff in that collaboration from multiple departments was necessary to provide consistent messaging to the hospitals. The value of the Champion Training program is reflected in both external and internal data we are able to collect and provide after the end of each year. The tangible difference is seen by the increase of organ, tissue and eye donors for each of the 6 years the program has been utilized resulting in the OPO recovering the most donors in 2018 than it has in its 30 year history.

### 2nd place award: Virginia Ashley Wood Honor Guard: A Multidisciplinary Tradition to Honor Patients and Families Choosing Organ Donation



In October 2016, a nurse caring for a child declared brain dead implemented her idea after discussing with the family. This first Honor Guard consisted of approximately 15 people, including a variety of clinicians. Family and staff were so touched by the ritual that it has continued. Since 2016, there have been 23 Honor Guards. Staff is notified with a page activating the Honor Guard procession. Anyone interested in participating may line the hallways from unit of origin to the operating room entry. All participants stand in a moment of silence as the patient and family pass through in a process that takes about 15 minutes in total. Nursing staff were asked to provide feedback regarding the Honor Guard along with other End of Life care resources. Among PICU staff (n=115), 63% responded. The Honor Guard was the highest rated resource with 90% "extremely satisfied".

3rd place award: Megan Bell, Rebecca Hill & Courtney Lepis Improving Volume and Reducing Burnout: Implementation of an On-Call Transplant Team





We are a large thoracic and abdominal transplant center that transplants an average of 260 deceased organs and 30 living organs a year. In 2017, our center's leadership decided to research and create a new solution for covering organ offer call. The goals of this undertaking: to reduce burnout for the current coordinators while simultaneously allowing them to focus on their daily responsibilities of evaluating patients in clinic, preparing patients for listing, and coordinating post-transplant care. An on-call transplant team was developed that would cover organ offer call for all programs, coordinate the set-up of transplant cases, triage after-hour patient calls, and coordinate urgent listings while being fiscally responsible. After evaluating call and the tasks needed to be performed by the on-call team, the structure of the team was created. The decision was made to create a team that consisted of a blend of registered nurses and non-clinical staff that would be trained to cover call for all organs. The team would work primarily from home, covering call 24/7, 365 days a year under the direct supervision of the on-call managers. The position of Donor Allocation Specialist (DAS), was created to fill the non-clinical role. The team was hired in February and March of 2018 and began an intensive training program. The call team went "live" on July 1st, 2018 with call being transitioned from the office to the call team in gradual steps.. From 2017 to 2018, our transplant center had a growth of 9.3% in the number of deceased organ transplants. The call team was implemented in Quarter 1 of Fiscal Year 2019 and there was a 25% increase in organ transplants performed from Quarter 1 to Quarter 2. Developing an internal call team is one-way transplant centers can ensure that all organ offers are reviewed thoroughly in a timely manner, patients are cared for and office staff is freed up to concentrate on their daily tasks. Furthermore, a call team may lead to an increase in organs

transplanted, job satisfaction and reduce staff burnout.

# NATCO 8th Annual Transplant Nutrition Conference

By: Marian Glick-Bauer, MS RD CDN CSR CNSC Dan Pieloch MS, RD, CPHQ Linda M. Ulerich, RDN, CNSC





Transplant Dietitians from all across the country gathered at the 8th Annual Transplant Nutrition Conference in Bellevue, WA July 31st to August 1st. From its grassroots beginning this conference continues to set the gold standard for transplant nutrition education by providing state-of-the-art information on the science and practice of transplant nutrition for all solid organ transplant dietitians and other transplant professionals.

An action packed 2 day conference provided twenty-seven transplant presentations and offered 15 hours of CPEUs in accordance with the Commission on Dietetic Registration and is the only conference offered specifically for Transplant Dietitians. Highlights included presentations on the following: 1) Non-Alcoholic Fatty Liver Disease by Dr. Stephanie Abrams, second author of the NASPGHAN Clinical Practice Guideline for the Diagnosis and Treatment of Nonalcoholic Fatty Liver Disease in Children 2) Diagnosing Criteria For Malnutrition by Mary Russell MS, RDN, LDN, FADA, immediate past president of the Academy of Nutrition & Dietetics 3) Advanced Recovery After Surgery (ERAS) in Transplantation by renowned transplant dietitian Jeanette Hasse PhD, RD, LD, FADA, CNSC and the Marijuana/CBD Oil Use in Solid Organ Transplant Recipients by transplant pharmacist Mariesa Cote, PharmD.

