

**OPTN/UNOS Transplant Coordinators Committee**  
**Report to the Board of Directors**  
**June 28-29, 2011**  
**Richmond, VA**

**Summary**

**I. Action Item for Board Consideration**

- The Board is asked to approve 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 is also asked to support the development of a guidance document to educate the community to be written in collaboration with AOPO, NKF, NATCO, and HRSA. [Item 1, Page 3]

**II. Other Significant Items**

- Tiedi Documentation Project. On May 10, 2011 the Working Group reviewed definitions in the help documentation for six fields that exist universally for all organs on the TCR, TRR and TRF and offered recommendations for modifications. This process will be repeated until all the fields on all the Tiedi forms have been considered. Other OPTN/UNOS Committees having expertise with particular fields will be asked to review what recommendations for modifications have been made. [Item 2, Page 4]
- Transplant Coordinators Listserv. There are currently 272 members to date that subscribe to this listserv. Recent discussion threads have included: deceased donor information; multiple listing; vessel storage; outreach programs; and assistance with CMS transplant surveys. [Item 3, Page 5]

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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 meetings by conference call and Microsoft LiveMeeting on October 26, 2010, November 23, 2010, December 28, 2010, March 8, 2011, and April 26, 2011. In addition, the Tiedi® Documentation Project Working Group met by conference call and Microsoft Live Meeting May 10, 2011, and the Patient Information Sharing Task Force (coordinated by the Committee) met in Chicago April 28, 2011.*

### **1. Patient Information Sharing Task Force**

In November 2010, the OPTN/UNOS Board of Directors charged the OPTN/UNOS Transplant Coordinators Committee to form a Task Force to develop guidelines regarding the standards for the sharing of donor and recipient information (i.e. type of work, parent, child, quality of life, etc) that should be provided to donors, donor families and recipients, and the appropriate timeframe to share this information.

On January 18 and February 28, 2011, the Task Force met via conference call to lay the groundwork on what needs to be accomplished regarding the development of guidelines for Patient Information Sharing. It was reiterated that the goal is to standardize information sharing between transplant hospitals and OPOs for recipient information that could be conveyed to donor families and similar efforts the community has previously undertaken. Participants had concerns about the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Alexandra Glazier, VP and General Counsel at the New England Organ Bank, urged the Task Force to not allow HIPAA to drive the work and that legal challenges could surface regardless of what we recommend. The Task Force was given assignments to collect any related materials and talk with their peer constituents to obtain as much information as possible that would be able to supplement discussion during their in-person meeting in Chicago, April 28, 2011.

On April 28, 2011, the Task Force met in Chicago, IL to establish guidelines for the sharing of information between the donor, donor family, and their recipient. It was noted that it is clear that donor families derive great benefit getting feedback from their recipients; there is variability in what transplant centers are willing to share; and there is a general agreement on what and how much information should be shared. Constituent perspectives were shared. Ms. Glazier gave a presentation on the legal framework for sharing information in organ donation and transplantation. **[EXHIBIT A]** The members separated into two groups to discuss deceased and living donation issues and make recommendations. **[EXHIBIT B]**

The Task Force discussed the following action items:

- Collaborate with the American Society of Transplantation (AST), American Society for Transplant Surgeons (ASTS), Eye and Tissue Banks
- Two separate guidance documents, one for deceased donation and one for living donation, will be written in a way to separate recommendations and suggestions
- Consider recommendations for tissue and eye donations

- Consider insurance issues for living donation
- Consider a similar approach to what AOPO has done on surgeon credentialing regarding the initial approach to share information
- Create a standard form for transplant centers
- Put HIPAA in the “tool box” on the AOPO portal to educate their members
- Have the Transplant Administrators Committee develop a program to educate their constituents on HIPAA
- Have NATCO integrate this topic into their introductory course for coordinators
- Reach out to the American Hospital Association (AHA) and others involved with the Alliance to educate risk management officers on a local level
- Consider policy language on how to handle this exchange

The Task Force recommends the following for consideration by the Board:

**\*\*RESOLVED, The Board is asked to approve 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 is also asked to support the development of a guidance document to educate the community to be written in collaboration with AOPO, NKF, NATCO, and HRSA.**

Task Force Vote: (For: 16; Against: 0; Abstentions: 0)

## 2. Tiedi® Documentation Project

During its October 26, 2010, meeting, members tested a tool developed by UNOS staff for obtaining detailed information to be used in improving the help documentation found in UNet<sup>SM</sup>. It was noted that this project is intended to improve the help documentation by:

- clarifying definitions for data elements and making them more specific
- providing guidance as to possible locations in the patient chart for obtaining the information
- providing guidance as to how to choose between multiple values in a patient chart, and
- providing examples where appropriate

This effort began after numerous requests from both the OPTN/UNOS Transplant Coordinators and Transplant Administrators Committees to provide additional guidance regarding the information sought in the fields when completing the data collection forms (e.g. Transplant Recipient Registration (TRR) form).

Committee members want to know how the fields are interpreted and how many differing positions are completing these forms?

It was suggested to begin by reviewing factors affecting expected survival because it is significant for transplant outcomes.

During its March 8, 2011 Live Meeting, the Committee was presented with a new template for reviewing fields on the Tiedi® forms and determining which fields need further explanation or modifications to the language. Members agreed that the new format is much easier to work with and a working group will meet in April to review fields that are universal on all forms.

On May 10, 2011 the Working Group reviewed definitions in the help documentation for six fields that exist universally for all organs on the TRR, Transplant Candidate Registration (TCR), and Transplant Recipient Follow Up (TRF) forms and offered recommendations for modifications. [EXHIBIT C] This process will be repeated until all the fields on all the Tiedi forms have been considered. Other OPTN/UNOS Committees having expertise with particular fields will be asked to review what recommendations for modifications have been made.

### 3. Transplant Coordinators Listserv

There are currently 272 members to date that subscribe to this listserv. Recent discussion threads have included: deceased donor information; multiple listing; vessel storage; outreach programs; and assistance with CMS transplant surveys.

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. Review of Policies and Bylaws Issued for Public Comment

The Committee reviewed the following proposal released for public comment on November 23, 2010 during its Live Meeting by the sponsoring Committee's Staff Liaison:

**Proposal to Clarify which Transplant Program has Responsibility for Elements of the Living Donation Process and to Reassign Reporting Responsibility for Living Donation from the Recipient Transplant Program to the Transplant Program Performing the Living Donor Nephrectomy or Hepatectomy.**

The Committee voted in support of this proposal [For 10; Against 0; Abstentions 0] with no comments.

**Proposal to Clarify Adult Heart Status 1A Language to Enable Consistent Interpretation of Policy and Reflect Current Programming in UNet<sup>SM</sup>.**

The Committee voted in support of this proposal [For 8; Against 0; Abstentions 1] with no comments.

**Proposal to Require Collection of Human Leukocyte Antigen (HLA) Type for Thoracic Organs.**

The Committee voted in support of this proposal [For 11; Against 0; Abstentions 0] with no comments.

**Proposal to Prohibit Storage of Hepatitis C Antibody Positive and Hepatitis B Surface Antigen Positive Extra Vessels.**

The Committee voted in support of this proposal [For 10; Against 0; Abstentions 1] and the following comments were offered:

It was reiterated that this proposal is prohibiting the storage of Hepatitis C Antibody positive and Hepatitis B Surface Antigen Positive extra vessels when they are not transplanted into the intended recipient for whom the organ and extra vessels were procured. There was discussion about removing the requirement for the implanting transplant center to provide a detailed explanation to the OPTN when Hepatitis positive extra vessels are transplanted into a secondary recipient. It was noted that if

you can't store the positive vessels, you cannot transplant into a secondary recipient obviating the need for documentation.

One member asked, is there any circumstance in real time that vessels would be needed urgently before stored to be transplanted in a secondary recipient? It was noted that it is possible with two transplants going on at same time in the same hospital but this is a rare circumstance. It was also noted that this rare circumstance would be self-reported to MPSC as a unique event. The disposal of vessels is not addressed in this policy proposal and is addressed in a different section of policy.

