

OPTN/UNOS PATIENT AFFAIRS COMMITTEE INTERIM REPORT

January 5, 2012

I. The OPTN Bylaws Rewrite Project Review

The Committee met via Livemeeting to review the OPTN Bylaws Rewrite Project. The Committee received an overview of the project from the Bylaws Writer.

Committee members were assigned individual bylaws for review one month prior to the call. Reviewers were asked to complete a written version of the online review survey. Survey responses and overall perceptions were to be shared with the Committee during the conference call. The Committee then, had opportunity to give input on each Bylaw. The Bylaw Writer was present and participated in the discussion. Each written review was forwarded to the Bylaw Rewrite team via the email at bylaws.rewrite@unos.org

Overall, Committee input was extremely positive. In comparison to the current bylaws, reviewers found the rewritten bylaws to be much easier to understand and to follow. The language was very user friendly. The formatting was easy to follow. Patients and families felt that lay persons, having no transplant background, would be able to understand the rewritten bylaws with very little difficulty. Reviewers liked having a glossary.

Reviewers requested hyperlinks when a bylaw referenced another bylaw or policy. Reviewers also requested hyperlinks to the glossary when new technical terms were used. Reviewers requested changes in wording, punctuation, and structure in various bylaws for clarification and consistency. Many of these requests were captured in the verbal discussion with the bylaw writer.

II. What Every Patient Needs to Know(WEP) Update

The newly rewritten WEP is now available in a limited printing. Because of the demand for the book, hard copies will only be shared with persons who were involved in the writing of the new WEP. Copies will be provided for the Committee after the full printing order is received.

The J.C. Walter Transplant Center at The Methodist Hospital (TMH), Houston TX requested that the Committee investigate possibilities for a mechanism for TMH to pay for printing of 1000 copies of WEP for use within their center, during the interim, while waiting for Astellas authorization.

It was determined that Creativeaid can provide a print-on-demand service which allows transplant programs to individualize WEP through advertisements. These individualized books could then be ordered in bulk at a reasonable price for the center. This service was

provided for TMS. Creativeaid is exploring options for offering print-on-demand as a service to the OPTN.

III. Upcoming Meetings

The Committee will have conference calls on the following dates:

- Thursday February 2, 2012 3:00 – 5:00 PM EST
 - Due Process Rewrite Process
- Thursday March 1, 2012, 3:00 – 5:00 PM EST

Chicago Meeting Date

- Monday April 30, 2012 – Meeting,