OPTN/UNOS TRANSPLANT COORDINATORS COMMITTEE SUMMARY

- I. <u>Action Items for Board Consideration:</u>
 - None
- II. <u>Other Significant Items:</u>
 - The Committee discussed the Board-approved Goals for the Committee. (Item 3, Page 3)
 - The Committee considered policy proposals distributed for public comment. (Item 5, Pages 4-5)
 - The Committee discussed Waitlist Management. (Item 9, Page 6)



REPORT OF THE OPTN/UNOS TRANSPLANT COORDINATORS COMMITTEE TO THE OPTN/UNOS BOARD OF DIRECTORS June 20, 2008

Cheryl Edwards RN, MSN, CCTC, CPTC, Chair Michael Thibault RN, BSN, CPTC, Vice-chair

This report represents the OPTN/UNOS Transplant Coordinators Committee (TCC) deliberations for meetings held on October 24, 2007 and April 2, 2008.

- 1. <u>Update on HHS Program Goals</u>. The Committee was provided with an update on the HHS Program Goals. These include the goals for increasing the number of deceased donors, organs recovered per donor, and increasing the use of DCD and ECD organs. This information is provided as a regular part of all meeting packets in order to keep Committees continually updated on the progress toward the goals.
- 2. <u>HRSA Update</u>. The Committee was provided with an overview of the resources that HRSA is developing for transplant professionals. These resources include donation kits for doctors, "History of Transplantation" training film for medical professionals, and copies of "No Greater Love" video. The kits, which can be placed in physicians' offices, are comprised of information cards, posters, "discussion" cards, calendar and donor cards.
- 3. <u>Board-approved Goals for the Transplant Coordinators Committee</u>. The Committee discussed the following Committee specific goals:
 - Identify ways to decrease the cost and workload that DonorNet® has placed on transplant centers. The TCC felt that ongoing list maintenance and truth in listing would decrease the number of offers received, and a 40 hour per week full time night employee to take call and complete data entry on slow nights would decrease overtime and attrition. The TCC hopes to communicate these ideas by partnering with NATCO.
 - Input on DonorNet® issues to ensure that the new system does not create new communication issues. The TCC will be included to provide input on relevant Operational issues, and the TCC added a cross-over member from the Operations Committee.
 - Continue to be involved in the Transplant Growth and Management Collaborative, establishing the TCC as a resource to help transplant centers deal with growth and volume expansion. TCC members continue to be involved with the Collaboratives which aim to increase organ donation and transplantation.
- 4. <u>Number of Red Topped Tubes of Blood for ABO Verification</u>. On December 18, 2007, the Executive Committee approved modifications to Policy 2.5.5 (Organ Procurement Quality) and Policy 3.5.9.1 (Essential Information for Kidney Offers) which clarified the number of red topped tubes of blood required to accompany each organ for ABO verification. These modifications will prevent further confusion and ensure consistency in the interpretation of these policies.

5. <u>Public Comment Proposal Distributed on September 28, 2007</u>. The Committee discussed and voted on the proposal released for public comment:

1. Proposed Modification to the OPTN Bylaws, Appendix B, *Transplant Hospitals;* Section B. *Survival Rates;* and Section C "*Inactive Membership Status*"; and Attachment I, Section II, "*Inactive Program Status*"; and to the UNOS Bylaws, Attachment I, Section II "*Inactive Program Status*" and Attachment II, Section XIII, C, (10) "*Survival Rates*." (Membership and Professional Standards Committee)

The Committee supported the proposed modification by a vote of 8-3-0. Concerns included:

What is the time frame between the program being notified of an issue and the interview?
Will the program have an opportunity to provide updated data?

<u>Public Comment Proposals Distributed on February 8, 2008</u>. The Committee discussed and voted on the proposals released for public Comment:

1.Proposal to Limit Mandatory Sharing of Zero Antigen Mismatch Kidneys to Children and Sensitized Adult Candidates (Modifications to Policy 3.5.3 (Mandatory Sharing of Zero Antigen Mismatched Kidney))

The Committee supported this proposal by a vote of 13-0-0.

