

OPTN/UNOS Patient Affairs Committee
Report to the Board of Directors
November 8-9, 2010
St. Louis, Missouri

Summary

I. Action Items for Board Consideration

- None

II. Other Significant Items

- The Committee is drafting a Plain Language Version of the Patient Information Letter. (Item 1, Page 3)
- The Committee completed an Early Evaluation Tool to explore language clarification and proper positioning of UNOS Bylaw Section II Transplant Hospitals, B.11.F Patient Notification. (Item 2, Page 3)
- The Committee is continuing its work on a re-write of *What Every Patient Needs to Know*. The goal is to present a patient-focused perspective on preparing for transplant. (Item 3, Page 3)

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Ray Gabel, Chair
Laura Ellsworth, Vice Chair

This report reflects the work of the Patient Affairs Committee during its May 24, 2010, meeting in Chicago, Illinois, as well as Committee conference calls on 7/13/2010 and 9/14/2010.

1. Proposal to Modify the OPTN Contractor Patient Information Letter to More Simplified Language.

The Committee solicited input regarding effective wording for a plain language version of the Patient Information Letter from the following stakeholders:

- Transplant Administrators Committee
- Transplant Coordinators Committee
- DEQ Surveyors
- Regional Administrators

A Subcommittee was formatted to synthesize this information into a concise document for review by the UNOS Executive Committee.

2. Exploration of Proposal to Clarify Language and Properly Position UNOS Bylaw Section II Transplant Hospitals, B.11.F (Patient Notification).

Patient Notification errors are the most cited errors per input received from the Department of Evaluation and Quality (DEQ). The most recent DEQ data is available for survey of centers conducted over a 9 month period. This survey was based on patients listed and removed in the last three year period. DEQ found notification of listing errors in 17% of patients reviewed at that time. Notification of removal errors were found in 36% of patients reviewed during this same time period. Recent discussions within the TAC and on the HRSA Health Disparities List Serv further highlight a general lack of clarity regarding Patient Notification within the Transplant Community.

Research and anecdotal input indicate a two-pronged issue:

- Centers have difficulty finding the Patient Notification Requirement within Bylaws. Transplant Centers generally find clinical direction in Policy.
- Center staff relates a lack of clarity regarding the process for meeting the requirement.

The Committee proposes to address these concerns through clarification of the language within the Bylaw and proper positioning of the requirement in Policy.

3. Rewrite of ‘What Every Patient Needs to Know’

The Committee continues its work on the rewrite of *What Every Patient Need to Know* (WEP). WEP is used by individual patients and families. *What Every Patient Needs to Know* is also used as a key component of patient education programs by many transplant centers and dialysis units. Individuals request WEP through the UNOS Patient Services line. Bulk orders for organizations are processed

through the UNOS Online Store. Historically, corporate funding has been used for this resource. Thus far, no funding has been secured.

4. Post-Transplant Handbook

The Liason led the Committee in a brainstorming activity designed to solicit input regarding key issues which should be addressed in the design of a post-transplant education resource for patients and families. Committee input reinforced results from the literature and the anecdotal input from the Subcommittee. The resource should incorporate a more holistic approach to life after transplant which would encourage:

- avoidance of health crises through adherence to health maintenance schedules
- improved quality of life, through early identification of life goals after transplant
- incorporation of social supports during life after transplant

Further, the resource should:

- be written in a personal tone
- incorporate a brief question-answer format
- address psychosocial impact of transplant on recipients and families

5. Organ Allocation

Members of the Committee attended the Spring Liver Forum and brought updates back to the Committee. The Committee was pleased to find that the issues raised by PAC were clearly addressed in the Liver Forum. The Committee has continued to follow the implementation of the Kidney Paired Donation Pilot.

The Committee heard presentations on Pancreas Allocation during the May 24, 2010 Face-to-Face Meeting in Chicago. The Committee raised three questions:

- How will the new system impact persons seeking a second transplant
 - *The proposal would disentangle pancreas allocation from kidney allocation, allowing the Pancreas to be allocated before the kidney when indicated.*
- How many pancreas are offered with organs other than kidney's annually and
 - *100 – 200 Pancreata are allocated with organs other than kidneys annually*
- What is the impact to adult kidney candidates if Pediatric donor's and SPK's are moved to a pancreas only match.
 - *Simulation results showed no difference in the number of kidney transplants and waiting time for kidney transplants between the current system and a system with a combined match run.*

The Pancreas Committee Liaison responded to all questions to the satisfaction of the Committee. The Committee chose to delay its vote until after the Pancreas Forum. Individual Committee members listened to the Pancreas Forum.

The Committee asked that consideration be given to doing a high PRA kidney match run before letting a kidney follow the pancreas if there is only one kidney available (eg. An anatomically abnormal donor, or an instance where the other kidney has gone to a liver/kidney or heart/kidney recipient. The Committee voted to accept the Pancreas Proposal [For 11: Against 0: Abstentions 0]

6. Patient Notification Practices within the Transplant Community

The Committee received a presentation on the Transplant Coordinator Committee Inactive Waitlist Study. TCC surveyed transplant centers regarding waitlist management in a representative sample of transplant centers. The survey indicated disparities in defining inactive on the waitlist among centers and in notifying patients of inactive status on the waitlist. Committee members raised concerns over the accepted definition for inactive versus temporary on the waitlist. TCC requests PAC support in establishing standard definitions for inactive and temporary on the waitlist. After careful consideration, PAC requested that TCC provide further clarification regarding the request.

The Committee received a presentation on Patient Notification Findings from DEQ Surveys. The presentation reviewed the survey process, the role of the Site Surveyor, administrative policies for patient notification and common notification errors found in site surveys. The Committee noted concerns regarding the percentage of programs that are found to be out of compliance with patient notification expectations. The Committee further found that data from this presentation reinforced issues previously identified with the OPTN Contractor Patient Information Letter and the TCC Waitlist Inactivity Report.

