OPTN/UNOS Transplant Coordinators 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 examined inactive registrations on the waiting list. As a result, the Committee formed two working groups. The Education Working Group will meet to: a) plan a webinar and b) write a publication using the data presented on April 2nd; and c) collaborate with the Patient Affairs Committee to define "inactive" and "active". The Policy Working Group will meet to: 1) review additional data requested during the April 2nd meeting for inactive registrations removed from the waiting list for death or too sick during 2007-2011, by removal type and organ, then decide if patient notification; listing requirements; or time limits having an inactive status can be pursued. (Item 1, Page 2)

- The Committee agreed to recommend that language be changed in all policies to read "temporarily inactive" where "inactive" is currently written to eliminate existing confusion as temporarily inactive is also the term used throughout UNet℠; and 2) recommend that a column be added in UNet℠ that gives a snapshot of inactive patients and how many days they are inactive from greatest to least when a center runs its reports. The Committee agreed that this will assist centers in keeping up with their patients having an inactive status. (Item 1, Page 2)

- RESOLVED, that the TCC recommends that a Task Force be created including members from all organ-specific and constituent OPTN Committees to standardize the definitions for all fields used in the data collection (Tiedi®) forms. (Item 2, Page 3)

- On April 16, 2012, the Toolkit was distributed as a resource in the UNOS monthly communications newsletter. (Item 5, Page 7)

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Melissa A. Dunbar-Forrest RN, BSN, Chair

The following report represents the OPTN/UNOS Transplant Coordinators Committee's deliberations and recommendations on matters considered during its meetings by conference call and Microsoft LiveMeeting on October 25, 2011, November 22, 2011, January 24, 2012, February 28, 2012 and March 27, 2012. The Tiedi® Documentation Project Working Group met by conference call and Microsoft LiveMeeting November 9, 2011, December 12, 2011, January 25, 2012 and March 15, 2012. In addition, the Committee met in person in Chicago October 17, 2011 and, April 2, 2012.

1. Inactive Waitlist Management

During its October 17, 2011, in person meeting in Chicago, the Committee discussed various issues of waitlist management and the possibility of kidney wait time being based on dialysis time. Another issue the Committee discussed was standardizing what minimum information needs to be collected for a patient evaluation prior to listing. The Committee would like to know what basic requirements transplant centers are using to list patients and plans to further discuss "truth in listing."

During its November 22, 2011, meeting, the Committee discussed other issues of waitlist management at programs such as patient-specific internal holds. The Committee agreed that programs define their "active" and "inactive" patients differently, and centers do not notify patients when their status changes. In addition, it was noted that there is a lack of wait list monitoring, and people are listed when they are not ready for transplant. One member suggested that a maximum thirty day inactive point accrual be put in place for kidney patients similar to the intestine patients and after the thirty days, the patient would then stop accruing time on the list.

During its January 24, 2012, meeting, the Committee discussed the manuscript to be submitted to *Progress in Transplantation,* NATCO's publication, and agreed that program-specific activity wouldn't add value in the discussion of the manuscript. It was suggested to include a summary of results of the survey regarding center practices and how patients gain varying waiting times while having an inactive status, depending on the organ, and recommend that this is more closely monitored in the future. In addition, the manuscript will recommend more education about which organs gain time and why and which organs do not gain time and why. Four members volunteered to complete the discussion part of the manuscript.

Members then discussed what the actual number of patients are who can accept an organ for transplant on the waiting list. As a result, the Committee requested the following data to be reviewed at its upcoming in person meeting in Chicago, April 2, 2012:

- Number of inactive candidates - for how long and for what organ.
- Number of candidates listed as inactive.
- Total days listed on the waiting list and of those days, the number of days listed as inactive.

The Committee additionally discussed patients who are listed at more than one center. The concern is that unless the patients tell the center they are listed at another, the center will not know. This notion creates another set of concerns regarding inactive waitlist management such as:

- Who is legitimately listed as being inactive and who is not legitimately listed as being inactive?
- Patients are easily forgotten when listed as inactive for long periods of time.
- Patients shouldn't think they are listed when they are not.

During its meeting in Chicago on April 2, 2012, the Committee was presented data to examine inactive registrations on the waiting list. As a result, the Committee decided to split into two working groups. The Education Working Group will meet to: a) plan a webinar and b) write a publication using the data presented on April 2nd; and c) collaborate with the Patient Affairs Committee to define "inactive" and "active". The Policy Working Group will meet to: 1) review additional data requested during the April 2nd meeting for inactive registrations removed from the waiting list for death or too sick during 2007-2011, by removal type and organ, then decide if patient notification; listing requirements; or time limits having an inactive status can be pursued.