Another key highlight were the results of the 2019 Transplant Dietitian Survey. This survey captured 194 transplant programs (that's over 80% of all programs nationally that perform over 5 transplants per year) and updated or established benchmarks for most everything transplant dietitian and/or nutrition related for all organ types in every phase of transplant and living donation as well as pediatric transplant. Transplant dietitian productivity, staffing ratios, and billing were just a few of the results discussed.

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 2020 Transplant Nutrition Conference is already being planned and will take place in Kansas City, MO on August 4th - 5th. Please share with your Transplant Leadership and Transplant Dietitian(s)!

# **EMERGING LEADERS PROGRAM**





Combining the proven leadership solutions designed by Franklin Covey with the trusted educational solutions provided by NATCO.

# Are you ready to invest in the future?

Emerging or high-potential leaders are just starting out on their leadership journey. The role of the emerging leader and the first-level leader has always been a challenge. People skills typically account for 80 percent of success in this role. Yet many of these people are promoted because of their clinical and technical capabilities. Both new and experienced first-level leaders can struggle when it comes to excelling at leading teams in today's workplace.

- Emerging leaders need to learn more about being a leader
- New team leaders need the foundations of leadership
- Front-line leaders need to be equipped with basic skills and tools



NATCO recognizes the challenges that organizations in our community have in meeting the training and development needs of the talented front-line staff and future leaders in our Organ Procurement Organizations, Hospitals, and Transplant Programs. That is why we have partnered with FranklinCovey, a recognized, world leader in helping organizations achieve results that require lasting changes in human behavior.

The success of the Emerging Leaders Program is based on a commitment from the individual participant and the participant's supervisor or manager. The program calls for a collaboration between the program facilitators and the participant and the supervisor/manager over a period of one year.

The program timeline can be found <u>HERE</u>. Specific workshop dates can be found on our website at <u>http://www.natco1.org/Education/emerging-leaders.asp</u>

Applications are now being accepted for enrollment beginning January 2020. Apply <u>HERE</u>. Applications are due by December 15, 2019.

## Class size is limited. Enroll NOW!

For more information, please contact Donna Dickt at donnad@natco1.org or 703-483-9817

NATCO would like to thank LifeShare of Oklahoma for hosting our two, live in-person sessions scheduled to take place March 10-13, 2020 and October 13-16, 2020.



# **Dietitian's Corner**

By: AJ Horvath, RD | Kidney/Pancreas Transplant Dietitian, Sentara Norfolk General Hospital

#### Nutrition and Frailty

The impact of frailty on post-transplant outcomes is an emerging area of focus in the transplant community. However, limited data exists on how pre-transplant frailty quantitatively impacts post-transplant outcomes. At Sentara Norfolk General Hospital, we started assessing frailty in all kidney and pancreas candidates 10 months ago. Initial data from 100 kidney transplant candidates were analyzed. It was found that age of a patient alone does not significantly correlate with being frail but higher estimated post-transplant survival (EPTS) scores do. These preliminary findings suggest that EPTS scores may correlate better to frailty than the more widely believed age of a kidney transplant candidate.

Forty-percent of all programs formally assess frailty in their kidney candidates based on the 2019 Transplant Dietitian Survey. This survey captured data from 194 transplant programs and identified wide variation in frailty tools utilized. The Fried Frailty Index was the most common way programs evaluated frailty (13%) followed by a novel program created frailty tool (8%). The remaining programs utilized 12 other tools to measure frailty. This lack of standardization reflects the paucity of data available on frailty and transplantation. Further research is needed to identify and validate a practical frailty tool that can be used for kidney transplant candidates.

