OPTN/UNOS Transplant Coordinators Committee
Report to the Board of Directors
June 21-22, 2010
Richmond, VA

Summary

I. Action Items for Board Consideration

- None

II. Other Significant Items

- HRSA Directives. The Committee was requested to tie its activities into the strategic priorities of the system. The Committee was requested to provide recommendations regarding key priorities for systems improvements, managing the inactive waitlist, and evaluating how DonorNet® is working, and what can be implemented to result in effective allocation of organs and improve overall outcomes. (Item 1, Page 3)

- Tiedi® Documentation Project. UNOS staff will evaluate what definitions are needed in the help documentation for the Tiedi® forms and the Committee will review the information and make recommendations as appropriate. (Item 3, Page 4)

- New Business. The Committee plans to address how the CDC definition of "High Risk" will be revised by the CDC at a later meeting. (Item 7, Page 9)

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OPTN/UNOS Transplant Coordinators Committee
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Michael R. Thibault, RN, BSN, Chair
Melissa A. Dunbar-Forrest, RN, BSN, Vice-Chair

The following report represents the OPTN/UNOS Transplant Coordinators Committee's deliberations and recommendations on matters considered during its meeting, April 30, 2010 in Chicago, IL; Live Meetings on November 24, 2009, January 26, 2010, and March 31, 2010; and Inactive Waitlist Management Survey Live Meetings on November 19, 2009, January 19, 2010, and February 25, 2010.

1.   **HRSA Directives**

Chris McLaughlin, OPTN Project Officer for HHS, HRSA, Division of Transplantation, began the meeting by describing the priorities at HRSA. The most important being insuring living donation protection. He added that policies for living donation are being developed and will continue to be developed that function similar to policies for deceased donation and there will be a growth in policy making for living donation over the next several years. Additionally, operational guidelines for kidney paired donation will be developed to replace the OPTN interim policies currently in place for the pilot. Lastly, the OPTN should develop stronger and more detailed compliance methodologies for that living donation and kidney paired donation.

Mr. McLaughlin requested the Committee to tie its activities into the strategic priorities of the system and requested the Committee provide recommendations regarding key priorities for systems improvements, managing the inactive waitlist and determining what the number on the Waiting List means, and evaluating how DonorNet® is working and what improvements can be implemented to improve overall outcomes.

2.   **Joint OPTN/UNOS TCC/TAC Inactive Waitlist Management Survey Working Group**

Results from the Inactive Waitlist Management Survey were presented by Leah Edwards, PhD, UNOS Research, during its January 19, 2010 and February 25, 2010, Joint TCC/TAC Inactive Waitlist Management Survey Live Meetings. **[EXHIBITS A and B]** Members tried to identify best practices from the results but ultimately identified common practices and opportunities to influence practice through education and/or policy.

During the February 25, 2010, Live Meeting, Dr. Edwards presented reasons for inactivity on the Waiting List that indicated the most commonly cited reason for inactivity at listing for kidney and liver was "candidate work-up incomplete." In addition, "temporarily too sick" was the most common reason for liver registrations (37%) with "temporarily too well" comprising 22% of registrations. For heart, temporarily too well was the most common reason for inactivity (36%) and "ventricular assist device" was the next most frequent reason (21%).

At its February 25, 2010, Live Meeting, the Committee determined that it will not make recommendations to the Board of Directors but that these common practices should be disseminated into the community.

During its April 30, 2010, meeting, UNOS staff, noted that the results of the survey will be incorporated into a manuscript and submitted to NATCO's journal, *Progress in Transplantation,* this year. Additionally, the results have been presented at the Transplant Management Forum in April 2010, and an abstract has been submitted to both NATCO and HRSA's National Learning Congress for presentation consideration.

