

OPTN/UNOS Patient Affairs Committee  
Interim Report  
August 2, 2012

I. Policy Rewrite Review

The Committee received a presentation introducing the Policy Rewrite Project. 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 with a focus on the following questions:

- Are there substantive changes in the policy
- Is the policy easily understood from a lay perspective
- Is the policy language clear and concise

Reviewers shared their input. Comments were overwhelmingly positive regarding the proposed formatting. The Committee found the new format to be:

- user friendly
- easy to follow
- well organized
- necessary tools or supportive documentation was easily accessible

The Committee made the following general requests:

II. Work Review

The Committee reviewed all current work as follows:

*Patient Notification:*

During the May Committee meeting, the Committee voted to work towards making distribution of the Patient Information Letter required for living donor candidates. The Living Donor Committee is reviewing consent for living donor candidates. Patient Notification of the UNOS Patient Services Line number could be addressed in conjunction with the comprehensive review of living donor consent by the Living Donor Committee. Currently, the subcommittee is reviewing the Patient Information Letter to ascertain if it can appropriately be used with living donors with its current format and wording. The Committee will share the consensus with the Living Donor Committee and determine how to proceed from there.

*Teen Adherence:*

The Teen Adherence Project is newly assigned work for the Committee. The goal of the project is to increase adherence to medical treatment plans among teens and young adults through the use of educational resources that:

- Are developmentally appropriate

- Are socially engaging
- Engage both the family and the healthcare team in the educational process
- Incorporate varying educational modalities, including social media, smartphone gaming and traditional written materials

The Committee determined to begin by developing standard curriculum for education. This curriculum would serve as the content guide for the development of educational resources using varying delivery modalities.

The Committee set up a subcommittee to begin working on the curriculum. This Subcommittee will report at the October Committee Meeting.

*What Every Patient Needs to Know – Organ Specific:*

This is a newly assigned project for the Committee. The Committee is aware of the value of the existing *What Every Patient Needs to Know* to the transplant community. The Committee was interested in identifying cost effective and efficient ways to update *What Every Patient Needs to Know*. One possibility is to develop small organ specific companion pieces of 2 – 4 pages, in a brochure format. The Policy Oversight Committee recognized the benefit of having pieces that could more easily be updated, but asked for documentation of the varying educational needs of patient by organ group. Dr. Amy Waterman of Washington University, Saint Louis MO, agreed to assist in developing a study of phone line contacts that could help to highlight education needs by organ. After reviewing the Phone Line and the types of information currently gathered in the Phone Line Database; Dr. Waterman suggested that the study should begin with an analysis of the data currently in the Patient Services Phone Line Database. The Phone Line Database currently contains more than 10 years of un-reviewed data. The Liaison to the Committee will work with UNOS Information Technology Department to lift the information from the Patient Services Phone Line Database into a format that is accessible and allows for manipulation and analysis of the available data. The Liaison will report on the progress with this effort at the October Committee Meeting.

*Social Media Subcommittee*

This Committee received a presentation on the benefits on potential risks to the rising use of social media within the transplant community. The Committee voted to assess methods for increasing public awareness of the importance of online safety and caution in all use of social media. The Subcommittee has met once and is working on a proposal to bring back to the full Committee during the October Committee Meeting.

III. Intra-Committee Work

Members of the Committee are involved in the following workgroups, which are led by other Committees:

*MAC subcommittee on education and awareness of patient options for kidney transplantation:*

This is a joint workgroup with Minority Affairs Committee (MAC). The focus of this workgroup is to develop guidance resources to be used by dialysis staff and nephrologists in making transplant referrals. The Workgroup has met once. Workgroup members will keep the Committee apprised of developments.

*TCC Education Group:*

This is a multi-committee collaboration with the Transplant Coordinators Committee (TCC) to define 'active and inactive' on the waiting list.

*TCC Policy Group:*

This is also a multi-committee collaboration with the Transplant Coordinators Committee (TCC) to develop policy and /or criteria for patient notification and center justification for having an inactive status after a as yet, undetermined number of days. A group task will be to determine an acceptable number of days for which a center can keep a patient inactive before having to make a final disposition.

Both the TCC Education and Policy Groups will meet in August to begin to ascertain the pattern for work. Committee members will participate on these calls.

IV. Upcoming Meetings

October 4, 2012 – Conference Call to begin reviewing Public Comment Proposals

October 22, 2012 – Face-to-face Meeting in Chicago