OPTN/UNOS TRANSPLANT ADMINISTRATORS COMMITTEE

Report to the Board of Directors June 25-26, 2012 Richmond, VA

Summary

I. Action Items for Board Consideration

None

II. Other Significant Items

- The Committee continues to support various committee Work Groups by providing the transplant administrator perspective regarding issues related to transplant center operations and financial issues. (Item 1, Page 2)
- The Committee continues to work on various projects including: Transplant Management Forum, Staffing Survey, Request for Information, and Transplant Administrator Listserv. (Items 4-7, Page 5)

Report of the OPTN/UNOS Transplant Administrators Committee To The Board of Directors June 25-26, 2012

Timothy Stevens, RN, BSN, CTCC, Chair Nancy Metzler, Vice Chair

The Committee meets monthly by conference call/Live Meeting except in April, when the Transplant Management Forum occurs, and July and October when the Committee meets in person.

- 1. OPTN Committee Goal: To provide input regarding all proposals with potential to impact transplant program operations, and particularly with regard to: Member and patient communications regarding a new kidney allocation system and the OPTN kidney paired donation program (KPD); and Proposed revisions to living donor data submission policies and forms. The Transplant Administrators Committee (TAC) has two representatives on the KPD Financial Subcommittee. Current subcommittee efforts include:
 - Developing a standardized business associate agreement template in conjunction with UNOS legal counsel and other academic medical centers
 - Developing a financial guideline document
 - Developing a release of health information template
 - Medicare cost reporting
 - Monthly updates on KPD Pilot Program match runs

The Committee will continue to have representatives on the KPD Financial Subcommittee and will provide feedback related to transplant center operations and financial issues regarding the KPD Pilot Program. The TAC representatives will also continue to provide the full Committee with updates during the TAC monthly Live Meetings and in-person meetings.

The Committee reviewed and provided comment on various sections of the US PHS Guidelines to the OPTN leadership, which were incorporated into the OPTN response in October 2011.

The TAC had two representatives who supported the Membership and Professional Standards Committee (MPSC) Inactive Waiting List Reviews Focus Group. The Performance Analysis and Improvement Subcommittee (PAIS) of the MPSC has been monitoring transplant programs that exceed 15 or more consecutive/28 or more cumulative days of waitlist inactivity in a rolling 365 day cohort. In 2009, a joint work group of the Patient Affairs Committee (PAC) and MPSC developed suggested language that transplant programs could use to notify candidates of periods of wait list inactivation. The bylaw language that was approved was not specific in terms of requirements for these notices (e.g. who gets the notices, what is required to be in the notice); therefore, a focus group was created to work on modifications to the existing bylaw.

At a PAIS meeting, the focus group modifications were presented to the Subcommittee. There was little debate over the required elements for patient notifications; however, the group had difficulty deciding who should get the notifications when a portion of a program ceases performing transplants (e.g. Pediatrics/Adults in all-ages facility, Living Donor Kidney/Liver). The PAIS/MPSC requested

that the focus group reconvene, with the addition of representatives from the Patient Affairs Committee and Transplant Administrators Committee.

This focus group met via Live Meeting on October 13, 2011, to discuss the above-mentioned issues and made suggestions to modify the bylaw language.

In the course of reviewing the Patient Notification bylaw, questions arose within the PAC about the information patients receive in writing from the transplant center regarding the two following critical situations:

- When patients are deemed not to be candidates following completion of the initial evaluation;
 and
- When candidates are delisted.

The PAC requested feedback from the Committee on whether centers include an explanation of the decision to list or to delist a patient in the center notification letters in these two instances. They also questioned whether including a written explanation in the center notification letter was a common practice within the transplant community? The Committee responded as follows:

- There is some variability between organ groups primarily driven by the variances in processes. Heart and lung letters are typically preceded by a conversation that is most often face to face but occasionally takes place over the phone. Since the particulars regarding why someone is not listed or will be removed from the list are discussed during that conversation, the specifics are not repeated in the letter. The letter generally includes a statement along the lines of "as per your recent conversation with" or "as we discussed during your recent office visit." The kidney program includes reasons why a patient is not being listed or is being taken off of the list primarily because there is no further contact with that patient. They return to their primary nephrologist.
- One center provides a general summary as to why. Here is an example: "Our Liver Transplant Medical Review Board discussed your case and carefully reviewed your recent diagnostic testing. We regretfully inform you that you are not a candidate for liver transplant due to progression of your disease." However, regarding living donors, a reason is not provided.
- A rationale is provided for both instances.
- Reasons are discussed and also documented in a letter.
- Yes, an explanation is included in the official communication in both of these situations. Additionally, coordinators are required to call and explain the Patient Selection Committee decision PRIOR to the letter going out. Patients should never receive the letter without getting the information from the person they have been working with. The Patient Information Letter is included with all correspondence so that people know that the resource is out there.

The Committee was asked to review the Living Donor Organ for Transplant label on November 11, 2011. There were no concerns regarding this label from the Committee.

The TAC's response to the Living Donor Committee's (LDC) request for pre-public comment feedback on the Proposal to Require Reporting of Unexpected Potential or Proven Disease Transmission Involving Living Organ Donors is described below and was submitted to the LDC for consideration on February 3, 2012.

• This proposal was reviewed and the concerns, which are no different than the concerns with the deceased donor policy, surround the language "potential transmission." This can be defined very differently from center to center, and there is also concern with the potential lack of consistency in which this policy will be implemented.

The Committee continues to have representatives on various committee Work Groups. Those Work Groups include: KPD Financial Subcommittee, ABO Verification Policy Modifications and Standardization of Documentation, and Operations and Safety Committee's Vessel Policy. These Committee representatives participate in Live Meetings with these Work Groups to provide the transplant administrator perspective on proposals that may evolve from the Work Group's sponsoring committees. These representatives are also responsible for reporting any of these Work Group updates and activities on the TAC monthly Live Meetings.

Committee members on the Donor and Recipient Information Sharing Task Force assisted in the development of an online Toolkit that includes guidelines regarding the standards for the sharing of donor and recipient information (i.e. type of work, parent, child, quality of life, etc.) that should be provided to donor families and recipients, and the appropriate timeframe to share this information. The guidelines were approved by the Board of Directors in June 2011. On October 5, 2011, UNOS produced a live Webcast titled *Sharing Donor and Recipient Information: Understanding HIPAA*. This Webcast highlighted the Donor and Recipient Information Sharing guidelines and reviewed HIPAA regulations associated with sharing patient information. The online Toolkit was subsequently approved by the Executive Committee in November 2011. A presentation on this topic was also given at the 2012 Transplant Management Forum.

- 2. OPTN Committee Goal: To develop educational strategies for members regarding more effective use of DonorNet[®]. The Committee will continue to consider developing other DonorNet[®] educational resources as needed.
- 3. OPTN Committee Goal: To work with staff to develop potential strategies for improving the quality of data submission. The Committee will provide ideas regarding improving Program Specific Reports (PSR) by discussing concerns about the PSRs, and will provide suggestions to the SRTR on how to address those concerns. SRTR released the PSRs in January 2012 with the below changes:
 - Pancreas risk-adjustment models will not be included in the reports publicly released in January;
 - A pediatric/adult age breakdown will be added to the descriptive waitlist data in the upcoming reports; and
 - Beta-release of PSR with new formatting:
 - No new content
 - Easier to read summary tables and color figures
 - o Available on the secure website only
 - Requesting feedback

Other SRTR activities included a consensus conference on transplant program quality and surveillance held on February 13-15, 2012. This consensus conference was sponsored by SRTR and the OPTN, and was designed to identify and discuss strengths and weaknesses of the current process for assessing solid organ transplant programs' performance. The SRTR presented the recommendations from this conference at the 2012 Transplant Management Forum. An SRTR representative will continue to provide the Committee with SRTR updates at each in person meeting and on the TAC monthly Live Meetings.

