

OPTN/UNOS Patient Affairs Committee - INTERIM REPORT

Chicago Illinois –November 9, 2009

- The Committee discussed the proposal from the Policy Oversight Committee to Improve the Variance Appeal Process. As the Committee did not identify any issues relating to patients, they approved the proposal with a vote of 19-0-0.
- UNOS Staff presented the Valuable Consideration Proposal that has been distributed by the Living Donor Committee, which was released for Public Comment on 11/13/2009. The Committee did not find any problems relating to patients. The proposal was approved by a vote of 19-0-0. The Liaison to the Living Donor Committee presented updates on Living Donor Follow up. Living Donor follow up is a patient quality issue which is of concern for PAC.
- UNOS staff presented concerns raised by a few transplant programs regarding the Patient Notification Letter, which the centers found to be misleading to patients. The committee discussed their concerns and a subcommittee was established to review the letter and make recommendations for wording clarification.
- Updates were given on the status of the Kidney Allocation System and the Pancreas Allocation System. Both of these are areas of interest to PAC .
- The Committee discussed the development of Post-transplant educational materials and will be further addressed in the December 1, 2009 conference call.
- UNOS staff provided a SharePoint Tutorial; as PAC is transitioning to using SharePoint.
- UNOS Director of Patient Affairs presented Ethics in Allocation Policy Development. The Presentation provided an introduction to Ethical Values and Distributive Justice as reflected within OPTN/UNOS.
- UNOS Director of Patient Affairs provided an overview of legislative accomplishments over the last 5 years, and current pending legislation which is of interest to transplant patients.
- UNOS staff presented summary of the TCC Survey which evaluated practices and timing for listing patients as inactive on the waiting list. The purpose of the study was to identify best/most common practice for listing patients as inactive across organ systems.
- A PAC Committee Member and Liver Transplant Surgeon presented a summary of the issues in Regional Allocation of Livers. Significant discussion was generated, specifically around regional allocation allowing greater access to organs. A decision was made to assess ways that PAC might become more involved in these discussions.
- Freda Wilkins, new UNOS liaison to PAC attended meeting.

Ray Gable,
Midwest Transplant Network

Laura Ellsworth, Kidney Recipient
Vancouver WA

Freda Wilkins

UNOS Staff/Patient Services Coordinator