Additionally, the Committee agreed to recommend that language be changed in all policies to read "temporarily inactive" where "inactive" is currently written to eliminate existing confusion as temporarily inactive is also the term used throughout UNet℠; and 2) recommend that a column be added in UNet℠ that gives a snapshot of inactive patients and how many days they are inactive from greatest to least when a center runs its reports. The Committee agreed that this will assist centers in keeping up with their patients having an inactive status.

2. Tiedi® Documentation Project

The goals of this Working Group are to improve the accuracy and completeness of OPTN data by:

- Identifying problems with existing documentation;
- Providing recommendations for educating users; and
- Identifying situations where input from other groups (e.g. clinical experts) is needed.

Summary of its Working Group Calls. During its November 9, 2011, LiveMeeting, UNOS Staff presented the Working Group with modifications recommended from their previous call for the following fields: malignancies between listing and transplant, cognitive development, and motor development. The following new fields were reviewed from the Transplant Recipient Registration (TRR) forms: acute rejection between transplant and discharge; pretransplant dialysis; date of most recent initiation of chronic maintenance dialysis; serum creatinine at time of transplant; graft status; date of graft failure; primary cause of graft failure; pretransplant blood transfusions; total cold ischemia time; kidneys received on ice, pump; final resistance at transplant; final flow rate at transplant; resumed maintenance dialysis; date maintenance dialysis resumed; most recent serum creatinine prior to discharge; patient need dialysis within first week; and previous pregnancies.

It was noted that all data fields containing "just prior to" be reviewed on one call due to the fact that "just prior to" occurs in many places. There is concern that it is probably being interpreted in different ways such as in the case of a patient having an acute or chronic condition.

During its December 12, 2011, meeting, the working group reviewed modifications recommended on the Working Group's previous call and reviewed the following new fields from the TRR forms: fracture in the past year; avasular necrosis; is growth hormone therapy used between listing and transplant; average daily insulin units; graft placement; operative technique; duct management;

venous vascular management; arterial reconstruction; venous extension graft; total pancreas preservation time; pancreatitis; anastomotic leak; abscess or local infection; method of blood sugar control; date insulin/medication first resumed; contributory cause(s) of graft failure; retransplanted organ; and weight post transplant.

During its January 25, 2012, meeting the working group reviewed modifications recommended by the Working Group's previous call and reviewed the following new fields from the TRR liver forms: patient on life support; ventilator; artificial liver; previous abdominal surgery; graft status; split type; total ischemia time; portal vein thrombosis; transjugular intrahepatic portacaval stint shunt; pathology confirmed liver diagnosis of hospital discharge; and causes of graft failure. Additionally, from the pediatric liver TRR form, cause of graft failure and vascular thrombosis were reviewed, and from the TRR pediatric/adult intestine form the following were reviewed: total bilirubin, serum albumin, and serum creatinine.

During its March 15, 2012, meeting, the working group reviewed modifications recommended by the Working Group's previous call and the following new fields were reviewed from the TRR intestine forms: intestine venous drainage; native viscera venous drainage; organ type; total ischemic time; recent septicemia; exhausted vascular access; dilated/non-functional bowel segments; total parenteral nutrition (TPN) dependent; intravenous (IV) fluids dependent; oral feeding; tube feed; and primary cause of graft failure.

Feedback from the Full Committee on the Working Group. During their January 24, 2012, meeting, members from the Tiedi® Documentation Project Working Group updated the full Committee on their progress, and it was noted that during the Working Group calls, members continuously ask who is filling out the forms. The concern is that non-clinician personnel are being asked to fill in clinical patient information and the field "unknown" is being utilized too much due to the lack of clinical knowledge and experience. A data request to tabulate how many times "unknown" is utilized on the follow-up forms was requested.

Additionally, during their January 24, 2012, meeting, members expressed another concern that the information being collected is used for reporting to the Centers of Medicare and Medicaid, and it is unsure how much of the data is accurate. The Committee would like to know: 1) what specifically do people collecting these data want to know and why; 2) who developed these forms; and 3) what is the basis of developing the questions and does it apply in the real world today? It was noted, for example, that after five years, none of the fields are collected for liver patients so why collect at three years?

