OPTN/UNOS Transplant Coordinators Committee
Report to the Board of Directors
November 16-17, 2009
Orlando, FL

Summary

This report is a resubmission of the June 2009 Report to the Board of Directors. An interim report will be provided in the November 2009 Board Book.

I. Action Items for Board Consideration

- None

II. Other Significant Items

- The Committee discussed Waitlist Management and the Inactive Waitlist Survey. (Item 4, Page 6)
- The Committee discussed updates on Kidney Paired Donation. (Item 5, Page 7)
- The Committee discussed the Tiered Acceptance project. (Item 7, Page 9)
- The Committee discussed the addition of a NATCO faculty member to the TCC membership. (Item 8, Page 9)

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OPTN/UNOS TRANSPLANT COORDINATORS COMMITTEE
Report to the Board of Directors
November 16-17, 2009
Orlando, FL

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

This report represents the OPTN/UNOS Transplant Coordinators Committee (TCC) on matters discussed during its October 15, 2008 in Chicago, IL, and teleconferences held on January 6, February 24, March 31, and April 28, 2009.

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1. Update on HHS Program Goals.

   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 was provided as a regular part of the meeting packet for the October 15, 2008, meeting in order to keep Committee updated on the progress toward the goals.

2. Board-approved Goals for the Transplant Coordinators Committee.

   The Committee reviewed the following Committee specific goals:
   - Review current strengths/opportunities for improvement in DonorNet® and/or organ placement practices/community training and education in collaboration with Transplant Administrators and Operations Committee (Maximum Capacity, Operational Effectiveness);
   - Develop specific recommendations to address waitlist status (inactive vs. active) issues (Patient Safety, Operational Effectiveness); and
   - Evaluate implementation and impact of paired kidney donation programs (Maximum Capacity, Operational Effectiveness).

3. Review of Policies and Bylaws Issued for Public Comment.

   The Committee reviewed four proposals released for public comment on October 10, 2008, during its October 15, 2008, meeting.

   1. Proposal to allow candidates who need a pancreas for technical reasons as part of a multiple organ transplant to be listed on the pancreas waiting list. Policies Affected: Policy 3.2.7 (Pancreas Waiting List Criteria) and Policy 3.2.9 (Combined Kidney-Pancreas Waiting List Criteria)

      The Committee did not take a formal vote on this proposal. It was felt by committee members that there was not adequate input from Organ Procurement Organization (OPO) personnel at this meeting. The Committee did offer the following concerns for consideration:

- OPOs should receive credit for pancreas allocation, at the minimum, as an organ transplanted;
- There should be a field to indicate the reason(s) of pancreas requirement on the waiting list for priority allocation;
- There is a small technical fee for procurement due to operating time;
- What is the survival of recipients that receive a pancreas or not in documented multivisceral cases;
- Look at cost of pancreas transplant vs. compliance in use of the organ;
- Added burden of follow up forms to complete; and
- Will there be DonorNet® offers for pancreata with multivisceral candidates?

2. Proposal to clarify islet allocation protocol. Policy Affected: Policy 3.8.1.6 (Islet Allocation Protocol)

    The Committee had no comment on this proposal.

3. Proposal to increase the safety of allocations to candidates who do not appear on the match run. Policies Affected: Policy 3.1 (Definitions), Policy 3.2.4 (Match System Access), and Policy 3.9.3 (Organ Allocation to Multiple Organ Transplant Candidates)

    The Committee reviewed this proposal and voted to support it (14-supported; 0-opposed; 1-abstained) and stated that more requirements/guidelines would be needed for directed donations.

4. Proposal to clarify, reorganize and update OPO policies to align with current practices. Policy Affected: Policy 2.0 (Minimum Procurement Standards for Organ Procurement Organization. Proposal to Clarify, Reorganize and Update Policy 2.0 – Minimum Procurement Standards for an Organ Procurement Organization)

    The Committee reviewed this proposal and voted to support it (15-supported; 0-opposed; 0-abstained) if sputum specimen requirements are moved to the lung section.