2.Proposal to Allow an Additional Method for Waiting Time Reinstatement for Pancreas Recipients (Modifications to Policy 3.8.8 (Waiting Time Reinstatement for Pancreas Recipients))

The Committee supported this proposal by a vote of 13-0-0.

3.Proposal to Change the OPTN/UNOS Bylaws to Require Written Notification (or Disclosure) to Living Donors from the Recipient Transplant Programs (Proposed Modifications to Appendix-B, Section II, (F) "Patient Notification of the OPTN Bylaws and Appendix B, Attachment I, XII, D (13) of the UNOS Bylaws)

The Committee opposed this proposal by a vote of 0-13-0. The TCC felt that the 10 day time frame would not be effective for living donors and would create a situation where transplant centers may fail to meet policy.

4.Proposal to the OPTN and UNOS Bylaws: Restoration of Membership Privileges Following an Adverse Action (Proposed Changes to Appendix A, Section 3.01A Paragraphs (1) and (3) and Section 5.05A, Addition of Section 5.07A) The Committee supported this proposal by a vote of 13-0-0.

5.Proposal to Change the Elector System for Histocompatibility Lab Members and Medical/Scientific Members (OPTN and UNOS Bylaws Article I, Sections 1.9 and 1.12; Article II, Section 2.2 and 2.4; Article VI, Section 6.1) No comment. 6.Proposal to Change Organ Time Limits to Organ Offer Limits for Zero Antigen Mismatched Kidneys, Pancreata, and Kidney/Pancreas Combinations (Modifications to: Policy 3.5.3.5 (Organ Offer Limit), Policy 3.8.1.7.1 (Time Limit), and Policy 7.6.1.2 (Validation of Offers of Organs Places through the Organ Center))

The Committee supported this proposal by a vote of 13-0-0. In response to the specific requests for comment:

- The TCC felt that cross clamp is an appropriate starting point for the OPO reporting requirement.
- The TCC felt that 5 business days is a more reasonable time limit for the OPOs to report a zero antigen mismatch share.
- The TCC felt that a UNetSM warning would be helpful.
- The TCC felt that it would be best to use the same Kidney Payback Form.

7.Proposal to Require Transplant Centers to Inform Potential Recipients about Known High Risk Donor Behavior (Proposed Revisions to Policy 4.0 – Acquired Immune Deficiency Syndrome (AIDS), Human Pituitary Derived Growth Hormone (HPDGH), and Reporting of Potential Recipient Diseases or Medical Conditions, Including Malignancies, of Donor Origin)

The Committee opposed this proposal by a vote of 0-13-0.

The TCC requested clarification on how the Host OPO must communicate this information regarding donor history (4.1.1). The TCC felt that documentation of discussion should be sufficient and that a signed consent form should not be required. The TCC also felt that the HIV policy language should be its own unique policy and separate from reporting of potential diseases and medical conditions which include malignancies of donor origin.

8.Proposal to Change How 0-10 Year-Old Donor Livers and Combined Liver-Intestines are Allocated (Modifying Policies 3.6 (Allocation of Livers) and 3.11.4.2 (Combined Liver-Intestinal Organs from Donors 0-10 Years of Age))

The Committee supported this proposal by a vote of 13-0-0.

The TCC suggested a review of liver/intestine allocation policy for teenagers because they may be getting "short-changed."

9.Proposal to Change Allocation of Pediatric Lungs and Allow Creation of a Stratified Allocation System for 0-11 year-old Candidates (Modifying Policies 3.7.6.2 (Candidates Age 0-11), 3.7.11 (Sequence of Adult Donor Lung Allocation), and 3.7.11.1 (Sequence of Pediatric Donor Lung Allocation))

The Committee supported this proposal by a vote of 13-0-0.

The TCC suggested monitoring the older cystic fibrosis candidates with disease-related growth retardation to ensure that fair allocation occurs.

10.Proposal to Allocate Pediatric Donor Hearts More Broadly (Modifying Policies 3.7.5 (Allocation of Adolescent Donor Heart to Pediatric Heart Candidates) and 3.7.10.1 (Sequence of Adolescent Donor Heart Allocation))

The Committee supported this proposal by a vote of 13-0-0.