### DONATE LIFE AMERICA By: Lida Pieterman, Communications and Outreach Coordinator, Donate Life America



### New Donate Life Pin - Coming Soon!

DLA was proud to present and exhibit at the NATCO 2019 Annual Meeting, and we were heartened by the enthusiasm shown by attendees for the Donate Life pins. As a result of your feedback, DLA is pleased to announce that we are committed to releasing a "Donate Life Dietician" lapel pin in time for NATCO's 2020 meeting. For now, we would love to see you wearing your new Donate Life pins in action! Please send photos to Lida Pieterman (<u>lpieterman@DonateLife.net</u>).





## Donate Life - The National Symbol for the Cause of Organ, Eye and Tissue Donation

Speaking of Donate Life, DLA would like to express its appreciation for NATCO community's embracing of the Donate Life logo as the national symbol for the cause of organ, eye and tissue donation. Since the advent of donation and transplantation, a variety of images have been used which can be confusing. A common example is the green ribbon, which is also currently used to represent more than 25 causes ranging from environmental issues to bipolar disorder awareness and the legalization of marijuana. Though there is nothing "wrong" with the green ribbon, it falls short of the message conveyed by the Donate Life image.



In addition to serving as the national symbols for the cause of increasing organ, eye and tissue donation, the registered *Donate Life* and *Done Vida* phrases and logos conceptually link the call to action to become a donor with a powerful visual image. This effectively associates organ, eye and tissue donation with the hope and promise of saving and healing lives. The consistent use of the brand marks helps strengthen our collective branding efforts, reinforces the life-based positioning of donation and transplantation, and engenders trust.

As a member of the Donate Life Community, you are allowed and encouraged to use the *Donate Life* and *Done Vida* logos in your materials. Please be sure to reach out to us for the official registered logos first. Also, please note that you must use one of DLA's two licensed vendors, <u>DonationPromotions.com</u> or <u>DonationMerchandise.com</u>, for promotional items featuring the Donate Life logo. Together, with consistent messaging, we are inspiring the public to Donate Life. Please direct logo requests and questions to Valerie Gray (vgray@DonateLife.net).

> ADVANCING PUBLIC POLICY By: Wade Delk



This past July, President Trump signed an Executive Order,

Advancing American Kidney Health, that focuses on reducing end-stage kidney disease by twenty five percent by 2030, and eighty percent of new ESRD patients receiving home dialysis or receiving a transplant by 2025.

The Administration is hoping their efforts will double the number of transplants. This Order directs HHS to release a proposed required payment model to adjust payment incentives encouraging preventative kidney care, home dialysis, and kidney transplants. The focus is starting to shift toward prevention rather than paying to treat the disease, as has been the case in the past.

Additional items called for in the Order include:

- A public awareness campaign of chronic kidney disease
- Reforming organ procurement to increase the supply
- · Compensating living donors for lost wages and child care

There will be a great deal of discussion on how to operationalize the new proposed models. The incentives directed at home dialysis is what the Administration believes is a big part of the solution. To learn more about the payment models look here:

https://cms.gov/newsroom/press-releases/hhs-transform-care-delivery-patients-chronic-kidney-disease

The Living Donor Protection Act (H.R. 1224/S. 511, identical bills), continues to be something we are working to see passed. I last reported that there were 51 co-sponsors in the House and 7 in the Senate. I am happy to share that there are now 67 House co-sponsors, and 14 in the Senate. We are hoping to get to the 100 co-sponsor threshold in the coming months and see action taken on this legislation.

There has been action taken by two Senators (Roy Blunt, R-MO; Jerry Moran, R-KS) who have concerns, and have shared them with HHS Secretary Azar, about the OPTN's moving toward not using donation service areas and regional boundaries for the allocation of organs for transplantation. They believe the policies reward low-performing organ procurement organizations without seeking improvement in their performance to help more people in need of organs. They are requesting that HHS not implement any new policies at this time.