The Committee reviewed the following proposal released for public comment on November 23, 2010, during its Live Meeting by the sponsoring Committee's Staff Liaison:

**Proposed Model for Assessing the Effectiveness of Individual OPOs in Key Measures of Organ Recovery and Utilization.**

The Committee voted in support of this proposal [For 5; Against 4; Abstentions 2] and discussion, including questions, ensued:

- One member asked how OPOs will be impacted if CMS keeps their OPO Performance Metrics in place. It was noted that more regulation requires more money that will become cost prohibitive to the OPOs. It was further asked if there be competing interest between CMS and OPO regulations
- One member opined that this is a great proposal and this will demonstrate the potential number of organs that could be recovered
- The members then discussed whether consent would be factored into the model. It was noted that this policy is more about donor management and what happens with the organs after consent. It was asked if you are only given consent for kidneys and liver, how that will affect the outcomes. It was explained that the expected number of organs transplanted would be lower if the donor does not meet certain criteria to transplant. The hope is that over time, the model will compensate for circumstances not accounted for
- It was noted that this model will not run on a trial basis before implementation which might have unintended consequences

The Committee reviewed the following proposals released for public comment on April 26, 2011 during its Live Meeting by the sponsoring Committee's Staff Liaison and voted.

**Proposal to Require Confirmatory Subtyping of Non-A<sub>1</sub> and Non- A<sub>1</sub>B Donors Affected Policies: 3.1.2 (Transplant Center), 3.1.13 (Definition of Directed Donation), 3.2.4 (Match System Access), 3.5.9.1 (Essential Information for Kidney Offers), 3.6.2 (Blood Type Similarity Stratification/Points), 3.6.9.1 (Essential Information for Pancreas Offers), 5.0 (Standardized Packaging, Labeling, and Transporting of Organs, Vessels, and Tissue Typing Materials).**

The Committee voted in support of this proposal [For 12; Against 0; Abstentions; 0] and offers the following recommendation: sampling blood on two separate occasions means two separate sticks in the current document; however members opined that "occasion" sounds like blood will be sampled two separate times or days and the language needs to better reflect the timeframe sought after.

**Proposal to Improve the Packaging and Shipping Requirements of Living Donor Organs, Vessels and Tissue Typing Materials.**

The Committee voted in support of this proposal [For 11; Against 0; Abstain 0] with no comments.

**Proposal to Improve Reporting of Living Donor Status.**

The Committee voted in support of this proposal [For 13; Against 0; Abstain 0] and offers the following input: 1) if there are no repercussions for not submitting data, people won't be as faithful to report; 2) if we provide informed consent on living donation to patients, there needs to be information on the serum creatinine and glomerular filtration rate (GFR) as far out as 5 and 10 years to convince folks that it is the right thing to do. Kidneys are not going to fail in year 1 and 2, ask for improvement plans so all the centers won't go before the MPSC; and 3) there needs to be information about the donors for the recipients. It is better to be able to provide creatinine and GFR at 5 years post-transplant than just telling people living donors are alive or dead.

**Proposal to Encourage Organ Procurement Organizations (OPO) to Provide Computed Tomography (CT) Scan if Requested by Transplant Programs.**

The Committee voted in support of this proposal [For 11; Against 2; Abstain 0] with no comments.

**Proposal to Require Updates of Certain Clinical Factors Every 14 Days for Lung Transplant Candidates whose Lung Allocation Scores (LAS) are at Least Fifty.**

The Committee voted in support of this proposal [For 12; Against 1; Abstain 0] with no comments.

**Proposal to Allow Outpatient Adult Heart Transplant Candidates Implanted with Total Artificial Hearts (TAH) Thirty Days of Status 1A Time.**

The Committee voted in support of this proposal [For 9; Against 3; Abstain 1] and offers the following comments: it was noted that this is a clinical trial setting a new standard of care for ventricular assist device (VAD) patients; however it is not evidence-based practice; patients are taking a risk going home with an artificial heart and we don't know if they are safe; this policy is taking away some incentive to participate in the study; it was suggested to wait until it is safe then support a 30-day cap; it was additionally noted that patients should maintain a 1A status whether they are in or out of the hospital until the data is released from the trial, as long as the clinical trial is active, they should maintain their 1A status.