The Committee requested the following data to be reviewed at their meeting in Chicago April 2, 2012:

- The number of registrations and candidates currently on the waiting list by organ type and waiting list status (active vs. inactive).
- The number of registrations currently on the waiting list by organ type and total time waiting.
- The number of registrations currently on the waiting list that were initially listed as inactive, by organ type.
- For registrations currently waiting, total time spent in active and in inactive status by organ type.
- For registrations currently waiting in inactive status, the most recent reason for inactivity, by organ.
- For registrations currently waiting in inactive status, the amount of time spent in that most recent inactive status, by organ.

- The number of multiple listed candidates currently waiting who are listed as active with at least one center and as inactive with at least one other center by organ type.
- For inactive registrations removed from the waiting list with a removal code of 8 (death), tabulate cause of death by organ.

During their March 27, 2012, meeting, the Committee both sought and provided comments with the SRTR Staff on how fields in the data collection forms impact program outcomes. It was noted that there needs to be more education in the community and understandable language explaining how the analyses work. The Committee requested that the SRTR Staff give a presentation at its upcoming meeting in Chicago, April 2, 2012, explaining the Program Specific Reports (PSR) and how the information ultimately affect outcome data.

During its April 2, 2012, meeting in Chicago, the SRTR Staff presented the Committee with information on the Program Specific Reports Risk Adjustment Models. The Committee had previously inquired about missing data, and it was explained that missing data are usually treated as its own categorical predictor in PSR models and sometimes missing is grouped with "no" responses in a "missing/no" category. It was further noted that a recommendation from the PSR Consensus Conference, February 2012, is to treat missing data as equivalent to the lowest risk category to encourage centers to produce complete data.

Another concern the coordinators had that was addressed was the lag time in the data collected and subsequently analyzed. It was explained that the PSR models won't stay the same over time because a covariate is in the model today doesn't mean it'll be in the model a few years from now. Additionally, just because a covariate is not in the model today doesn't mean it won't be in the model a few years from now. The SRTR considers all the OPTN data elements fair game for inclusion in models and as models are developed and updated, previously unused data elements will get used.

RESOLVED, that the TCC recommends that a Task Force be created including members from all organ-specific and constituent OPTN Committees to standardize the definitions for all fields used in the data collection (Tiedi®) forms.

Committee Vote: 14 For, 0 Against, 0 Abstentions

3. Transplant Coordinators Listserv

There are currently 295 members who subscribe to this listserv. Recent discussion threads have included: iPad use on call; transplant list maintenance; ex vivo lung perfusion; pending labs; the post-transplant clinical coordinator role; genetic testing for polycystic kidney disease; the process when a patient is evaluated but not able to become a candidate for transplant; and general announcements regarding UNOS offerings such as the kidney paired donation webinars and UNOS Presents Live Webcasts.

This listserv has given coordinators across the country a way of posting questions and receiving feedback on hot topics and day-to-day issues for both the procurement and clinical coordinator constituents.

4. Review of Policies and Bylaws Issues for Public Comment

During its October 17, 2011, meeting in Chicago, the Committee reviewed and voted on the following proposals distributed for public comment on September 16, 2011:

- Proposal to Clarify Requirements for Waiting Time Modification. The Committee voted in full Support [For 14: Against 0: Abstentions 0].
- Plain Language Modifications to the Adult and Pediatric Heart Allocation Policies, Including the Requirement of Transplant Programs to Report in UNet^{SM} a Change in Criterion or Status within Twenty-Four Hours of that Change. The Committee voted in full support [For 14: Against 0: Abstentions 0].
- 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. The Committee voted in Support for the following concepts of the proposal:
    - Delete policies that are not enforceable [For 14: Against 0: Abstentions 0]
    - Change placement of organ export policy language [For 14: Against 0: Abstentions 0]
    - Delete rule regarding 6 ad hoc organ imports [For 14: Against 0: Abstentions 0]
    - Eliminate the greater than 5% audit trigger policy ("5% rule") [For 14: Against 0: Abstentions 0]