We anxiously await the introduction of Immunosuppressive Drug Coverage legislation. In discussions with the Senate and the House we know that both sides are ready to introduce identical bills, on or about the same time. They are waiting to do so until they see if the Congressional Budget Office (CBO) scores it as a savings, a cost, or neutral. As of this writing the CBO had not made a decision, but is expected to do so at any moment. Many, if not all in the transplant community believe this might be the very best time to see this long sought after legislative initiative become law. Once introduced it will be an all hands on deck situation, and I will make sure you know what you can do to make a difference and help us all achieve final victory.

We will keep you updated on issues of importance in Congress, or state legislatures that may affect organ donation and transplantation. If you have questions or would like additional information please contact me at

wadebdelk@gmail.com or 202-253-7862.

-Wade

**OPTN/UNOS** 



## **OPTN Board action**

- 1. Key actions from the June OPTN Board of Directors meeting June 10 are outlined in this executive summary and include:
- The Board approved policy updates to heart and VCA allocation policies to replace donation service area (DSA) and region as units of distribution, consistent with requirements in the OPTN Final Rule and direction from the OPTN Executive Committee. For heart allocation, the most local distribution area will be for candidates listed at transplant hospitals within 250 nautical miles of the donor hospital. VCA distribution will now begin with candidates listed at transplant hospitals within a 500 nautical mile distance from the donor hospital
- The Board approved an amendment to the OPTN's variance for the HIV Organ Policy Equity (HOPE) Act. Programs meeting HOPE Act research and experience requirements will now be able to recover additional organ types from donors identified as HIV-positive and transplant them into candidates who are also HIVpositive. This measure broadens organs transplantable from liver and kidney to also include heart, lung, pancreas, kidney-pancreas and intestinal organs.
- The Board endorsed two guidance documents: one outlining ethical implications of multi-organ transplants and one describing effective practices in broader distribution.
- The Board approved the OPTN budget for fiscal year 2020. Due to continued strong totals of patient registrations and completion of target funding for the OPTN reserve, the OPTN registration fee will be reduced. Pending HRSA approval, the combined OPTN and UNOS registration fee amount will be \$926 effective October 1, 2019, a decrease of \$26 from the current fiscal year.

## Nominations sought for 2020-2021 Board and committees

The OPTN is seeking nominations for 2020-2021 vacancies on the Board of Directors and committees. To find out about specific vacancies and indicate interest in service, visit the <u>Get Involved</u> section of the OPTN website and submit the online biography form by **September 30, 2019.** 

## Public comment

The current public comment cycle is open until October 2. All proposals and documents are available on the <u>Public</u> <u>Comment</u> section of the OPTN website, along with a schedule and registration information for webinars addressing the proposals. For the first time, each public comment item will include a brief "at-a-glance" summary to help the reader assess interest in commenting without needing to read the proposal at length.

### Kidney, pancreas distribution proposals

Among the items out for public comment are proposals approved by the OPTN Kidney Transplantation and Pancreas Transplantation Committees to improve equity in access to deceased donor kidney and pancreas

transplants.

The proposals would replace distribution based on donation service area (DSA) and region with a model that considers the relative distance from donor hospital to transplant hospital. The proposals would establish, for most deceased donors, an initial distribution area of 500 nautical miles from donor to transplant hospital. If the organs are not accepted for any candidates within that radius, they would then be offered for candidates at hospitals beyond 500 nautical miles.

Both inside and outside the 500 nautical mile zone, candidates may receive proximity points, with the highest number of points given at each level for candidates listed at hospitals closest to the donor hospital.

### New report allows visualization of offer acceptance and refusal

UNOS recently released a Center Acceptance and Refusal Evaluation (CARE) tool, allowing transplant centers to see outcomes for organ offers they accept as well as all of those they refuse.

This interactive tool allows centers to review their own organ acceptance rates for specific types of donors, along with transplant-specific and aggregate outcomes information on the organs they refused that were transplanted elsewhere

Updated monthly, the tool includes information on all organs (other than VCA) offered to the center during the most recent two-year period available. The data are divided into two separate reports for thoracic and abdominal organs.