- 4. Corporate 2012 Transplant Management Forum (TMF). The 2012 Transplant Management Forum was held April 25-27 in Rio Grande, Puerto Rico. A total of 409 participants attended the meeting and the Committee accepted 50 abstracts. There were 50 exhibitors, 12 sponsors and 7 abstract award sponsors supporting the meeting. The agenda included nine plenary sessions and four breakout session tracks. The Committee has received several suggestions for 2013 sessions and several exhibitors have expressed interest in participating in the 2013 forum. Nursing contact hours (14.25) were applied for and obtained from the Virginia Nurses Association for the 2012 TMF. The Committee will begin planning the 2013 agenda at the July in person meeting.
- 5. Corporate Staffing Survey. The 2011 Staffing Survey was released on the Transplant Administrators section of the UNOS Secure Enterprise Web Site in late January. There were only minor changes to the survey compared to last year. Items for the number of VAD post-implant clinic visits and VAD coordinator FTEs were added. In an effort to continue the trend of increased participation that began last year with a shortened time frame, the survey once again has a deadline of June 30. The limited window of opportunity appears to incentivize programs to submit surveys in a timely manner. In accordance with last year's methodology, several reminders to submit the survey have been sent to the community by eNewsletter, Update Magazine, Regional Meetings, Transplant Management Forum, and Transplant Administrator listsery messages. Thus far, the response rates are at the same level as they were at this time last year. Assuming this trend continues, there will be sufficient data for reporting results by June.
- 6. Corporate Request for Information (RFI). The Committee continues to explore how the Request For Information (RFI) Payer Work Group could assist the Committee in understanding the perspectives and concerns of payers while balancing the needs of transplant centers for adequate reimbursement. The purpose of the RFI is to provide transplant centers the efficiency of entering essential organ transplant program information and data in one location for payers to review. The RFI form resides within the Transplant Administrators application in UNetSM. The Work Group discussed the 2012 RFI updates and changes on July 14, 2011, in Chicago. The following updates were implemented in January 2012:
 - Updated the form to reflect year 2012;
 - Added text to the help documentation in the Grant Payer access section;
 - Updated text in Section A;
 - For the liver program for Adult and Pediatric added a breakdown for transplant volume:
 - Whole Grafts
 - Technical Variant Grafts (reduced, split or living donor grafts)
 - Updated text in Section C; and
 - The process to request January or July Release SRTR Data buttons was streamlined.

The Committee has begun planning for the bi-annual payers meeting which will be held July 2012 in Chicago. For the payer meeting, the Work Group solicits feedback from payers for RFI updates/improvements and provides payers with educational information. The draft agenda includes presentations by the American Society for Bone Marrow Transplant (ASBMT), an update on the KPD Pilot Program and other KPD financial issues.

7. Corporate - Transplant Administrator Listserv. The Committee established the Transplant Administrators Listserv in 1999. The Committee oversees access and content of the Listserv. A working sub-group of the TAC comprises of the Listserv moderators. The objective of this listserv is to facilitate the sharing of information regarding the practice of transplant operations and

administration. Membership is open to transplant administrators or managers of UNOS approved (or pending approval) transplant providers within the United States. Membership is also open to employees of UNOS, HRSA and other governmental or governmental contract agencies that participate in the management or oversight of organ transplantation. Currently, there are 332 Listserv members with individuals requesting membership daily. Current work of the Listserv Work Group includes:

- Reviewing requests for new memberships;
- Approve/decline membership requests according to Listserv guidelines; and
- Work to develop better ways to manage archives.
- 8. <u>Public Comment Responses.</u> The Committee discussed and made recommendations for the following proposals released for public comment:

1. Proposal to Establish Requirements for the Informed Consent of Living Kidney Donors: Living Donor Committee

Transplant Administrators Committee:

The Committee reviewed and supported the proposal. The Committee agreed that no specific risks need to be disclosed to the recipient and feel sharing recipient outcomes would suffice. (14-Support, 0-Oppose, 0-Abstain)

2. Proposal to Establish Minimum Requirements for Living Kidney Donor Follow-Up: Living Donor Committee

Transplant Administrators Committee Response:

The Committee did not support this proposal as written and has the following comments for the LDC to consider: (0-Support, 14-Oppose, 0-Abstain)

- Oppose as written (90% considered unrealistic).
- Percentage should be driven by population who can be followed (e.g. if several attempts are made, consider them lost to follow-up and exclude from the percentage; propose 3 attempts (telephone, written, and exhausted current contact information) prior to the due date to consider as lost).
- Make threshold based on how many lost to follow-up.
- Have DEQ role written to the policy (what are the consequences of non-compliance).
- Unfunded mandate.
- Base the threshold on evidence.