**Proposed Committee-Sponsored Alternative Allocation System (CAS) for Split Liver Allocation.**

The Committee voted in support of this proposal [For 13; Against 0; Abstain 0] with no comments.

**Proposal to Eliminate the Requirement that Pediatric Liver Candidates Must be Located in a Hospital's Intensive Care Unit to Qualify as Status 1A or 1B.**

The Committee voted in support of this proposal [For 12; Against 0; Abstain 0] with no comments.

<b>TRANSPLANT COORDINATORS COMMITTEE</b>		<b>MONTH</b>	October	November	December
		<b>DAY</b>	26	23	28
		<b>FORMAT (select)</b>	Live Meetings		
<b>NAME</b>	<b>COMMITTEE POSITION</b>				
Michael Thibault, RN, BSN	Chair	x			
Melissa Dunbar-Forrest, RN, BSN	Vice Chair	x	x		x
Lindsay Arnott, RN, BS	Regional Rep. 1	x	x		x
Heather Shank-Givens, RN	Regional Rep. 2	x	x		x
Barbara Robinson, RN	Regional Rep. 3	x			x
Pattie Manning, RN	Regional Rep. 4	x	x		x
Jill Stinebring, RN	Regional Rep. 5	x	x		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			x
Rose Rodriguez, RN, MS	Regional Rep. 9	x			x
Jennifer Berry-Edwards	Regional Rep. 10	x	x		x
Laura Butler, FNP-BC	Regional Rep. 11	x	x		x
Donna Ennis, RN, BS	At Large	x			x
Suzanne Fitzpatrick	At Large	x	x		x
Sheila Harms, RN, MSN	At Large	x			x
Joseph Carder, BS	At Large	x	x		x
Beverly Reynolds, RN, BSN, MS	At Large	x			x
Holly Berilla, MSW	HRSA Liaison	x	x		x
Kim Johnson, MS	Committee Liaison	x	x		x
Leah Edwards, PhD	UNOS Support Staff	x			x
Stacey Burson	UNOS Support Staff	x	x		x



<b>TRANSPLANT COORDINATORS COMMITTEE</b>		<b>MONTH</b>	
		March	April
		<b>DAY</b>	
		8	26
		<b>FORMAT (select)</b>	
		Live Meetings	
<b>NAME</b>	<b>COMMITTEE POSITION</b>		
Michael Thibault, RN, BSN	Chair	x	x
Melissa Dunbar-Forrest, RN, BSN	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
Pattie Manning, RN	Regional Rep. 4	x	x
Jill Stinebring, RN	Regional Rep. 5	x	x
Jessica Buck, RN, BSN	Regional Rep. 6	X	x
Karen Kasinger, RN, APN	Regional Rep. 7		x
Laurel Salonen, RN, MSN	Regional Rep. 8	x	x
Rose Rodriguez, RN, MS	Regional Rep. 9	x	x
Jennifer Berry-Edwards	Regional Rep. 10	x	x
Laura Butler, FNP-BC	Regional Rep. 11	x	x
Donna Ennis, RN, BS	At Large	x	x
Joseph Carder	At Large	X	x
Suzanne Fitzpatrick	At Large	x	x
Sheila Harms, RN, MSN	At Large	x	x
Beverly Reynolds, RN, BSN, MS	At Large	x	x
Holly Berilla, MSW	HRSA Liaison	x	x
Raelene Skerda, RPh, BPharm	HRSA Liaison		x
Tabitha Leighton, MPH	SRTR Liaison	x	x
Kim Johnson, MS	Committee Liaison	x	x
Leah Edwards, PhD	UNOS Support Staff	x	x
Stacey Burson	UNOS Support Staff	x	x
Jacqueline O'Keefe Erik Edwards, PhD	UNOS Staff	x	