

**OPTN/UNOS Patient Affairs Committee
Report to the Board of Directors
November 12 – 13, 2012
St. Louis, MO**

Summary

I. Action Items for Board Consideration

- None

II. Other Significant Items

- The Committee has provided input on the development of the *Print-on-Demand* Project to be launched by UNOS Communications and Creative Aid (Item 1, Page 2)
- The following patient education resources are now available to the public in Spanish as well as English (Item 2, Page 2):
 - *What Every Patient Needs to Know*
 - *What Every Kid Needs to Know*
 - *Living Donation*
- The Committee is working with the Living Donor Committee regarding the inclusion of the OPTN Contractor Patient Information Letter as part of the required consent for all Living Donor Candidates. (Item 3, Page 3)
- The Committee will consider the possibility of offering priority to non-renal recipients who are now listed for a renal transplant. The Committee will receive a data report on the incidence of this problem during the Fall 2012 meeting. (Item 4, Page 3)

**OPTN/UNOS Patient Affairs Committee
Report to the Board of Directors
November 12 & 13, 2012
St. Louis, MO**

**Laura Ellsworth, Chair
Kristie Lemmon, Vice Chair**

This report reflects the work of the Patient Affairs Committee during conference calls held between June 6, 2012 and September 30, 2012.

1. Print on Demand

With input from the Committee, CreativeAid has now announced the planned launch of *Print-on-Demand*. This new option will provide a simple and cost-effective web-based resource for transplant centers to access and customize the following patient education materials in bulk:

- *What Every Patient Needs to Know*
- *What Every Kid Needs to Know*
- *Living Donation*

The target launch date for this new resource is October 18, 2012.

The goals for *Print-on-Demand* are to:

- Decrease dependence on corporate sponsorship for educational resources,
- Increase access to privately funded patient education resources, and
- Provide transplant centers with an option for personalization of patient education resources for a reasonable price

While acknowledging the benefits of a resource like *Print-on-Demand* to the transplant community; the Committee has expressed concern that *Print-on-Demand* not limit the individual patient's ability to request one or two items for personal use. UNOS Communications and UNOS Instructional Innovations Departments have acknowledged the concerns of the Committee. Patients and Families will continue to be able to receive individual *Patient Information Packets* through the UNOS Patient Services Line at 888/894-6361.

The implementation of *Print-on-Demand* will limit the number of copies of the aforementioned resources that transplant centers can order at no cost. *Print-on-Demand* will not replace the existing UNOS Online Store. Instead, the targeted resources will link from the UNOS Online Store to the UNOS *Print-on-Demand* site.

Staff will introduce the new *Print-on-Demand* function at an upcoming Committee Meeting.

2. Spanish Language Patient Education Resources Available

In response to continual requests from the Committee; Spanish-language versions of *What Every Patient Needs to Know*, *What Every Kid Needs to Know* and *Living Donation* are now available. The Committee assisted in a plain language review of these resources, prior to the final printing. The Committee received this update during the June 6, 2012 conference call.

3. Living Donor Consent and Patient Notification

During the May 21, 2012' meeting, the Committee received an update on the work of the Patient Notification Subcommittee. The Committee focused on the benefits of the UNOS Patient Services Line to patients and families. The Patient Information Letter provides the recipient with the UNOS Patient Services Phone Line (888/894-6361) number. Callers can receive help with accessing information on transplant data, transplant policy, location of transplant centers, and patient education resources.

The Committee felt strongly that transplant centers should be required to provide the OPTN Contractor Patient Information Letter (hereafter referred to as the Patient Information Letter) to living donor candidates as early in the transplant process as possible.

The Committee cited the problems that lack of education raises for patients in all areas of transplantation. Living donors and recipients of living donor transplants related personal stories of feeling disconnected and not knowing where to turn for information. Transplant Coordinators and Social Workers within the Committee related the positive impact of the Independent Living Donor Advocate in keeping living donor candidates informed and connected to the transplant system. The Committee persisted supports of providing the Patient Information Letter to living donor candidates at the time that they enter the transplant system.

The Committee unanimously agreed to develop policy language requiring that transplant centers provide the Patient Information Letter to living donor candidates at the point that the candidate formally enters the donor evaluation process.

The Living Donor Committee is considering developing a standardized consent process for Living Donors. The Living Donor Committee asked that the inclusion of the Patient Information Letter be incorporated into the larger consent standardization process for living donors. The Living Donor Committee asked that the Committee review the existing Patient Information Letter to determine its appropriateness for use with living donor candidates. The Committee is also to make recommendations for changes if indicated. These recommendations will be presented to the Committee at its October 22, 2012 meeting.