The report features three separate visualizations for each organ type: Accept, Offers, and Survival. For kidney and kidney-pancreas offers, a fourth visualization allows review of the rate of delayed graft function of organs accepted by the center as compared to those refused and transplanted elsewhere.

More information on the tool is available here.

## Kidney Accelerated Placement Project underway

On July 18, as part of the response to the <u>Executive Order on Advancing American Kidney Health</u>, the OPTN launched the Kidney Accelerated Placement Project (KAPP) to assess whether accelerating the placement of extremely hard-to-place kidneys via the Organ Center can increase their utilization. The KAPP was developed to improve placement of national kidney offers and was based on feedback from the transplant community.

The KAPP is an organ placement innovation that does not require a change in OPTN policy. The project's goal is to transplant more hard-to-place kidneys during the national allocation phase by having the Organ Center offer them to centers with an established history of transplanting them.

If you have questions about the project, please e-mail <u>theorgancenter@unos.org</u>.

# UNOS Transplant Coordinator Committee By: Christopher Wholley, M.S.A. and Karen Sokohl

## We Want Your Feedback

As a transplant coordinator, your feedback is critical to the policy development process. Right now the OPTN is actively seeking feedback on several initiatives that will impact the organ donation and transplant communities. <u>Visit</u> the public comment site now to let us know how you feel about these issues:

- Use of a 500 nautical mile (NM) distance for kidney and pancreas distribution (replacing Donation Service area and Region)
- Expedited Liver Placement
- Modifications to OPTN Data Submission Policies
- Clarifications on Pre-Existing Liver Disease
- Data Collection on Broader Organ Distribution
- Modifications to the Histocompatibility Vice Chair Appointment Process

### Looking for Committee and Board Members

The OPTN is actively recruiting for new members of the Board and several committees. We are looking for energized individuals with a variety of backgrounds. You'll find information about current vacancies in <u>this section</u> of the OPTN website. You can even submit a bio form online. Just click the Get Started button at the bottom of the page. Submit your form by September 30, 2019.

### **Educational Resources**

Access UNOSConnect for a comprehensive collection of learning modules that will teach you about policy changes, system updates, and other topics. This free educational resource offers free CEPTCs and also maintains your transcript when recertifying your ABTC credentials. Plus, new OPO and transplant staff members can now access <u>UNet University</u>, a series of 101 training modules that will orient you to all the applications within UNet. Supervisors can also use the <u>manager feature</u> to assign modules to their staff.

#### Accessing UNOS Connect:

- If you're logged onto UNet, just click the Resources tab, then select UNOSConnect from the dropdown menu.
- If you don't have access to UNet, you can still access the educational content by visiting <a href="https://unosconnect.unos.org/">https://unosconnect.unos.org/</a>, and clicking *How to Login*.

Other helpful info:

- Check the <u>dates for your fall regional meetings</u> and consider attending, particularly if you've never been before.
- <u>Join the TCC Listserv</u> and participate. The listserv is a quick and easy way to collaborate and communicate with your colleagues from across the country.
- <u>Subscribe to the monthly Transplant Pro eNewsletter</u>for the latest updates about policy and newly available resources.

Questions? Contact Chris Wholley, UNOS Transplant Community Administrator at christopher.wholley@unos.org.

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

#### Indefinite cytomegalovirus prophylaxis with valganciclovir after lung transplantation

Human cytomegalovirus (HCMV) infections and reactivations are common after lung transplantation and are associated with the development of bronchiolitis obliterans syndrome. Against this background, temporary HCMV prophylaxis is an established standard regimen after lung transplantation in most centers. However, the optimal duration of prophylaxis is unclear. We conducted a retrospective two-center study to determine the efficacy of indefinite lifelong HCMV prophylaxis with oral valganciclovir in a cohort of 133 lung transplant recipients



with a mean follow-up time of approximately 5 years. During the follow-up period, HCMV DNA was detected in 22 recipients (16.5%). In one case, HCMV pneumonitis developed after prophylaxis had been terminated. We observed a beneficial safety profile and tolerability in our cohort, as the majority of patients still received valganciclovir after a 1- and 3-year observation period, respectively. Compared to the literature, these data indicate a beneficial effect of extended valganciclovir prophylaxis with an acceptable safety profile.