3. Proposal to Establish Requirements for the Medical Evaluation of Living Kidney Donors: Living Donor Committee

Transplant Administrators Committee Response:

The Committee reviewed and supported this proposal but would like the policy to clarify if it is acceptable for a nurse practitioner to complete the psychosocial on the living donor and including that language in the policy. (14-Support, 0-Oppose, 0-Abstain)

4. Proposal to Clarify and Improve Variance Policies: Policy Oversight Committee (POC) Transplant Administrators Committee Response:

Upon review, the Committee supported this proposal and suggested listing all variances in one location. (14-Support, 0-Oppose, 0-Abstain)

5. Proposal to Clarify Requirements for Waiting Time Modification Requests: Kidney Transplantation Committee

Transplant Administrators Committee Response:

Although a quorum was not present, members of the Committee supported the proposal but requested policy clarification regarding centers that are submitting reinstatement requests for kidney graft loss that occurs after 90 days. (9-Support, 0-Oppose, 0-Abstain)

6. Proposal to Extend the "Share 15" Regional Distribution Policy to "Share 15 National": Liver and Intestinal Organ Transplantation Committee

Transplant Administrators Committee Response:

Although a quorum was not present, members of the Committee supported this proposal. (6-Support, 0-Oppose, 0-Abstain)

7. Proposal For Regional Distribution of Livers for Critically Ill Candidates: Liver and Intestinal Organ Transplantation Committee

Transplant Administrators Committee Response:

Although a quorum was not present, members of the Committee supported this proposal. (6-Support, 0-Oppose, 0-Abstain)

8. Proposed Revisions to and Reorganization of Policy 6.0 (Transplantation of Non-Resident Aliens), Which Include Changes to the Non-Resident Alien Transplant Audit Trigger Policy and Related Definitions: Ad Hoc International Relations and Ethics Committees Transplant Administrators Committee Response:

Although a quorum was not present, members of the Committee supported this proposal but would like clarification regarding what areas would automatically require a referral to MPSC in this proposal, to include the residency categories. (7-Support, 0-Oppose, 0-Abstain)

9. Proposed Update to the Calculated PRA (CPRA): Histocompatibility Committee Transplant Administrators Committee Response:

Although a quorum was not present, members of the Committee supported this proposal. (8-Support, 0-Oppose, 0-Abstain)

10.OPTN Bylaws Substantive Rewrite of Appendix A: Application and Hearing Procedures for Members and Designated Transplant Programs

Transplant Administrators Committee Response:

Although a quorum was not present, members of the Committee supported this proposal. (9-Support, 0-Oppose, 0-Abstain).

TRANSPLANT ADMINISTRATORS					T
COMMITTEE	MONTH	October	November	January	February
	DAY	20-21	16	25	22
	FORMAT	In Person Meeting	Live Meeting	Live Meeting	Live Meeting
NAME	COMMITTEE POSITION				
Timothy Stevens RN, BSN, CCTC	Chair	X	X	X	X
Nancy Metzler	Vice Chair	X	X	X	X
Sharon Mathews MS, RN, CPTC	Region 1		X	X	X
Joseph Anton RN, MSN	Region 2	X	X		X
Leigh Ann Burgess RN, BSN, CCTC	Region 3	X		X	X
Katherine Stark MHSA	Region 4		X		X
Amy Peele RN	Region 5	X	X	X	X
Pamela Hester RN, BSN, CCTC	Region 6	X	X	X	X
Sara O'Loughlin MHA	Region 7	X	X	X	X
Nancy Long RN, CCTC	Region 8		X	X	X
Karen Berger	Region 9		X	X	X
Laura Murdock-Stillion	Region 10	X	X	X	
Robert Teaster RN, MBA, CPTC	Region 11	X		X	
Leroy Walker	At Large	X	X		X
Vikram Acharya BS, MPH	At Large		X	X	X
Grace Chang Esq.	At Large	X			
David Hefner	At Large	X			
Beth Fetter RN, CPTC	At Large	X		X	X
Richard Spong MD	At Large	X	X	X	X
Angel Carroll MSW	Liaison	X	X	X	X
Cherri Carwile	Assistant Liaison	X	X	X	X
Jude Maghirang MS	Support Staff	X	X	X	X
Tabitha Leighton	SRTR Liaison	X	X	X	
Chiquita Braxton	UNOS Meeting Partners	X	X	X	X
Erma Edmiston	UNOS Meeting Partners	X	X		X
Cheryl Hall	UNOS Staff Support			X	X
Robert Walsh	Ex. Officio				
Chinyere Amaefule	Ex. Officio	X	X	X	X
Gene Ridolfi BA, RN, MHA	Ex. Officio	X	X	X	X