The Committee was then asked to select the most important issue in three categories: Education, Programming, and Policy documented as a response to the question, "how can UNOS assist transplant centers with managing their inactive waitlist?" on the inactive waitlist management survey. In the Education category, the most popular response was have a series of webinars addressing the following inactive waitlist management practice issues: what is available to you for assistance; how to manage your waiting list correctly; best practices utilized in small, medium and large-volume transplant centers; guidelines; communicating between the OPO and transplant centers; and the presentation given at the Transplant Management Forum. It was suggested that the Committee could collaborate with HRSA to deliver the webinars similar to HRSA's webinars (Get Connected, Foundations and Transplant) and have participating coordinators receive continuing education credits for their participation.

In the Policy category, the Committee selected three issues having equal importance: 1) mandate only patients that complete workups can be listed; 2) do not allow points for inactive status for candidates on the Kidney Waiting List; and 3) mandate time limits for reasons of inactivation. The Committee decided to educate the community first through the webinar series and consider policy at a later time. The Committee agreed to collaborate with the OPTN/UNOS Patient Affairs Committee to develop a document to define what "inactive" is.

In the Programming category, the most popular selection was creating a "tickler" feature as a way of reminding the coordinator that their patients need to be either reevaluated or reactivated on the Kidney Waiting List. The coordinator would be able to set the time (i.e. days) for the reminder depending on how often they want to review the center's Waiting List. It was noted that a tickler feature already exists for 1A Heart status.

3.   **Tiedi® Documentation Project**

The Committee was provided with an update on the Tiedi® Documentation Project. It was noted that the end result would be guidance for providing additional information on the Tiedi® (data collection) forms. A pilot will assist with determining whether enough information is being collected, what the correct information is, and to test the data collection tool. It was noted that requirements would be obtained from a few Committees (TCC, TAC, OPO) to test the adequacy and completeness of the tool. UNOS research staff will guide the Committees through this process and the Committee's feedback will be reviewed. Suggested revisions will be incorporated and the tool will be ready in August 2010 for all forms. UNOS staff will evaluate what definitions are needed in the help documentation for the Tiedi® forms and the Committee will review the information and make recommendations as appropriate. This effort will focus on existing documentation and should not require computer programming. It was suggested that the Transplant Recipient Registration (TRR) form be the first form reviewed because it is the only form used to calculate data published by the

SRTR and subsequently reviewed by the Centers for Medicare & Medicaid Services (CMS). The Committee will create a Working Group to assist UNOS Research with this project.

4.   Review of Policies and Bylaws Issued for Public Comment

The Committee reviewed the following proposal released for public comment on November 13, 2009 during its January 26, 2010 Live Meeting.

Proposal to Add a Valuable Consideration Disclosure to the Bylaws (Living Donor Committee)

The Committee voted in support of the proposal. [For: 14; Against: 1; Abstentions: 0] The Committee agreed that the word "understand" should be replaced with "informed" because one really cannot determine if information is truly understood by another. In addition, the Committee agreed that "valuable consideration" be clearly defined. It was noted that "valuable consideration" could be considered as babysitting services, reimbursement for lodging and other forms of assistance that would not likely be prosecutable. It was suggested that a statement is included outlining what can be reimbursable (travel, loss wages, etc.).   One member opined that no one donating an organ should profit (have financial/monetary gain) from the process, further, there should be an agreement between the donor and recipient that any costs related to the donation be reimbursed in keeping with the spirit of the National Organ Transplant Act. Conversely, it was noted that defining every single reason for reimbursement or compensation could be problematic. It would leave out random incidences (i.e. the person who needs dog care paid for in order to travel) or whatever the case may be.

The Committee reviewed the following proposal released for public comment on March 5, 2010, during its March 31, 2010 Live Meeting.

Proposal Modifications to Data Elements on the following Tiedi® forms: Transplant Candidate Registration (TCR), Transplant Recipient Registration (TRR), Transplant Recipient Follow-up (TRF), Living Donor Registration (LDR), Living Donor Follow-up (LDF), Deceased Donor Registration (DDR), Histocompatibility Form (HF), and approval of a new Explant Pathology Form for Liver Recipients.