6. Patient Affairs Candidate Letter. The TCC discussed the memo from the Patient Affairs Committee (PAC) regarding patient notification of the patient services line. David Burgio, Chair OPTN/UNOS Patient Affairs Committee, sent the TCC a memo on February 29, 2008 requesting suggestions/feedback on how to better communicate with patients the number for the UNOS patient services hotline as patients believe they are calling their transplant center and leaving messages regarding appointments and no contact information. UNOS staff estimates that 10-15% of the current calls are from individuals who believe they are actually calling their centers. Over 450 calls are typically received through the hotline each month.

The TCC suggestions/recommendations are:

- The TCC felt that the information should come from UNOS to be clear to the patient that this is a UNOS hotline and not their transplant center's 1-800 number.
- The transplant center could send a brochure created by UNOS that includes the UNOS hotline number. This brochure could then be referenced in the listing letter.
- The transplant center could send a letter from UNOS on UNOS letterhead to the patient in the transplant center's packet.
- The TCC felt that the draft letter does not contain appropriate language to meet patients' reading level needs.
- <u>Kidney Paired Donation</u>. The TCC supported Kidney Paired Donation (KPD) by a vote of 13-0-0. The TCC felt that a national KPD program would serve a larger population (than the separate existing programs) and create uniformity in practice.
- 8. <u>Vascularized Composite Allografts</u>. The TCC discussed the Federal Register Notice soliciting feedback from stakeholders and the public on whether vascularized composite allografts should be included within the definition of organs covered by the regulations governing the operation of the Organ Procurement and Transplantation Network (OPTN) and whether vascularized composite allografts should be added to the definition of human organs covered by section 301 of the National Organ Transplant Act of 1984 (NOTA). The TCC chose to defer comment at this time because it felt that it needed more information to make an informed decision.
- 9. <u>Waitlist Management</u>. The TCC felt that the tools that UNOS has created and plans to create will help members better manage their waitlists. A TCC member felt that if more tools are available, then more members will be more likely use the tools. A TCC member commented that some centers could be hesitant to remove a candidate from the waitlist because it costs \$500 each time a candidate is added to the waitlist (even if recently removed.)
- Social Security Numbers as Identification for UNOS. The TCC expressed concern about UNOS' use of social security numbers (SSN) for candidate identification. HRSA responded that it is not a HIPAA violation to collect SSNs because SSNs are needed to collect data outside of the OPTN. UNOS has discussed using other identifiers for use in UNetSM.

TRANSPLANT COORDINATOR		7/1/2007 to 12/31/2007	1/1/2008 to 6/30/2008
	MONTH	OCTOBER	APRIL
COMMITTEE	DAY	24	2
	FORMAT (select)	In Person	In Person/On Phone
NAME	POSITION		
Cheryl Edwards RN, MSN, CCRN, CPTC	Chair	X	X
Michael Thibault RN, BSN, CPTC	Co-Chair	X	X
Susan Noska RN, CCTC, CNN	Regional Rep.	X	X
Geri Libetti RN, CCTC	Regional Rep.	Х	X
Judy Boughton RN, CCTC	Regional Rep.		X
Barbara Nuesse RN,BSN,CCTC,CPTC	Regional Rep.	X	X
Linda Ellery RN, BSN	Regional Rep.	X	X
Veronica Maguire RN, BSN, CPTC	Regional Rep.	X	X
Katherine St. Clair RN, MSN	Regional Rep.	X	X
Maureen Burke-Davis RN, NP-C, CCTC	Regional Rep.	X	X
Heather Bradley RN, CCTC	Regional Rep.		
Debra Bernardina	Regional Rep.	X	X
Lynne Kelsey	At Large	X	
Jim McCabe MS, CPTC	At Large	X	X
Joseph Nespral CPTC	At Large		X
Nancy Carothers RN	Ex Officio	X	
Richard Laeng MPH	Ex Officio		X
Nichole Pettus	Committee Liaison	X	X