The Committee received a summary of the calls received through the Patient Services Line over the last 5 years. Of note was the consistency in the types of calls, topics for discussion, and numbers of calls during that time frame.

7. Public Comment Proposals

- Proposed Ohio ALU:

The Committee supports broader geographic sharing and prioritization of sicker patients for transplantation. The Committee further agreed that this proposal meets ethical principles for allocation. The Committee voted to support this proposal. [Yes: 13, No: 0, Abstain: 3]

- Proposed One Legacy and Region 2 Split Liver ALU:

Because of the similarities between the Proposed One Legacy and Region 2 Split Liver ALU proposals, the Committee opted to vote for the proposals together. The Committee voted to support both proposals with a request that Region 2 clarify the recipient of the left lobe. [Yes: 16, No: 0, Abstain: 1]

- Placement of Non-Directed Living Donor Kidneys:

After discussion the committee approved the proposal as presented. [Yes: 17, No: 0, Abstain: 0]

- Proposal to Require Reporting of Non-utilized and Redirected Living Donor Organs:

The Committee agreed to accept the proposal with a request that transplant centers be mandated to provide a written description for why organs are not used. [Yes: 17, No: 0, Abstain: 0]

- Ad Hoc Disease Transmission Advisory Committee (DTAC) Proposal to Modify OPO and Transplant center Requirements for Screening and Communicating and Reporting All Potential or Confirmed Donor-Related Disease and malignancy Transmission Events :

The Committee raised concerns that an increased emphasis on consent may discourage use of high risk organs. An unintended consequence of this proposal could be increased deaths on the

waiting list. Committee members were further concerned that many patients will refuse organs out of fear of disease transmission. Dr. David Zaas strongly encouraged DTAC to consider providing statistical data on the risk of transmission for each of the disease categories deemed as high risk by the CDC. Committee members noted that disease transmissions represent only 1% of all transplants that occur. Committee members further, felt strongly that DTAC should provide diagnosis specific data on the incidence of disease transmission for use by transplant centers. [Yes: 17, No: 0, Abstain: 0]

- Proposal to Require a Use of a Standardized, Internal A Label that is Distributed by the OPTN and that Transplant Centers Notify the Recovering OPO when they Repackage an Organ: Committee Members raised questions about how multi-viscerals would be labeled. [Yes: 17, No: 0, Abstain: 0]
- 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:

The Committee did not formally discuss or vote on this proposal as the issues were not directly patient related.

PATIENT AFFAIRS COMMITTEE ATTENDANCE

NAME	COMMITTEE POSITION	05/24/2010 Meeting
Ray Gabel	Chair	x
Laura Ellsworth	Vice Chair	x
Keith Diaz JD	Regional Rep.	
Michelle Christenson	Regional Rep.	x
Kathleen Giery, APR, CPRC	Regional Rep.	x
G. Rodney Davis, EMT	Regional Rep.	x
Kristie Lemmon, MBA	Regional Rep.	x
Alison Walsh	Regional Rep.	x
Kim Burdakin	Regional Rep.	x
Charles (TED) Lawson	Regional Rep.	
Laura Murdock, MHA	Regional Rep.	x
Karen Starr, MSN, APRN, BC, LADC	Regional Rep.	x
Kim McMahon	At Large	x
Megan Lewis, PhD	At Large	x
Kathe LeBeau	At Large	x
Thomas Starr	At Large	x
Isabel Stenzel Byrnes, MSW, MPH	At Large	x
Heidi Yeh, MD	At Large	x
David Zaas MD, MBA	At Large	x
David Burrigion	UNOS Board	x
Richard Laeng, MPH	HRSA Ex-Officio	x
William(Bill) Lawrence	UNOS Staff	x
Anna Kucheryavaya	UNOS Staff	x
Stacey Burson	UNOS Staff	
Beverley Trinkle	UNOS Staff	
Freda Wilkins MSW, M.Div	Liaison	x

PATIENT AFFAIRS COMMITTEE ATTENDANCE

NAME	COMMITTEE POSITION	07/13/2010 Conference Call	9/14/2010 Conference Call
Ray Gabel	Chair	x	x
Laura Ellsworth	Vice Chair	x	x
Keith Diaz JD	Regional Rep.	x	
James Gleason	Regional Rep.	x	x
Kathleen Giery, APR, CPRC	Regional Rep.	x	x
Joseph Sharp	Regional Rep.		x
Lee Ann Stamos	Regional Rep.		x
Kristie Lemmon, MBA	Regional Rep.	x	x
Alison Walsh	Regional Rep.		
Merle Zuel	Regional Rep.	x	
Shari Kurzrok Schnall	Regional Rep.	x	x
Laura Murdock, MHA	Regional Rep.	x	x
Karen Starr, MSN, APRN, BC, LADC	Regional Rep.		
Kathe LeBeau	At Large		x
Sidney Locks	At Large		x
Kim McMahan	At Large	x	x
Thomas Starr	At Large		x
Isabel Stenzel Byrnes, MSW, MPH	At Large		x
Heidi Yeh, MD	At Large		x
David Zaas MD, MBA	At Large		
Doni Bell	At Large *Added after 7/13		x
Donna Banks	UNOS Board		
Tom Falsey	UNOS Board		
Richard Laeng, MPH	HRSA Ex-Officio	x	x
William(Bill) Lawrence	UNOS Staff	x	
Anna Kucheryavaya	UNOS Staff	x	x
Stacey Burson	UNOS Staff		
Beverley Trinkle	UNOS Staff		x
Freda Wilkins MSW, M.Div	Liaison	x	x