The Committee voted in support of the proposal. [For: 8; Against: 6; Abstentions: 2] Concerns were shared regarding the lack of definitions and the Committee agreed that the information be considered erroneous without definitions. In addition, the Committee agreed that moving forward, there should be standard definitions before a data element is collected; the information in these forms is powerful and have the ability to shut programs down. The general feeling from members was to support the proposal after the data elements are defined.

Additionally, comments collected via email include:
- New data needs to have definitions that are clear and specific, so that all programs interpret them in the same manner. In addition, the definitions need to have uniformity throughout so that everyone is entering the data the same way and understands what it means
- With the complexity of additional data elements, would a nurse or other healthcare professional assigned to complete the forms have a difficult time interpreting the information they document leaving more room for mistakes and/or inconsistencies?

The Committee reviewed the following proposals released for public comment on March 19, 2010 during its March 31, 2010 Live Meeting and April 30, 2010 meeting in Chicago, IL.

1. **Proposed Ohio Alternative Local Unit (ALU) (Liver and Intestinal Organ Transplantation Committee)**

   The Committee voted to support this proposal. [For: 6; Against: 1; Abstentions: 2] Comments: the 4th OPO is not participating with the 3 other OPOs; the Board disapproved the current system as programmed and this policy is a response to that decision.

2. **Proposed OneLegacy Split Liver Alternative Allocation System (Liver and Intestinal Organ Transplantation Committee)**

   The Committee voted to support this proposal. [For: 5; Against: 2; Abstentions: 2] Comments: members asked which bypass codes would be used when offering split livers; it was noted that the current policy is to offer to the local list but it is not working because the centers are not splitting; after the BOD vote, the Liver Committee will consider bypass codes; it was suggested that there is documentation for patient turndowns that show on the list between the index patient and the patient accepting the split liver; it was noted that CMS requires that a patient must be informed of the split liver option because it is considered an organ donor risk factor and that this will be left to the center to address; it was asked if pediatric patients would benefit and the answer is yes but the policy is also incentivizing the receive a split.

3. **Proposed Region 2 Split Liver Alternative Allocation System (Liver and Intestinal Organ Transplantation Committee)**

   The Committee voted to support of this proposal. [For: 6; Against: 2; Abstentions: 2] Comments: the Pancreas Transplantation Committee plans to investigate reasons why patients are being skipped and why; what is the percent of pediatric patients that would benefit?

4. **Proposal to Develop an Efficient, Uniform National Pancreas Allocation System: Affected Policies: Policy 3.8 (Pancreas Allocation Policy), Policy 3.5 (Kidney Allocation Policy), Policy 3.2 (Waiting List), Policy 3.3 (Acceptance Criteria), Policy 3.4 (Organ Procurement, Distribution And Alternative Systems For Organ Distribution Or Allocation), and Policy 3.9 (Allocation Systems for Organs not Specifically Addressed) (Pancreas Transplantation Committee)**

   The Committee supported this proposal. [For: 6; Against: 1: Abstentions: 3] Comments: it was noted that this new system will not result in change unless the kidney payback system is fixed; it was also noted that this proposed language includes that KPs do not have to follow the payback system, a debt will not incur for keeping a SPK; it was noted that paybacks for kidneys will rise and these implications are not considered in this proposal.

5. **Proposal to Modify OPO and Transplant Center Requirements for Screening, Communicating and Reporting All Potential or Confirmed Donor-Related Disease and Malignancy Transmission Events: Affected/Proposed Policies: Policies 2.0 (Minimum Procurement Standards for An Organ Procurement Organization), 4.0 (Acquired Immune Deficiency Syndrome (AIDS), Human Pituitary Derived Growth Hormone HPDGH), and Reporting of Potential Diseases or Medical Conditions, Including**

Malignancies, of Donor Origin), and 5.5 (Documentation Accompanying the Organ or Vessel) (Ad Hoc Disease Transmission Advisory Committee)

The Committee supported this proposal with no comments. [For: 11; Against: 0; Abstentions: 0]

6. **Proposal to Update HLA Equivalences Tables Affected/Proposed Policy: UNOS Policy 3 Appendix A (Histocompatibility)**

The Committee did not feel that this issue pertained to transplant coordinators and did not vote.