The Committee reviewed the eight proposals released for public comment on February 6, 2009, and provided the following feedback during its February 24, 2009 and March 31, 2009, meetings:

1. Proposed listing requirements for simultaneous liver-kidney transplant candidates. Policy affected: 3.5.10 (Simultaneous Liver-Kidney Transplantation)

    The Committee voted to propose a change in language to this proposal by replacing CMS Form 2728 with Medicare's entitlement form for dialysis. (9-supported; 0-opposed; 0-abstained)

    The Committee states that the CMS form 2728 may be eliminated with the national pilot for Crown Web (the Medicare online program to replace the 2728 and 2938 forms. The pilot is currently on hold), and this form may become obsolete over the next few months. The Committee's concern for the proposal language relates to the CMS form 2728. It may be beneficial to investigate the purpose and use of form 2728, as it could possibly become obsolete in the near future. The Committee also commented that the biggest impact of this proposal will be with those listing candidates because fields will not be able to be bypassed during listing.

2. Proposal to create regional distribution of livers for Status 1 liver candidates. Policy affected: Policy 3.6 (Allocation of Livers)

   The Committee voted unanimously in support of this proposal (9-support; 0-opposed; 0-abstained) stating that most regions are already doing this.

3. Proposal to create regional distribution of livers for MELD/PELD candidates. Policy affected: Policy 3.6 (Allocation of Livers)

   The Committee did not support this proposal (0-support; 7-opposed; 2-abstained). The Committee felt that this proposal would create an additional travel burden on some OPOs as there would be increased expense of acquisition due to increased time to manage donors, accommodation of procurement teams on-site, and the need for staff to travel longer distances. The Committee also felt that these increased costs may not be reimbursed by Medicare. The Committee requested a detailed review of the cost impact on all OPOs related to this proposal versus the benefit of only a 1.6% reduction in mortality, and the long term survival data/life years gained. Is it worth the expense of non-reimbursed expenses to OPOs?

4. Proposal to Standardize MELD/PELD Exception Criteria and Scores. Policy affected: Policy 3.6.4.5 (Liver Candidates with Exceptional Cases)

   The Committee considered this proposal and it was felt to be very objective and that most regions already have this as a regional practice. (5-support; 0-opposed; 4-abstained)

5. Proposal to add the factors “current bilirubin” and “change in bilirubin” to the lung allocation score (LAS). Policy affected: Policy 3.7.6.1 (Candidates Age 12 and Older)

   The Committee commented that it was an unintended consequence that the change in bilirubin was not added to the Lung Allocation System when implemented. Concerns were expressed by the Committee that categorization should be considered in the use of change of bilirubin, specifically to show deterioration of the candidate. Committee vote: (7-support; 0-opposed; 2-abstained)

6. Proposal to modify the high risk donor policy to protect the confidential health information of potential living donors. Policy affected: Policy 4.1.1 (Communication of Donor History)

   The Committee supports this proposal (11-support; 0-opposed, 0-abstained).

7. Proposal to change the OPTN/UNOS Bylaws, to clarify the process for reporting changes in key personnel. Bylaws affected: Appendix B, Section II, E (Key Personnel); Appendix B, Attachment 1, Section III (Changes in Key Personnel)

   The Committee had no comment regarding this proposal.

8. Proposal to clarify, reorganize and update OPTN policies on OPO and transplant center packaging, labeling and shipping practices. Policy affected: Policy 5.0 (Standardized Packaging, Labeling and Transporting of Organs, Vessels and Tissue Typing Materials)

   The Committee supports this proposal (11-support; 0-opposed, 0-abstained).

