

**OPTN/UNOS Transplant Coordinators Committee
to the Board of Directors
November 14-15, 2011
Atlanta, GA**

Summary

I. Action Items for Board Consideration

- None

II. Other Significant Items

- Donor and Recipient Information Sharing Task Force. Since the June 2011 board meeting, task force members developed a guidance document that will become part of a resource (e.g. Toolkit) to be distributed to organ procurement organizations (OPOs) and transplant centers. (Item 1, Page 3)
- Tiedi® Documentation Project. The goals of the 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 (Item 2, Page 4)
- Committee Orientation and Planning. Agenda items for the October 17th meeting include: 1) Inactive Waitlist Management; 2) Policy Proposals Issued for Public Comment; 3) US PHS Guidelines for Reducing Transmission of HIV, HBV and HCV through solid organ transplantation; 4) and a new collaboration with the Living Donor Committee (Item 5, Page 5)

This page is intentionally left blank.



OPTN/UNOS Transplant Coordinators Committee
Report to the Board of Directors
November 14-15, 2011
Atlanta, GA

Melissa A. Dunbar-Forrest RN, BSN, Chair
Laurel Salonen RN, BSN, MSN, Vice-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 May 24, 2011 and July 26, 2011. In addition, the Tiedi[®] Documentation Project Working Group met by conference call and Microsoft LiveMeeting August 17, 2011, and October 6, 2011.

1. Donor and Recipient Information Sharing Task Force

On June 28, 2011, the Board approved a resolution acknowledging that patient information sharing will give greater meaning to the gift of life and positively enhance the donation experience for all donors and recipients. The Board also approved the development of a guidance document to educate the community to be written in collaboration with AOPO, NKF, NATCO, and HRSA.

In addition, the Board approved the following language modification at its meeting, when referencing the Patient Information Sharing Task Force and guidance document titled: Guidance for Patient Information Sharing: that "Patient" shall be changed to "Donor and Recipient."

Since the June 2011 Board meeting, Task Force members developed a guidance document that will become part of a resource (e.g. Toolkit) to be distributed to organ procurement organizations (OPOs) and transplant centers. Other contents of the Toolkit will include:

- Sample language for Information Sharing
- Sample language for the OPO-Transplant Center memorandum of agreement (MOA) addressing confidentiality of donor and recipient information shared as part of coordinating the donation and transplant including recipient outcome information
- Sample form for routine recipient outcome information exchange
- Sample of transplant center policies for screening initial contact letters
- Standard list of "Need to Know" staff at the transplant center
- Best practices for maintaining confidentiality for donor information
- Sample HIPAA authorization form for living donation
- Written guidance explaining benefits and considerations of contact between deceased donor families and recipients/recipient families

On October 5, 2011, a Live Webcast on HIPAA and donor and recipient information sharing occurring at the organ procurement organization and transplant center took place. During this program, the development of the guidance document and specific guidelines was reviewed. Moderating the program was Charles Alexander, RN, MSN, MBA, OPTN/UNOS Immediate Past President and CEO of the Living Legacy Foundation of Maryland OPO. Presenters were Alexandra Glazier, JD, MPH, Vice President and general counsel for New England Organ Bank OPO and Chair of the OPTN/UNOS Ethics Committee; Lori Brigham, MBA, President and CEO of the Washington Regional Transplant Community OPO and President of the Organ Donation and Transplantation

Alliance; and Edward Garrity, Jr. MD, MBA, Professor of Medicine, Vice-Chair of Clinical Operations at University of Chicago and Co-Director of the University of Chicago Transplant Center. There were nearly 2500 registered individuals. Registrants from all over the country included: transplant and donation coordinators, social workers, research analysts, case managers, transplant administrators, program and quality managers, family services coordinators, quality and regulatory affairs officers, compliance and bereavement coordinators and a biological scientist.

The next Live Webcast will be a demonstration and instruction on packaging and labeling of deceased and living donor organs in January 2012.

2. Tiedi® Documentation Project

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

- Identifying problems with existing documentation
 - Items that lack sufficient detail
 - Confusing or inappropriate descriptions
- Providing recommendations for educating users
 - How can we make sure that data coordinators are using the help documentation?
- Identifying situations where input from other groups (e.g., clinical experts) is needed

During its August 17, 2011, Live Meeting, the importance of this project was reiterated, and it was additionally noted that information documented in the Tiedi® form fields ultimately affects the accuracy of the program-specific reports that calculate the expected survival rate.

UNOS Support Staff presented the Working Group with modifications recommended on the Work Group's previous call.

- a. Academic Progress and Activity Level – it was recommended that the Pediatric Committee consider how homeschooled children are entered.
- b. Permanent Residence – it was recommended to insert “Foreign Country” at end of list in chart.
- c. Permanent Zip Code – it was recommended that “Zip Code” refers to the patient's full time residence.

Several new fields were reviewed and the following directives were given:

- Have members share recommended modifications with their colleagues and garner as much feedback as possible
- Have the organ-specific TCC members review them as well, especially Primary Cause of Death
- Solicit input from organ-specific committees (e.g. Primary Diagnosis) because information gets outdated
- Solicit input from the SRTR on Date of Admission to Transplant Center
- Have the TAC review the Source of Payment field and determine how the table contents are interpreted

During its October 6, 2011, Live Meeting, UNOS Support Staff reviewed the Working Group recommendations from the previous call for the following data elements: 1) national provider identifier (NPI); 2) patient status date; and 3) patient status.

