

**OPTN/UNOS Patient Affairs Committee
Report to the Board of Directors
June 21-22, 2010
Richmond, Virginia**

Summary

I. Action Items for Board Consideration

- None

II. Other Significant Items

- The Committee considered requests from member transplant centers to simplify the language of the Patient Notification Letter. The Committee formed a subcommittee to draft a plain language version of the letter. (Item 1, Page 3)
- The Committee continued its work on a re-write of *What Every Patient Needs to Know*. to present a patient-focused perspective on preparing for transplant. (Item 2, Page 3)
- The Committee reviewed a representative sampling of patient education materials from transplant centers, patient advocacy groups, pharmaceutical company patient education programs and transplant-related materials published for mass marketing. The Committee determined that there was a dearth of educational information that addressed long-term graft maintenance from a holistic approach. A subcommittee was formed to develop a plan for a post-transplant educational resource to be used with patients and families. (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 November 9, 2009, meeting in Chicago, Illinois, as well as all monthly conference calls. Additionally, the Committee's Subcommittees have met by teleconference and LiveMeeting[®] since the November 2009 meeting.

1. Proposal to Modify the Patient Notification Letter to More Simplified Language.

Transplant centers contacted the Committee stating that the language in the Patient Notification Letter was written at a reading level above that of many of their patients, and that the intent of the Patient Notification Letter is unclear. Committee members reviewed the letter during the November 2009 meeting and concurred that the issues raised were valid (**Exhibit A**).

The Committee formed a subcommittee to work on a plain language re-write of the Patient Notification Letter. Members further enlisted the support of UNOS staff to ensure that the language of the letter continued to reflect the original intent of the document, but is done so in a way that minimizes barriers to comprehension.

2. Rewrite of 'What Every Patient Needs to Know'

The Committee became aware that there had not been a rewrite of *What Every Patient Needs to Know* in more than three years. *What Every Patient Needs to Know* is a patient education resource designed to introduce persons who have been newly diagnosed with End Stage Disease to the transplant process. More than 60,000 copies of *What Every Patient Needs to Know* are provided to transplant centers, dialysis centers and individual constituents per year, through UNOS Professional Services store and Patient Services Line.

In considering the rapid pace of change within the transplant community, the Committee felt it important to undertake a complete re-write of *What Every Patient Needs to Know* to ensure that that the product reflects current transplant practice. The Committee felt that a re-write of *What Every Patient Needs to Know* should be more reflective of their actual experiences.

Thus, the Committee established a *What Every Patient Needs to Know* Subcommittee to develop a content outline for the re-write. This team will take an active role in editing content for the resource.

3. Post-Transplant Handbook

The Committee continues to review materials used in pre- and post-transplant education. Better education would empower recipients and their families to be more actively involved in the maintenance of their grafts. Empowered transplant recipients, would in turn lead to better graft survival rates, which would ultimately make more organs available to the larger transplant community.

The Committee reviewed materials from 10 transplant centers and pre- and post-transplant resources that are available from disease specific advocacy groups, and pharmaceutical companies. Finally, the Committee considered materials that were mass marketed to the general population. Due to the scope of

the resources being considered, a new subcommittee was tasked with synthesizing the available information and making recommendations to the full Committee.

The Subcommittee concluded that existing resources generally emphasized medical management of grafts. While in no way de-emphasizing the importance of medical management, the Subcommittee felt strongly that other factors such as attitude, were critical to long term graft maintenance. Further, the Subcommittee found the language of most of the transplant education materials to be sterile. They felt that a more personal tone in materials would be more likely to engage readers in the content and the process.

The Subcommittee unanimously agreed that its emphasis should be more on helping recipients to improve their quality of life, versus a more narrow view of impacting organ availability by focusing on graft maintenance. Psychoocial indicators in long term graft survival in organ transplant suggest that recipient education should emphasize the following:

- Prevention of Adverse Events;
- Presence of Active Social Supports; and
- Capacity to Return to Work.

The Subcommittee concurred with the findings in the literature, but felt that the return to work goal should be re-stated to reflect the value of having goals, as many transplant recipients can not and are not expected to return to work. The literature also emphasized the value of measuring the broad area of quality of life, versus a more narrow medical management measure of graft maintenance.

The Subcommittee identified 44 separate topic areas, which were routinely addressed to varying degrees in transplant education materials. The Subcommittee further grouped these topics under six headings:

- Preparation for Surgery;
- Post-Transplant Medical Management;
- Quality of Life Indicators;
- Maintenance/Enhancement of Family Life;
- Mental Health Issues; and
- Transplant Resources.

The Subcommittee found the following gaps in the existing resources:

- Return to Work/Health Insurance after Transplant;
- Emotional Impact of Transplant on recipients, donors and families;
- Living Donor Self-Care;
- Cultural Differences in Transplantation; and
- Sexual Issues/Body Image.

The Subcommittee has developed an outline for a Post-Transplant Handbook. The full Committee agreed that the Handbook should:

- reflect the perspective of patients;
- emphasize the quality-of-life indicators as identified from the literature review.

4. Liver Allocation Subcommittee

The Committee recognizes that organ allocation is a primary concern for donors, recipients and families in transplant. Organ allocation policy is generally a very complex process with many nuances. As a committee comprised of roughly 55% patients and families, the committee felt that it was important to establish a system to provide ongoing education to the committee on allocation issues.

To that end, the Committee received education on potential models for liver allocation. The discussion included:

- Issues that have been identified with the current system;
- Goals for a new system;
- Approaches to addressing concerns based upon the Final Rule;
- Issues of futility; and
- Distribution concepts which are being explored.