4. Waitlist Management and Inactive Waitlist Survey.

To address issues related to waitlist management of candidates who are inactive on the OPTN Waiting List, the Committee sent a survey to all transplant centers on February 10, 2009, to inquire about the real world practices of these centers in an attempt to identify best practices to share with the transplant community. The purpose of the survey was to identify day-to-day issues being faced by the Centers that impede waitlist management, and to identify performance best practices and patient advocacy best practices. At its October 15, 2008, meeting, the Committee reviewed a draft copy of questions to be asked of transplant programs within the inactive waitlist survey. The final draft of the inactive waitlist survey was reviewed by the Committee as its January 6, 2009 meeting (**Exhibit A**). With the approval of the Committee, the survey was distributed electronically to the primary program administrator that was listed in the UNOS membership database for each program at each transplant center. The survey was distributed electronically on February 10, 2009, with follow-up distributions to those programs that had not submitted a survey as of March 7, 2009, and April 6, 2009. A joint subcommittee was formed with the Transplant Administrator's Committee (TAC) to review the results of the survey and decide how to best disseminate the results to the community.

The joint subcommittee met on March 5, 2009 to review the number of submitted surveys, and plan electronic reminders to be sent to each program within transplant centers that had not submitted a survey to date. It was determined by the subcommittee that the survey should not be posted on the transplant administrators' listserv, or the UNOS and NATCO websites to avoid duplicate surveys submitted. In an effort to collect the greatest number of surveys possible, reminder emails would not only be sent to the primary program administrator, but also to clinical managers listed within the UNOS membership database.

At its March 25, 2009, meeting, the Committee again reviewed the number of surveys submitted. TAC representatives on the working group suggested that information regarding the survey be given at the Transplant Management Forum scheduled to be held on April 22-24, 2009, in an effort to increase interest among transplant administrators. Committee representatives suggested that regional representatives sitting on the Committee would give more detailed information regarding the survey at regional meetings and provide information, as interested, to centers that had not submitted surveys for their programs.

The joint subcommittee met on April 27, 2009, and reviewed surveys submitted by organ program, by region, and reviewed the number of outstanding surveys by transplant center. Each representative from the subcommittee, along with members of the Committee and UNOS staff, called centers with outstanding surveys in an effort to provide a last opportunity for submission by each program. The final submission date of April 30, 2009, was extended to May 10, 2009 to capture surveys that would be submitted by the programs that were contacted. The subcommittee will meet on May 20, 2009, to begin the review of information submitted by each center's program.

The Committee expects to identify multiple opportunities to provide educational resources to assist transplant centers in managing their waitlists. An education working group will be created to work on these initiatives once the data from the survey has been compiled and reviewed. The Committee will request the assistance of NATCO to provide these educational resources to the transplant community.

5. Kidney Paired Donation (KPD).

It its October 2008 meeting, the Committee agreed to address the goal of evaluating implementation and impact of the KPD programs. The Committee agreed that a national KPD program would serve a larger population and create uniformity in practice. As such, a representative from the Committee volunteered to participate on the subcommittee, education, and financial working groups KPD.

This representative to the KPD subcommittee and working groups provided an update to the full Committee on February 24 and April 28, 2009. It was explained that the KPD education subcommittee met in December 2008 to identify the purpose of the subcommittee. The subcommittee determined that it was charged to create an effective education and training campaign for both professional and public awareness of the national KPD program. An update of educational efforts was discussed during that meeting. UNOS staff and members of the KPD working group submitted an abstract to ATC on the development of the National KPD. The abstract was accepted for presentation. The subcommittee also developed an informed consent form for living donors with revisions being made to language for clarity and understanding by the community. KPD subcommittee members assisted in creating a "helpful hints" checklist for centers that have never participated in this type of kidney paired donation program but would be interested in starting one. A revised copy of the informed consent for living donors, KPD brochure, and frequently asked questions documents were shared with the Committee for feedback (**Exhibit B**).