  The Committee did not vote on the following concepts because it did not feel the policies addressed what the Committee set out to accomplish. It was noted that there needs to be more delineation of terms and follow up when the patients leave the country:
    - Classify a person who considers the US a primary place of residence as a 'resident.'
    - Allow review of all listings and transplants of non-citizens /non-residents.
- Proposal to Establish Requirements for the Informed Consent of Living Kidney Donors. The Committee voted in support [For 11: Against 0: Abstentions 1].
- Proposal to Establish Minimum Requirements for Living Kidney Donor Follow-Up. The Committee voted in support [For 12: Against 0: Abstentions 1].
- Proposal to Establish Requirements for the Medical Evaluation of Living Kidney Donors. The Committee voted in full support [For 14: Against 0: Abstentions 0].
- Proposal to Eliminate the Use of an "Alternate" Label when transporting Organs on Mechanical Preservation Machines and to Require the OPTN Distributed Standardized Label. The Committee voted in full support [For 14: Against 0: Abstentions 0].
- Proposal to Change the Term "Consent" to "Authorization" Throughout Policy When Used in Reference to Organ Donation. The Committee voted in full support [For 14: Against 0: Abstentions 0].
- Proposal to Modify the Imminent and Eligible (I&E) Neurological Death Data Reporting Definitions. The Committee voted in support [For 13: Against 1: Abstentions 0].

During its October 25, 2011, meeting, the Committee reviewed the policy proposal to update the calculated panel reactive antibody (CPRA) and the revision of the UNOS bylaws, the OPTN bylaws and the OPTN policies that govern HLA laboratories released for public comment on September 16, 2011. The Committee fully supported both proposals [For 11: Against 0: Abstentions 0].

During its November 22, 2011, meeting, the Committee voted on the proposal to extend the "Share 15" regional distribution policy to "Share 15 National" and the regional distribution of livers for critically ill candidates released for public comment on September 16, 2011. The Committee fully supported both the proposals [For 14: Against 0: Abstentions 0].

During its February 28, 2012, meeting, the Committee reviewed the proposed policy for the OPTN bylaws substantive rewrite of Appendix A: Application and Hearing Procedures for Members and Designated Transplant Programs. The Committee requested additional time to review this policy and suggested that they table the vote until their in person meeting in Chicago on April 2, 2012.

During its March 27, 2012, meeting the Committee reviewed and voted on the following proposals:

- Proposal to Revise the Lung Allocation Score (LAS) System. The Committee fully supported this proposal. [For 9: Against 0: Abstentions: 0]
- Proposal to Clarify Priority Status for Prior Living Organ Donors Who Later Require a Kidney Transplant. The Committee fully supported this proposal. [For 9: Against: 0: Abstentions 0]
- Proposal to Establish Kidney Paired Donation (KPD) Policy. The Committee fully supported this proposal. [For 9: Against 0: Abstentions 0]
- Proposal to Include Bridge Donors in the OPTN Kidney Paired Donation (KPD) Program. The Committee fully supported this proposal [For 9: Against 0: Abstentions: 0] and sought clarification on: 1) why patients needed to be contacted every three months; 2) how this would be tracked, and what would the benefit be to put a time limit on being able to donate; and 3) if the evaluation process is done before the patients are entered in the KPD program how would you handle outdated tests when a transplant occurs much later.
- Proposal to Require Extra Vessel(s) Disposition to be Reported to the OPTN within Five Days of Transplant or Disposal. The Committee fully supported this proposal. [For 9: Against 0: Abstentions: 0]

During its April 2, 2012, meeting in Chicago, the Committee reviewed and voted on the following policy proposals released for public comment March 16, 2012:

- OPTN Bylaws Substantive Rewrite of Appendix A: Application and Hearing Procedures for Members and Designated Transplant Programs. The Committee voted in full support [For 14: Against 0: Abstentions 0].
- Proposal to Update Data Release Policies (Policy Oversight Committee). The Committee voted in full support [For 14: Against 0: Abstentions 0]
- Proposal to Update and Clarify Language in the DCD Model Elements (OPO Committee). The Committee voted in full support [For 14: Against 0: Abstentions 0].
- Proposal to Document All Locally Assigned Unique Identifiers in the Donor Record (OPO Committee). The Committee voted in full support [For 14: Against 0: Abstentions 0].
- Proposal to Require Reporting of Unexpected Potential and Proven Disease Transmission Involving Living Organ Donors (Living Donor Committee). The Committee voted in full support [For14: Against 0: Abstentions 0].

5. Donor and Recipient Information Sharing Toolkit

At the November 14, 2011, Executive Committee meeting, a guidance document containing recommendations for sharing donor and recipient information and contents for a Toolkit including resources to assist transplant centers and OPOs in this process was approved.

On April 16, 2012, the Toolkit was distributed as a resource in the UNOS monthly communications newsletter. It contains resources to assist both transplant centers and OPOs in this process such as: 1) contacting families; 2) examples on how to write to families; 3) and forms that can be used as templates to develop your own consent and confidentiality policies and procedures.

