

OPTN/UNOS PATIENT AFFAIRS COMMITTEE INTERIM REPORT

April 5, 2012

I. Due Process Public Comment Review

The Committee received a presentation on the OPTN Bylaws Rewrite, Appendix L: Reviews, Actions and Due Process. Appendix L constitutes a substantive rewrite of the portion of the current Appendix A. This appendix addresses how the OPTN Contractor and the MPSC will review and act on potential violations and non-compliance.

The Committee felt the addition of the expedited review pathway would be beneficial to transplant centers. The Committee also felt that the language used and the organization of the rewrite made the content easier to understand and to navigate, when considered from the perspective of an average patient. The Committee acknowledges the challenges of lowering the reading levels in materials that represent a legal process and must incorporate clinical language.

The Committee voted in support of the rewrite and the associated substantive changes:
Yes – 14, No – 0, Abstain – 0

II. Introduction to the New Transplant Living Website

The Committee received an introduction to the newly redesigned Transplant Living website

www.transplantliving.org

Transplant Living is the patient focused arm of the UNOS family of websites. The new Transplant Living site has a new look as well as new features. The overview included demonstrations of how to access information within the site. In response to questions from the Committee; it seems that the usage numbers did not support continuation of a *During the Transplant* page.

During this role-out phase, Transplant Living is highlighting the *Stories of Hope* section. *Stories of Hope* allows transplant recipients to tell their stories. Readers may then vote for each story. During April 2012, the writer of the story receiving the highest number of votes will receive a complimentary IPAD. UNOS Communications has solicited help from the Committee with encouraging recipients to submit their stories.

The Committee made the following suggestions for the new website:

- Include resources for the visually impaired
- Provide a link to the Spanish version of Transplant Living
- Include an explanation of paired exchange under the Living Donation section

- Expand the search capability of the Support Group section to
 - Allow interstate searches for persons who might access services across state lines
 - Incorporate additional intended groups i.e. donor families, recipients, living donors etc.
- Link to the resource and support group pages on other transplant related sites such as Transplant Recipients International (TRIO)
- Link to the med action plan under medications
- Include link to www.mymedschedule.com under *Medications*
- Include phone applications that assist with medication management and compliance

The Committee will provide information on phone applications that are currently being utilized with success in the community.

III. Proposal to Require Documentation of Second Unique Identifier Used for Tissue Typing Materials (OPO Committee)

The OPO Committee has identified a potential breakdown in the organ labeling system. OPO's and recovering living donor centers are required to use two unique identifiers when labeling tissue typing specimens. However, there is no corresponding requirement that the two identifiers be included in the donor record. This proposal would require that OPO's and living donor recovery hospitals document all unique identifiers in the donor record. The Committee suggested clarification of what constitutes the donor record for this proposal. Based upon feedback received during the presentation, the intent is that the donor record would be any paperwork that accompanies the organ.

The Committee voted to support this proposal:

Yes – 14, No – 0, Abstain – 0

IV. Proposal for the Substantive Rewrite of Data Release Policies (Policy Oversight Committee)

The intent of this proposal is to bring the data release polices in line with current practice. The proposal would:

- Increase the amount of data by program that the OPTN Contractor may release
- Provide an appeals process should the OPTN Contractor refuse a data request
- Set's requirements for release of confidential information
- Allow the OPTN Contractor to release data by institution to any requestor
- Allow greater flexibility regarding release of information between institutions

This proposal does not change the requirements for release of personal information.

The Committee consensus is that the proposal provides balance in that it allows for the release of more information to the public, while also protecting personal data. The

Committee noted that the restrictive nature of current policy may create the perception of secrecy on the part of the larger community. The Committee also noted the potential challenges of releasing information to persons or outlets that may not have the background to accurately interpret it. From this vantage point, the Committee stressed the importance of continued education. The consensus from the Committee is that the more transparent the system, the better, overall.

The Committee voted to support this proposal:
Yes – 14, No – 0, Abstain - 0

V. Regional Presentation Overview

Regional Representatives met with the Liaison to review the Committee presentation for the Spring Regional Meetings.

VI. Committee Work

The Teen Adherence Proposal and the Organ-Specific What Every Patient Needs to Know (WEP) proposals will be reviewed during the April 9, 2011 Policy Oversight Committee (POC) meeting.

VII. Upcoming Meetings

- May, 2012 – No Conference Call in deference to the May face-to-face meeting
- May 21, 2012 – PAC Meeting, Chicago Illinois
- June 7, 2012 - PAC Conference Call

Policy Proposals for the May and June Meetings are available for review in the Meeting folders on SharePoint.