At its April 2009 meeting, the KPD working group discussed a pilot program that is tentatively scheduled to be launched the end of September 2009. The working group discussed options of flexibility for real time discussion making for transplant centers, and how the centers would be able to choose which chain of KPD to participate in for the pilot program. Any emerging issues would be addressed during the pilot program in an effort to officially launch KPD programs in 2010. Public comment related to this proposal is scheduled to go out in June 2009. The Committee's representative to the working group explained that the Kidney Transplantation Committee along with the KPD working group will send out a request for participation (RFP) (**Exhibit C**) to members to get information regarding centers that wish to participate in the pilot program. Each program must meet minimal requirements to participate. The working group continues its work on finalizing the informed consent process and brochure for KPD programs.

6. OMB Donor, Candidate and Recipient Forms Review Working group Update

Current OPTN OMB-approved forms will expire November 2010. The Committee reviewed all transplant candidate registration (TCR), transplant recipient registration (TRR), transplant recipient follow up (TRF), living donor registration (LDR), living donor follow up (LDF), and deceased donor forms (DDR) to provide feedback regarding important variables that may be missing and variables that need clarification or no longer need to be collected. Working groups were created to review all forms related to thoracic, liver and intestine, kidney and pancreas, and donor forms.

The working group reviewing the DDR form had no requests for changes. It was discussed with the full Committee that the amount of data collected currently appears to be useful, but clear definitions for completion of some fields, i.e. life support, portal vein thrombosis, etc. has not been provided. There is variability in definitions and no standard definitions or guidance is provided. Thus, with risk adjusted expected survival, centers cannot be sure that data is accurate in comparison to other

centers. The working group concluded that under the current definitions, an OPO could have every donor listed as being on life support. Life support interpreted as vasopressors, ventilation, etc., because of the lack of a standard definition for this field. The working group agreed that this field would need to be defined for all TCR, TRR, and DDR forms.

The thoracic forms review working group made the following comments regarding TCR and TRR forms: The working group commented that few hospitals determine a patient's real ethnicity, but the data weight for SRTR risk adjusted outcomes is important and can make a significant difference in outcomes or expected survival. The Committee discussed the need for consistency among all centers when reporting data to the OPTN. A working group member questioned if, at the time of procurement, the donor ethnicity/race information is collected in regard to where the donor's parents or grandparents are from and if multi-ethnicity could be entered on the DDR. UNOS staff verified that multiple ethnicity/race options can be selected by the OPO that is entering information in DonorNet® or completing the DDR. The working group requested to add "registered inpatient" to the dropdown selections for the field "medical condition at the time of listing" to the TCR. Choosing the "hospitalized" selection in that dropdown could be too heavily weighted for risk adjusted outcomes when compared to the acuity of the patient. The working group felt that the other dropdown selections under the "life support" field on the TRR, needed a standard definition as well. Some centers consider tube feedings as life support. The working group discussed the functional status field on the TCR and TRR, and believes that the Karnofsky score is completely subjective. There were comments by members that some centers have re-written these scales to be more objective, but standard definitions are needed for consistency of data reported to the OPTN. The working group commented that there are different definitions for the option of "Medicare" under the "primary source of payment" field on the TCR and TRR. In different regions, there may be managed Medicare/Medicaid vs. traditional Medicare/Medicaid and public funded Medicare/Medicaid versus privately funded Medicare/Medicaid. In survival statistics, the concern is that this field is used as a variable (based on who pays for imunosuppression post-transplant). A working group member stated that Medicare patients are expected to have worse outcomes, making it important to get accurate information reported. The Committee agreed that centers need education and guidance for how to enter this information appropriately. The Committee also commented that the source of payment could be collected only on the TRR to reduce the burden of data entry. The working group commented that the diagnosis field should be re-aligned with CPT codes. There was discussion that some centers select from a list of diagnoses to get better outcomes. The working group discussed the need for standardization of the definition for the field, prior cardiac surgery. An answer of "yes" to this question could weigh heavily on outcomes expected survival data as this would indicate that the candidate was at higher risk than one without a history of prior cardiac surgery. The Committee voiced concerns that some centers may interpret this field for a history of chest tube placement, for instance, to be considered surgery if scar tissue were left behind. The Committee was concerned that there is no validation of these with site surveys, etc., so a standard definition is required for all variables. The Committee questioned what type of infection information need to be collected for the field, hospitalization for infection should the data entered be for transplant related infections or general infections such as urinary tract infection, upper respiratory infection, etc. The Committee felt that it would be most helpful to provide standard definitions for each variable collected by enabling those inputting data to move the cursor over the variable and have a definition appear to assist with accuracy of data entered.