6. Public Health Service Guideline for Preventing Transmission of HIV Through Transplantation of Human Tissue and Organs

During its October 17, 2011, meeting in Chicago, the Committee reviewed the Center for Disease Control's (CDC) sixty recommendations and provided several comments to include with the OPTN's response. Comments made were mainly about vague wording (e.g. "massive blood loss") and the organization of the recommendations. The Committee agreed that many of the recommendations were more for physician and histocompatibility lab review. Additionally, under the donor screening recommendation, the Committee unanimously disagreed with including the first and third bullet under sexual contact.

7. Other

During its February 28, 2012, meeting, the Committee welcomed a new member representing Region 4, Patricia Jones.

TRANSPLANT COORDINATORS COMMITTEE

	MONTH	Oct	April
	DAY	17	2
	FORMAT	In Person Meetings	
NAME	COMMITTEE POSITION		
Melissa Dunbar-Forrest, RN, BSN	Chair	X	X
Laurel Salonen, RN, BSN, MSN	Vice Chair	X	X
Lindsay Arnott, RN, BS	Regional Rep. 1	X	X
Heather Shank-Givens	Regional Rep. 2	X	X
Barbara Robinson, RN	Regional Rep. 3	X	
Patricia Manning, RN	Regional Rep. 4		
Patricia Jones, RN	Regional Rep. 4		X
Jill Stinebring, RN	Regional Rep. 5	X	
Marsha Larsen, RN	Regional Rep. 6	X	X
Nancy Carroll, RN	Regional Rep. 7		X
Monica Eaton	Regional Rep. 8	X	X
Charles Gonder, RN, MS	Regional Rep. 9	X	X
Michelle Crossley, RN, BSN	Regional Rep. 10	X	X
Marion Stewart, RN, BSN	Regional Rep. 11	X	X
John Belcher	At Large		
Jamie Bucio, EMT-P	At Large		X
Ann Kalis, RN	At Large	X	X
Christine Radolovic, RN, BSN	At Large	X	X
Beverly Reynholds, RN, BSN, MS	At Large	X	X
Michael Thibault, RN, BSN	Ex Officio		
Raelene Skerda, RPh, BPharm	HRSA Liaison	X	
Bertram Kasiske, MD	SRTR Liaison	X	
Chinyere Amaefule	HRSA Liaison		X
Kim Johnson, MS	Committee Liaison	X	X
Marissa Clark	Support Staff	X	X

TRANSPLANT COORDINATORS COMMITTEE

NAME	COMMITTEE POSITION	MONTH	Oct	Nov	Jan	Feb	March
		DAY	25	22	24	28	27
		FORMAT	Live Meetings				
Melissa Dunbar-Forrest, RN, BSN	Chair		X	X	X	X	X
Laurel Salonen, RN, BSN, MSN	Vice Chair		X	X		X	X
Lindsay Arnott, RN, BS	Regional Rep. 1		X	X			X
Heather Shank-Givens	Regional Rep. 2		X	X	X	X	X
Barbara Robinson, RN	Regional Rep. 3		X	X			
Patricia Manning, RN	Regional Rep. 4						
Patricia Jones, RN	Regional Rep. 4					X	X
Jill Stinebring, RN	Regional Rep. 5		X	X			
Marsha Larsen, RN	Regional Rep. 6		X	X	X	X	
Nancy Carroll, RN	Regional Rep. 7		X		X		
Monica Eaton	Regional Rep. 8			X	X		X
Charles Gonder, RN, MS	Regional Rep. 9		X	X	X	X	X
Michelle Crossley, RN, BSN	Regional Rep. 10				X		
Marion Stewart, RN, BSN	Regional Rep. 11			X	X	X	X
John Belcher	At Large						
Jamie Bucio, EMT-P	At Large		X	X			
Ann Kalis, RN	At Large		X	X		X	X
Christine Radolovic, RN, BSN	At Large		X			X	
Beverly Reynholds, RN, BSN, MS	At Large				X	X	
Michael Thibault, RN, BSN	Ex Officio						
Raelene Skerda, RPh, BPharm	HRSA Liaison		X	X	X		
Chinyere Amaefule	HRSA Liaison						X
Bertram Kasiske, MD	SRTR Liaison						
Tabitha Leighton, MPH	SRTR Liaison		X	X	X		X
Kim Johnson, MS	Committee Liaison		X	X	X	X	X
Marissa Clark	Support Staff		X	X	X	X	X