#### Kidney donor outcomes >50 years after donation

Many living kidney donors (LDs) are young at donation; yet there are little data on long-term LD follow-up. We report on 66 LDs who donated  $\geq$ 50 years ago: 22 (33.3%) are still alive (current age, 78.5 ± 7.25 years); 39 (59%) died (mean age at death, 74.2 ± 12.3 years); and 5 are lost to follow-up (mean age at last contact, 68.7 ± 4.6 years). Those who died were older at donation (P < .001). Causes of death included 12 (30.8% of deaths) cardiovascular diseases, 9 (23.0%) respiratory failures, 5 (12.8%) malignancies and 4 (10.3%) infections, and 9 (23%) were unknown or miscellaneous. Forty-nine living donors (74%) developed hypertension at a mean age of 59.9 ± 14.0 years; 12 (18%) developed diabetes at a mean age of 62 ± 19.4 years; and 11 (16.7%) developed proteinuria at a mean age of 60.6 ± 18.2 years-each at a similar incidence as seen in the age-matched general population. At last follow-up, the eGFR by CKD-EPI (mean ± SD) for donors currently alive was 60.2 ± 13.4 mL/min/1.73 m2; for those that died, 54.0 ± 21.5 mL/min/1.73 m2; for those lost to follow-up, 55.6 ± 7.5 mL/min/1.73 m2. ESRD developed in 2 (3.3%). SF-36 quality of life health survey scores (n = 21) were similar to the age-matched general population.

#### Does duration of donor brain injury impact heart transplantation outcomes?

Between 1997 and 2017, we assessed 173 patients. Kaplan-Meier analyses showed that prolonged donor BIT, BDI, allograft ischemia, and total injury time had no significant effect on mortality and rejections. Patients were subdivided into short BIT (<97 hours, n = 87) and long BIT (≥97 hours, n = 86) groups. No differences in rejection scores nor in time to first rejection were noted. Kaplan-Meier analysis showed a similar long-term survival in the two groups. Sub-analysis of both groups according to their median BDI (12 hours) revealed no differences in mortality or time to rejection. Pre-transplantation time intervals do not affect mortality or rejection. Our findings have important clinical implications regarding HT allocation and organ availability.

#### Healthcare transition in pediatric liver transplantation: The perspectives of pediatric and adult healthcare professionals

Transition from pediatric to adult services of young people with a liver transplant is an important priority due to increasing numbers of young people surviving into adulthood. There is increased incidence of graft loss and non-

adherence following transfer to adult services. Although studies have considered the views and perceptions of young people who have undergone liver transplantation and their parents about transition, there is currently no qualitative research with healthcare professionals working in the field of liver transplantation. The aim of this study was to elicit the views of this group of stakeholders about barriers and facilitators of an effective transition process.

#### **ABOUT OUR SPONSOR**

Organ Recovery Systems is committed to delivering exceptional clinical tools and services to preserve and protect donor organs. We support 289 transplant programs in 39 countries with the LifePort® Kidney Transporter and the gold-standard in preservation solutions, UW solution (SPS-1®) and UW machine perfusion solution (KPS-1®). From the start, Organ Recovery Systems' mission has been to support transplant professionals in their service to improve outcomes for their patients. Now over 20 years later, with over 100,000 kidneys preserved in the LifePort Kidney Transporter, we are honored that the organ donation and transplant community continues to give us the opportunity to help save and improve lives.



The LifePort Liver Transporter clinical trial is underway! PILOT<sup>™</sup> (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. This trial is registered with clinicaltrials.gov and has been approved by US Food and Drug Administration (Investigational Device Exemption) and the Center for Medicare and Medicaid Services (CMS). The FDA has approved 8 transplant center study sites and 140 subjects to participate in the trial; 70 patients will be in the study arm and 70 in the control cohort. Patients will be tracked for a year post transplant to accommodate all the outcomes to be measured.

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