The liver and intestine forms review working group had no requests for changes to the liver and intestine TCR, TRR, and TRF forms. Discussion from this working group centered on the topic of standardized definitions for all fields that required data to be entered. It was mentioned that the pediatric TRF includes a field under the viral detection section that is labeled, coronary artery disease since last follow up. The working group questioned why this question is asked on the

pediatric form but not the adult form and why it appears under the viral detection section of the form.

The kidney and pancreas forms review working group had no request for changes to the kidney, pancreas, or kidney/pancreas TCR, TRR, and TRF forms. Discussion from this working group also centered on the topic of standardized definitions for all fields that required data to be entered as these data are used for SRTR reporting. It was mentioned that the adult kidney TRF includes a field under labeled "KI-TRR diagnosis" under the disease recurrence section that is not included on the kidney/pancreas form. The working group agreed that all forms should be consistent in content related to the specific organ in which data is being requested.

The full Committee was asked to review living donor forms as well as each specific working group. As proposed by the Living Donor Committee, Committee members felt that fields collected on the LDR and LDF should be required fields to be able to collect long-term data on living donors. It was discussed that the burden of data entry would be increased, but that this information is important to collect to follow up care. As with all TCC working groups, the Committee agreed that standardized definitions would need to be applied to each variable collected on the LDR and LDF. It was suggested that laboratory dates of collection should be added to all laboratory values entered on the forms. A member commented that the living donor feedback form completed prior to the time of transplant asks if procedure was aborted after donor received anesthesia, and that this question cannot be answered until the time of surgery. The Living Donor Committee liaison provided a resource document to assist transplant centers when completing the living donor feedback form (**Exhibit D**). This resource document outlines the expectation that centers will go back and correct this field should the transplant procedure be aborted. Committee representatives were asked to share this information and resource document with those completing living donor feedback at their centers.

The proposed recommendations and comments were discussed and voted on by the full Committee on April 27, 2009. The Committee voted: 9-support, 0-against, 0-abstained.

7. Tiered Acceptance Project.

The Committee Chair reviewed the history of the "Tiered Acceptance" project that was proposed by the DSA working group in 2006 (**Exhibit E**). This project previously began in 2006 among Committees, but had been put on hold until DonorNet® was implemented and reviewed for its efficiency. It has been stated that DonorNet® has not provided the screening that was anticipated, and members report that there is sometimes an excessive number of offers being made. The intent of the project would be to change behavior and practice related to transplant center listing criteria and develop a mechanism for patient specific acceptance criteria. With tiered acceptance, specific criteria would be developed to focus on the ability of the transplant center to have criteria that would create a unique profile for specific candidates. This would provide centers the opportunity to "fine tune" offers that they receive from outside the region and within their DSA. However, it has been noted that DonorNet® deals with individual patient screening levels, while Tiered Acceptance creates candidate profiles that can be used for entire programs. The emerging need for more specific match screening criteria presents itself due to the implementation of DonorNet®. The Operations Committee has a working group to implement the work the Tiered Acceptance project. Two TCC representatives have volunteered to participate on this working group to provide transplant coordinator feedback and assistance.