The Working Group then reviewed the following new fields for consideration: 1) malignancies between listing and transplant; 2) four fields addressing any medications given currently for maintenance or anti-rejection; and 3) three pediatric data elements on the transplant recipient registration form: cognitive development, motor development and date of measurement.

Lastly, the Working Group discussed how “prior to” should be defined and agreed that the next working group call will be dedicated to reviewing each field that “prior to” is used to determine if a standard definition be considered or a more specific definition be given each time it is used.

3. Transplant Coordinators Listserv

There are currently 283 members who subscribe to this listserv. Recent discussion threads have included: lab schedules; altered work schedules; paired donation programs; ABO verification; letter for patients being removed from the list; positive drug screens; consent for sending UNOS personal patient information; and lab frequency.

This listserv has given coordinators across the country a way of providing and receiving feedback on hot topics and day-to-day issues for both the procurement and clinical coordinator populations. There is an opportunity for educating the coordinators with the issues discussed.

4. Proposal to Require Registration of all Living Donor Candidates

During its May 24, 2011 LiveMeeting, the Committee reviewed and provided feedback on a Proposal to Require UNetSM Registration of all Living Donor Organ Candidates Prior to Transplant, going out for public comment in August, sponsored by the Living Donor (LD) Committee. Specific issues the LD Committee wants the coordinators to address are: 1) fee; 2) impediments; and 3) exceptions. Discussion ensued and the following comments were made:

- One member began the discussion by referencing a recent scheduled living donor transplant that was aborted due to the recipient’s last minute decision. The policy doesn’t address this in particular but does address when it is the donor reconsidering whether to donate to the recipient
- One member asked why living donor recipients are treated differently from deceased donor recipients in regards to information having to be recorded within 24 hours of transplant
- It was noted that centers in California and Iowa register the donor and recipient prior to the transplant. It helps having the UNOS ID for paperwork etc. so their recipients are registered early in the process and the donor is registered a few days prior to the transplant once the OR is scheduled
- It was noted that most centers already have this in place. UNOS site surveyors currently review for this during their site visits (audits)

5. Committee Orientation and Planning

During the July 26, 2011, LiveMeeting, the staff liaison provided an orientation to include the committee’s strategic priorities over the next year, instructions on how to navigate in the committee’s external SharePoint site and transplant coordinators listserv in yahoo groups. In addition, UNOS Staff reviewed slides from the previous *Tiedi® Documentation Project* working group call, not only to stress the importance of this project for the committee, but also to recruit more folks into the working group.

The Committee plans to focus its efforts in two main areas over the next several months: defining fields in the data collection forms, and improving communication with candidates about their inactive status on the waiting list. The first is a long-term project due to the fact that thousands of fields in the forms will be closely reviewed, not only by members of the Committee, but other relevant OPTN/UNOS Committees. The latter will result in a publication in NATCO's journal, *Progress in Transplantation*, discussing common practices in waitlist management followed by an evaluation of how the coordinators and others can be educated in inactive waitlist management practices and/or consider a language modification in existing policy/bylaws to improve the transplant center process when communicating a patient's status.

Agenda items for the October 17th meeting include: 1) Inactive Waitlist Management; 2) Policy Proposals Issued for Public Comment; 3) US PHS Guidelines for Reducing Transmission of HIV, HBV and HCV through solid organ transplantation; and 4) Collaboration with the Living Donor Committee.

TRANSPLANT COORDINATORS COMMITTEE	MONTH	May	July
	DAY	24	26
	FORMAT (select)	Live 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		
Heather Shank-Givens	Regional Rep. 2		x
Barbara Robinson, RN	Regional Rep. 3	x	x
Pattie Manning, RN	Regional Rep. 4	x	x
Jill Stinebring, RN	Regional Rep. 5	x	x
Marsha Larsen, RN	Regional Rep. 6		
Nancy Carroll, RN	Regional Rep. 7		x
Monica Eaton	Regional Rep. 8		x
Charles Gonder, RN, MS	Regional Rep. 9		x
Michelle Crossley, RN, BSN	Regional Rep. 10		x
Marion Stewart, RN, BSN	Regional Rep. 11		x
John Belcher	At Large		
Jamie Bucio, EMT-P	At Large		x
Ann Kalis, RN	At Large		x
Christine Radolovic, RN, BSN	At Large		x
Beverly Reynolds, RN, BSN, MS	At Large		
Michael Thibault, RN, BSN	Ex Officio		
Raelene Skerda, RPh, BPharm	HRSA Liaison		x
Tabitha Leighton, MPH	SRTR Liaison	x	x
Kim Johnson, MS	Committee Liaison	x	x
Matt Harrison	UNOS Support Staff		
Leah Edwards, PhD	UNOS Support Staff	x	x
Jessica Buck, RN, BSN, CCTC	Regional Rep. 6 (2009-2011)	x	
Laura Butler, FNP-BC	Regional Rep. 11 (2009-2011)	x	
Joe Carder	At Large (2009-2011)	x	
Donna Ennis, RN, CCTC	At Large (2009-2011)	x	