4. Incidence of Former Non-renal Recipients Currently Waiting for Kidneys

During the spring regional meeting, Region 8 had discussion about potential inequities for recipients of non-renal organs, who later experience renal failure related to use of transplant medications. The subsequent renal failure then has potential negative impact on the transplanted graft, resulting in the loss of the initial graft as well. The region further felt that the loss of the initial graft was negatively impacted by the extended wait times for kidney transplant. Region 8 asked the Committee to consider whether renal candidates, with previously transplanted grafts, should be given priority for kidney transplant.

The Committee acknowledged the validity of the concerns. Strong opinions were held on all sides of the issue, with some members feeling that the potential loss of a healthy graft warrants special consideration and others adamantly stating prior transplant does not warrant special consideration. The discussion ended with a request for data on the number of candidates impacted. The Committee will review the requested data during the October 22, 2012 meeting.

5. Teen Adherence Project Curriculum Development

The goal of the Teen Adherence Project is to develop a comprehensive transplant education program for teens and young adults. A cornerstone of this project would be a smartphone game that proposes to educate about compliance in transplant. The smartphone game would be supported by more traditional educational resources that incorporate support from the transplant team, parents and peers. This work will be done with clinical support from the Pediatric Committee and OPTN member pediatric transplant programs.

A Subcommittee has begun preliminary work on the curriculum that will form the basis for the Teen Adherence Project. This information will be presented to the Committee during the October 22, 2012 meeting. At that time the Committee will participate in further refine the document, before it is sent back to the subcommittee for further input.

6. UNOS Patient Services Line Database Analysis

The Committee received an update on the Patient Services Line Database project during the June 6, 2012, conference call. There is over 10 years of data from calls to the UNOS Patient Services Line available through the phone line database. The Liaison is coordinating efforts with Dr. Amy Waterman, Associate Professor of Medicine and Social Psychologist from Washington University, St. Louis Missouri, and the UNOS IT Department to capture the data and develop a plan for analysis. This information will then be used to discern educational needs by organ group and patient group. The Committee, with support from Dr. Waterman, will further evaluate the data for relevant trends beyond educational needs

7. KDPI Presentation

During the June 6, 2012 Conference Call, the Committee received a presentation on the Kidney Donor Profile Index (KDPI) in preparation for the release of the proposed modifications to the Kidney Allocation policy.. The Committee has reviewed the information through its many iterations. The presentation was meant to review previously presented information on KDPI in preparation for the discussion of, and vote on the Kidney Allocation system proposal. The Committee received the presentation with very minimal discussion.

8. Policy Rewrite Project

The Committee received a presentation introducing the Policy Rewrite Project during the August 2, 2012, Conference Call. The rationale for the project was clearly stated. The presentation outlined the format and function of the Policy Rewrite Project.

Members of the Committee were asked to review policies based upon area of interest or expertise. Proposed policies were reviewed in comparison to the existing policy. Comments from the Committee were positive regarding both format and usability.

9. Public Comment Proposal Responses

The Committee received presentations on the following proposals without comments during the June 6, 2012 Conference Call.. The Committee did not take a formal vote on the proposals. The nine members present unanimously supported each of the proposals.

- Proposal to Allow Centers to Place Liver Candidates with HCC exceptions on HCC Hold Without Loss of Accumulated MELD Exception Score (Liver and Intestinal Transplant Committee)
- Proposal to Require reporting of Unexpected potential or Proven disease Transmission Involving Living Organ Donors (Living Donor Committee)
- Proposal to Require Extra Vessel(s) Disposition to be Reported to the OPTN within Five Days of Transplant or Disposal (Operations and Safety Committee)