Committee members raised specific concerns regarding regional allocation and the potential for persons to possibly be disenfranchised based on geographic location. The Committee further stressed the importance of considering the potential impact of a net benefit model on seniors, persons with hepatocellular carcinoma (HCC), and persons seeking re-transplant. The Committee further compared liver allocation models with the net benefit model used in lung allocation.

Committee members attended the Liver Forum or participated via LiveMeeting[®]. The Subcommittee wants to incorporate patient input into allocation policy during the development phase, when issues can be more adequately addressed.

5. Organ Allocation

The Committee received education on the current pancreas allocation system. Concerns regarding the current system were discussed. The goals for a new national Pancreas systems were outlined. The Committee members agreed with the goals of maximizing capacity in pancreas allocation and optimizing access to pancreas allocation for patients. The general consensus is that this type of discussion helps them to be better informed when asked to vote on proposals.

6. Committee Watchlist

The Committee has instituted a list of issues within transplant which its members should be more educated about. The watchlist consists of issues which the Committee has determined to be of interest in transplantation. The Committee's liaison will share information and facilitates educational opportunities on these subjects. Further, the liaison will keep Committee members updated on any developments within these areas. The Committee has asked to monitor organ transport, transplant tourism, education regarding expanded criteria donors (ECD), split livers and donor family follow-up.

PATIENT AFFAIRS COMMITTEE

NAME	COMMITTEE POSITION	11/9/2009	12/1/2010	2/2/2010	3/2/2010	4/6/2010	5/11/2010
Ray Gabel	Chair	x	x	x	x		x
Laura Ellsworth	Vice Chair	x		x	x	x	x
Keith Diaz JD	Regional Rep.					x	
Michelle Christenson	Regional Rep.	x	x	x	x	x	x
Kathleen Giery, APR, CPRC	Regional Rep.	x	x	x	x	x	x
G. Rodney Davis, EMT	Regional Rep.	x	x	x	x	x	x
Kristie Lemmon, MBA	Regional Rep.	x	x	x	x	x	x
Alison Walsh	Regional Rep.	x					x
Kim Burdakin	Regional Rep.	x	x	x	x	x	x
Charles (TED) Lawson	Regional Rep.	x		x	x	x	x
Laura Murdock, MHA	Regional Rep.	x	x	x	x	x	x
Karen Starr, MSN, APRN, BC, LADC	Regional Rep.	x					
Kim McMahon	At Large	x	x	x	x	x	x
Megan Lewis, PhD	At Large	x					
Kathe LeBeau	At Large	x		x	x	x	
Thomas Starr	At Large						
Isabel Stenzel Byrnes, MSW, MPH	At Large	x	x	x	x	x	x
Heidi Yeh, MD	At Large	x	x	x	x	x	x
David Zaas MD, MBA	At Large	x			x	x	x
Richard Laeng, MPH	HRSA 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
Stacey Burson	UNOS Staff						x
Beverley Trinkle	UNOS Staff			x			
Freda Wilkins MSW, M.Div	Liaison	x	x	x	x	x	x



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Dear Patient,

Because you are interested in organ transplantation, we want you to be aware of important resources and services provided by the national transplant network. We also encourage you to learn more about transplant data and policies and to take part in the policy development process.

United Network for Organ Sharing (UNOS) is a not-for-profit organization that administers the national Organ Procurement and Transplant Network (OPTN). This is made possible through a contract with the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS). The OPTN and UNOS help the transplant community and patients like you by:

- coordinating the organ matching and placement process;
- collecting data about every transplant that occurs in the United States;
- developing organ transplant policy with input from medical staff, transplant patients, donor families, and living donors;
- creating educational material for professionals, patients, and the public; and
- increasing public awareness of the need for donated organs and tissues.

UNOS Patient Services

An important service is the UNOS toll-free Patient Services line: 1-888-894-6361 (**Please do not call this UNOS number to reach your transplant center**). Transplant patients, family members/friends, living donors, donor family members, and the public can call this number to:

- discuss general information about organ donation, living donation, the transplant process, transplant policies, and transplant data;
- receive a free patient information kit with helpful booklets, waiting list and transplant data, and a list of all transplant centers;
- ask questions about information on the UNOS Web site for transplant patients and living donors: www.transplantliving.org; and
- discuss problems you may have with a transplant center related to a possible policy violation.
(Call your center directly to discuss questions or concerns about your personal medical care.)

Data access

Understanding transplant data can help you make informed decisions about your transplant care. The Federal government makes sure that important data about all transplant programs in the U.S. are available to the public. You can access transplant survival rate data at: www.ustransplant.org (choose “Program and OPO Data”). You can view the size of waiting lists and the number of transplants completed at each transplant center at <http://optn.transplant.hrsa.gov> (choose “Data,” then “View Data Reports”).

Transplant Policies

Patients have a role in the transplant policy-making process. When OPTN/UNOS Committees develop policy proposals, you can provide your opinion through the public comment process. To comment on a proposal, visit the OPTN Web site at <http://optn.transplant.hrsa.gov> (choose “Policy Management,” then “Public Comment”).

At this Web site, you can sign up to be notified every time proposals are ready for public comment. If you do not have internet access, UNOS will mail the public comment information to you. Please send your request to: OPTN/UNOS Public Comment Coordinator; United Network for Organ Sharing; 700 N. 4th Street; Richmond, VA 23218.

UNOS is happy to provide you with helpful information as you address your transplant needs. If you have questions about the role of UNOS and the OPTN, the transplant system, transplant data, or transplant policies, please contact the UNOS Patient Services line at: 1-888-894-6361.