7. **Proposal to Require that Deceased Donor HLA Typing be Performed by DNA Methods and Identify Additional Antigens for Kidney, Kidney-pancreas, Pancreas, and Pancreas Islet Offers Affected/Proposed Policy: UNOS Bylaws Appendix B Attachment IIA – Standards for Histocompatibility Testing D HLA Typing D1.000 Essential Information for Kidney Offers 3.8.2.2 Essential Information for Pancreas Offers (Histocompatibility Committee)**

The Committee did not feel that this issue pertained to transplant coordinators and did not vote.

8. **Proposal for the Placement of Non-Directed Living Donor Kidneys: Affected Policy: 12.5.6 (Recipient Selection for Organs from Nondirected Living Donor Organs) (Living Donor Committee)**

The Committee had too many questions and did not feel comfortable voting on this proposal at this time and will request that a member of the Living Donor Committee present this to the Committee during its next monthly Live Meeting.

9. **Proposal to Require Reporting of Non-utilized and Redirected Living Donor Organs – New Proposed Policy: Submission of Non-utilized Living Donor Organs (Policy 12.8.5) and Submission of Redirected Living Organs (policy 12.8.6) (Living Donor Committee)**

The Committee supported this proposal with no comments. [For: 14; Against: 0; Abstentions: 0]

10. **Proposal to Require a use of a Standardized, Internal Label that is Distributed by the OPTN and that Transplant Centers Notify the Recovering OPO when they Repackage an Organ Affected/Proposed Policy: Policy 5.0 – Standardized Packaging, Labeling and Transporting of Organs, Vessels and Tissue Typing Materials (Organ Procurement Organization (OPO) Committee)**

The Committee had too many questions and did not feel comfortable voting on this proposal at this time and will request that a member of the Organ Procurement Organization Committee present this to the Committee during its next monthly Live Meeting.

5. **Working Group Updates**

- **DonorNet® Education –** TCC members participate on the Transplant Administrators Committee's DonorNet® Education Working Group to offer recommendations from the

coordinator's perspective. This Working Group is currently urging the community to minimize the use of abbreviations in DonorNet® because some are ambiguous and others are not necessary anymore. A letter from the Transplant Administrators Committee was recently disseminated into the transplant community to encourage minimizing the use of abbreviations while the Working Group creates a manageable list of acceptable abbreviations. It was noted that Region 10 has a list that will be reviewed for consideration during this process.

- **DonorNet® Issues** – TCC members participate on the Organ Procurement Organization Committee's DonorNet® Issues Working Group to offer recommendations from the coordinator's perspective. This Working Group is currently addressing "when donor information changes after an offer has been made." A guidance document is being considered after this issue is vetted through multiple OPTN Committees.

- **Kidney Paired Donation -** TCC members participate on the Kidney Transplantation Committee's Kidney Paired Donation Working Group to offer recommendations from the coordinator's perspective. This Working Group is currently reviewing operational guidelines.

- **Effective Screening (formally Tiered Acceptance) –** TCC members participate on the Operations & Patient Safety Committee's Working Group to offer recommendations from the coordinator's perspective. This Working Group has been analyzing data to quantify the potential benefits of improved screening, relative to the costs. The group has recently refined its focus, changed its name, and will move forward with an educational initiative that will hopefully provide improvement of the current screening that is taking place.

6. **Other**

- **OPTN/UNOS Living Donor Committee Request for Assistance**

  In January 2010, the OPTN/UNOS Living Donor Committee requested assistance from the Committee to help identify initiatives that would provide financial coverage for living donor follow up and what currently exists that is working, and preventing living donors to follow up at their transplant center.