PATIENT AFFAIRS COMMITTEE 2011/12– Attendance, 2010-11

NAME	COMMITTEE POSITION	10/6 Call	10/13 Meeting	11/3/ Call	12/1C all	1/5 Call	2/2 Call	4/5 Call
Laura Ellsworth	Chair	x		x	x	x	x	x
Kristie Lemmon	Vice Chair	x	x	x	x	x	x	x
Stephen Bruno	Regional Rep.			x		x		
James Gleason	Regional Rep.	x	x	x	x	x		x
Kathleen Giery,	Regional Rep.	x	x	x	x		x	
Joseph Sharp	Regional Rep.	x	x	x	x	x	x	x
Lee Ann Stamos	Regional Rep.	x		x				
John Fallgren RN	Regional Rep.	x	x	x	x	x	x	x
Deepak Mital MD	Regional Rep.	x	x		x	x	x	x
Merle Zuel	Regional Rep.	x	x	x	x	x		
Shari Schnall	Regional Rep.	x		x	x	x		x
Annette Humberson	Regional Rep.	x	x	x	x	x		
Kim Phillips	Regional Rep.	x	x		x	x		
Kathe LeBeau BA	At Large	x	x	x	x	x	x	x
Sidney Locks	At Large							
Kim McMahan	At Large	x	x	x	x	x	x	x
Jennifer Browning	At Large	x	x	x	x	x	x	x
George Franklin	At Large	x	x	x	x	x	x	x
Carrie Simpkins	At Large	x	x	x	x			x
Alice Gray MD	At Large	x		x				
Doni Bell BA, EMT	At Large							x
Melvin Todd, JD	At Large							
Lan Phuong Vu-Yu	At Large		x	x	x			
Marie Cook	At Large	x	x	x	x	x	x	x
Chinyere Amaefule	HRSA Ex-Officio	x	x	x	x	x	x	x
Tabitha Leighton	SRTR Ex-Officio	x	x	x	x	x		x
William(Bill) Lawrence	UNOS Staff	x	x	x	x		x	
Anna Kucheryavaya	UNOS Staff	x	x	x	x	x	x	x
Stacey Burson	UNOS Staff							
Beverley Trinkle	UNOS Staff							
Freda Wilkins	Liaison	x	x	x	x	x	x	x

PATIENT AFFAIRS COMMITTEE 2011/12 – Attendance, 2012

NAME	COMMITTEE POSITION	5/21/12 Meeting	6/7/2012 Call
Laura Ellsworth BA	Chair	x	
Kristie Lemmon MBA	Vice Chair	x	
Stephen Bruno	Regional Rep.		
James Gleason	Regional Rep.	x	x
Kathleen Giery, APR,	Regional Rep.	x	
Joseph Sharp EMT-P	Regional Rep.	x	x
Lee Ann Stamos RN, MS	Regional Rep.		
John Fallgren RN	Regional Rep.	x	x
Deepak Mital MD	Regional Rep.	x	
Merle Zuel	Regional Rep.	x	
Shari Kurzrok Schnall BA	Regional Rep.	x	
Annette Humberson,	Regional Rep.	x	
Kim Phillips MSN, RN	Regional Rep.	x	x
Kathe LeBeau BA	At Large		x
Sidney Locks M.Div	At Large		
Kim McMahon	At Large	x	x
Jennifer Browning CPTC	At Large	x	x
George Franklin	At Large	x	
Carrie Simpkins	At Large	x	
Alice Gray MD	At Large		
Doni Bell BA, EMT	At Large		
Melvin Todd,	At Large		
Lan Phuong Vu-Yu	At Large		
Marie Cook	At Large		x
Chinyere Amaefule	HRSA Ex-Officio	x	x
Tabitha Leighton	SRTR Ex-Officio		
William(Bill) Lawrence	UNOS Staff	x	
Anna Kucheryavaya	UNOS Staff	x	x
Stacey Burson	UNOS Staff		
Beverley Trinkle	UNOS Staff		
Freda Wilkins	Liaison	x	x

PATIENT AFFAIRS COMMITTEE 2012/13 – Attendance 2012

NAME	COMMITTEE POSITION	8-2-2012 Livemeeting
Laura Ellsworth	Chair	
Kristie Lemmon	Vice Chair	
Stephen Bruno	Regional Rep.	
James Gleason	Regional Rep.	x
Lori Rush	Regional Rep.	x
Joseph Sharp	Regional Rep.	x
Lee Ann Stamos	Regional Rep.	
John Fallgren	Regional Rep.	x
Deepak Mital MD	Regional Rep.	x
Merle Zuel	Regional Rep.	x
Shari Kurzrok Schnall	Regional Rep.	x
Annette Humberson	Regional Rep.	x
Kim Phillips	Regional Rep.	x
Sidney Locks M.Div	At Large	
Jennifer Browning	At Large	x
George Franklin	At Large	
Carrie Simpkins	At Large	
Alice Gray MD	At Large	
Doni Bell	At Large	
Lan Phuong Vu-Yu	At Large	x
Marie Cook	At Large	x
Chinyere Amaefule	HRSA Ex-Officio	x
Tabitha Leighton	SRTR Ex-Officio	
William(Bill) Lawrence	UNOS Staff	
Anna Kucheryavaya	UNOS Staff	x
Beverley Trinkle	UNOS Staff	
Freda Wilkins	Liaison	x