8. NATCO Partnership.

The Committee invited a guest from NATCO to discuss the possibility that TCC and NATCO could partner in a collaborative effort to identify educational needs for transplant coordinators. The Committee voted to fully support the addition of a NATCO faculty member as At-Large representative to the Committee with the next rotation of members. In February 2009, a vacancy of the Region 10 representative to the Committee was replaced by a NATCO faculty member that works at a transplant center in that region. This change was approved by the OPTN/UNOS President.

At the Committee's April 2009 meeting, it was discussed that the OMB forms review and the Inactive Waitlist Survey data will lead to future endeavors for education to the transplant community and transplant coordinators in particular. The Committee discussed the opportunity for Webinars and resource documents that could be distributed as part of an educational effort. An education working group will be created to assist the Committee with the creation of these types of resources.

9. DonorNet®Tutorials.

At the October 2008 meeting, the Committee discussed the benefit of OPO's uploading images of organs being allocated through DonorNet®. The Committee discussed that this could possibly decrease costs associated with flying out to view organs with procurement. A member discussed that her transplant center has had increased success with transplant when visual images are available along with biopsy results. The Committee considered polling donor service areas to ask what images transplant surgeons would want to be viewed on DonorNet® to make decisions related to acceptance and transplant of organs. In April 2009, NATCO offered a webinar to address technical issues related to uploading images in DonorNet®.

10. MELD/PELD reports in UNet℠.

A UNOS IT representative sought input from the Committee at its October 2008, meeting regarding issues related to the critical and expected data reports as well as the liver candidate MELD/PELD report that is made available to transplant center members through UNet℠. It was discovered during testing of programming changes in UNet℠ that these three reports place candidates in groups based on match MELD/PELD scores rather than lab MELD/PELD scores. This discovery showed a number of fields that were not being populated by the system and the columns within the report were useless and confusing. The Committee discussed the frequency in which these reports are utilized by the centers. It was agreed that the reports should be corrected as a benefit for improving waitlist management.

TRANSPLANT COORDINATORS COMMITTEE	JULY 1, 2008 - DECEMBER 31, 2008		JANUARY 1, 2009 - JUNE 30, 2009			
		OCTOBER	JAN	FEB	MARCH	APRIL
		15	6	24	31	28
	FORMAT	In Person	Teleconf	Teleconf	Teleconf	Teleconf
NAME	**COMMITTEE POSITION**					
Cheryl Edwards RN, MSN, CCRN, CPTC	Chair	X	X	x	X	X
Michael Thibault RN,BSN,CPTC	Co-Chair	X		x	X	X
Beverly Reynholds RN, BSN, MS, CCRP	Regional Rep.	X		x	X	X
Valerie Price RN, BSN, CPTC	Regional Rep.	X	X			
Alan Hicks	Regional Rep.	X	X	x		
Jennifer Milton RN, MBA	Regional Rep.	X	X			X
Melissa Dunbar-Forrest RN, BSN	Regional Rep.	X	X	x	X	X
Linda Ellery RN, BSN	Regional Rep.	X				
Veronica Lawrence RN, BSN, CPTC	Regional Rep.	X	X	x	X	X
Katherine St. Clair RN, MSN	Regional Rep.	X	X	x	X	X
Maureen Burke-Davis RN, NP-C, CCTC	Regional Rep.	X	X	x	X	X
Heather Bradley RN, CCTC	Regional Rep.					
Debra Bernardina	Regional Rep.	X			X	
Joanne Dupuis, RN	At Large	X			X	
Lynne Kelsey, RN, BS	At Large	X	X			
Jim McCabe MS, CPTC	At Large	X	X	x		X
Wes Merritt	At Large					
Erin Wray	At Large	X				
Richard Laeng, MPH	Ex Officio	X		x	X	X
Kim Johnson	UNOS Liaison	X				
Kimberly H. Taylor, RN	UNOS Liaison	X	X	x	X	
Sherri Williams	UNOS Research	X	X	x	X	X
Donna Ennis, RN, BSN, CCTC	Guest/Region 10 Rep	X		x	X	X
Stacey Burson	Business Analyst				X	X