- **Committee Wish List**

  At its April 30, 2010, the Committee began the meeting by voicing areas of concern with coordinators that include the day-to-day and work week challenges; efficiency and lack thereof in the donation process; updating the donor highlights section of DonorNet® that captures ongoing changes to the donor's condition; and delays and errors occurring with serology testing. Members were encouraged to incorporate these issues into their educational initiatives.

- **OPTN/UNOS Ad Hoc International Relations (AHIR) Committee Request for Assistance**

  At its April 30, 2010, meeting, Vipra Ghimire, UNOS staff liaison to the Ad Hoc International Relations (AHIR) Committee presented a draft proposal for clarifying and improving policies on importing foreign deceased donor organs. The policies that would be affected by this proposal are 6.4.2 (Formal Protocol to Import Foreign Deceased Donor Organs) and 6.4.3 (Ad Hoc Import of Foreign Deceased Donor Organs). The Committee agreed to collaborate and co-sponsor the proposal with the AHIR Committee and selected two members to assist with the development of

final language for the proposal to be distributed for public comment November 2010 public comment.

7. New Business

- **Transplant Coordinators Yahoo Group**

  UNOS Staff set up a Yahoo Group for procurement and clinical coordinators to collaborate with each other across the country. The development of this group was first advertised through the newly developed electronic UNOS Communications newsletter distributed in April 2010, and received the most number of hits of any article included. Since that electronic distribution, over 100 coordinators joined the Yahoo Group. The Committee discussed how to disseminate this information to the organ donation and transplantation community and suggested advertising through the Transplant Administrator's Yahoo Group, with the International Transplant Nurses Society, NATCO, through HRSA's Transplant Growth and Management Collaborative Listserv, on the OPTN and UNOS websites, and at the UNOS Regional meetings.

- **Centers for Disease Control and Prevention (CDC) Guidelines**

  At its April 30, 2010, meeting, concerns were raised about how the CDC will change the definition for "High Risk" and guidelines for using organs from donors considered high risk. These changes are anticipated for release to the public in the Fall 2010. It was opined that there are already a lot of discarded organs due to the current high risk definition, and the new definition may limit a significant number of offers. It was noted that just the mention of high risk to a potential candidate results in a false sense of security. It was suggested that there be an expeditious way of offering these organs to candidates that have been waiting to receive a transplant for many years similar to the extended criteria donor (ECD) list. The Committee plans to address how the CDC definition of "High Risk" will be revised by the CDC at a later meeting.

TRANSPLANT COORDINATORS COMMITTEE		
	MONTH	April
	DAY	30
	FORMAT	In Person
NAME	COMMITTEE POSITION	
Michael Thibault RN, BSN	Chair	
Melissa Dunbar-Forrest RN, BSN	Vice Chair	x
Beverly Reynholds RN, BSN, MS	Regional Rep. 1	
Valerie Price RN, BSN	Regional Rep. 2	
Alan Hicks	Regional Rep. 3	x
Jennifer Milton RN, MBA	Regional Rep. 4	x
Megan Shaughnessy	Regional Rep. 5	x
Jessica Buck RN, BSN	Regional Rep. 6	x
Karen Kasinger RN, APN	Regional Rep. 7	x
Laurel Salonen RN, MSN	Regional Rep. 8	x
Rose Rodriguez RN, MS	Regional Rep. 9	x
Jennifer Berry-Edwards	Regional Rep. 10	x
Laura Butler FNP-BC	Regional Rep. 11	x
Joanne Dupuis RN	At Large	Via Phone
Donna Ennis RN, BSN	At Large	x
Suzanne Fitzpatrick	At Large	x
Joesph Carder	At Large	x
Cheryl Edwards	Ex. Officio	x
Chris McLaughlin	SRTR Liaison	x
Holly Berilla	SRTR Liaison	x
Kim Johnson	Committee Liaison	x
Leah Edwards, PhD	UNOS Support Staff	x
Stacey Burson	UNOS Support Staff	Via Phone
Manny Carwile	UNOS Support Staff	x