TRANSPLANT ADMINISTRATORS					
COMMITTEE	MONTH	October	November	January	February
	DAY	20-21	16	25	22
	FORMAT	In Person Meeting	Live Meeting	Live Meeting	Live Meeting
NAME	COMMITTEE POSITION				
	OPTN/UNOS Living				
	Donor Committee				
Christie Thomas MD	Member/Presenter	X			
Bertram Kasiske MD	SRTR Staff Liaison		X	X	
Mary D. Ellison PhD, MSHA	UNOS Staff		X		
,	UNOS				
Lori Gore	Staff/Presenter		X		
	UNOS				
Ciara Samana	Staff/Presenter		X		
	UNOS				
Vipra Ghimire	Staff/Presenter		X		
	UNOS/Staff				
Ann Harper	/Presenter		X		
	OPTN/UNOS Liver				
	and Intestinal Organ				
	Transplantation				
W W 11 MD	Committee		37		
Ken Washburn MD	Member/Presenter		X		
Sara Pederson	SRTR Staff Liaison				X
D.1	UNOS				37
Rebecca Anderson	Staff/Presenter				X
Chanan Chanhand	UNOS Starfs/Durantan				v
Sharon Shepherd	Staff/Presenter				X
Amy Dutnam	UNOS Staff/Presenter				X
Amy Putnam	UNOS				Λ
Cynthia Coleman	Staff/Presenter				X
Cynuna Coleman	UNOS Meeting				Λ
Shamel Jones-McCloud	Partners				X
ZIMILIOI VOITOD TITOCTOMA	1 41 111010	1	1	l	1 * *

TRANSPLANT		
ADMINISTRATORS COMMITTEE	MONTH	March
COMMITTEE	DAY	28
	FORMAT	Live Meeting
NAME	COMMITTEE POSITION	
Timothy Stevens RN, BSN, CCTC	Chair	X
Nancy Metzler	Vice Chair	X
Sharon Mathews MS, RN, CPTC	Region 1	X
Joseph Anton RN, MSN	Region 2	X
Leigh Ann Burgess RN, BSN, CCTC	Region 3	X
TBD	Region 4	
Amy Peele RN	Region 5	X
Pamela Hester RN, BSN, CCTC	Region 6	X
Sara O'Loughlin MHA	Region 7	X
Nancy Long RN, CCTC	Region 8	
Karen Berger	Region 9	X
Laura Murdock-Stillion	Region 10	X
Robert Teaster RN, MBA, CPTC	Region 11	X
Leroy Walker	At Large	X
Vikram Acharya BS, MPH	At Large	X
Grace Chang Esq.	At Large	
David Hefner	At Large	
Beth Fetter RN, CPTC	At Large	X
Richard Spong MD	At Large	
Angel Carroll MSW	Liaison	X
Cherri Carwile	Assistant Liaison	X
Jude Maghirang MS	Support Staff	X
Tabitha Leighton	SRTR Liaison	X
Chiquita Braxton	UNOS Meeting Partners	X
Erma Edmiston	UNOS Meeting Partners	X
Cheryl Hall	UNOS Staff Support	X
Robert Walsh	Ex. Officio	11
Chinyere Amaefule	Ex. Officio	X
Gene Ridolfi BA, RN, MHA	Ex. Officio	Λ
Leigh Kades	UNOS Staff/Presenter	X

TRANSPLANT ADMINISTRATORS COMMITTEE	MONTH	March
COMMITTEE	DAY	28
	FORMAT	Live Meeting
NAME	COMMITTEE POSITION	
Bertram Kasiske	SRTR Liaison	X
Karen Sokohl	UNOS Staff	X