# OPTN/UNOS Policy Oversight Committee Meeting Minutes August 16, 2017 Conference Call

# Jennifer Milton, BSN, CCTC, MBA, Chair Elizabeth Pomfret, MD, PhD, Vice Chair

## Introduction

The Policy Oversight Committee (POC) met via Citrix GoTo on August 16, 2017 to discuss the recent Executive Committee conference call and to receive an update on the SRTR Visiting Committee. The following is a summary of the Committee's discussions.

### 1. Committee Projects

The POC has no currently active committee projects.

### 2. Other Significant Items

### De-Brief on Executive Committee Call

The POC chair reported to the Committee the events and discussion at the Executive Committee call on July 28, 2107, where she presented the Committee's recommendation on the 13 public comment proposals and three committee projects. The Chair also shared a letter that the POC received from the Liver Transplant Alliance outlining some of their concerns about the liver proposal, reporting that she received this letter midway through the call where the POC was reviewing these proposals.

She further reported that 11 of the 13 public comment proposals were placed on the Executive Committee's consent agenda based on the POC's review of the proposals and subsequent recommendations. These 11 proposals were:

- 1. Addressing Approved Transplant Fellowship Training Programs Bylaws Membership & Professional Standards Committee
- 2. Broadened Allocation of Pancreas Transplants Across Compatible ABO Blood Types -Pancreas Committee
- 3. Guidance on the Benefits of Pancreas After Kidney (PAK) Transplantation Pancreas Committee
- 4. Implementation of A2\_A2B to Blood Group B Deceased Donor Kidney Transplant Allocation Guidance - Minority Affairs Committee
- 5. Improving Allocation of Dual Kidneys Kidney Committee
- 6. Improving Allocation of En Bloc Kidneys Kidney Committee
- 7. System Optimizations to Expedite Organ Allocation and Increase Utilization OPO Committee
- 8. Living organ donation by persons with certain fatal diseases who meet the criteria to be living organ donors Living Donor Committee
- 9. Congenital Heart Disease Exception Request Guidance for Review Boards Thoracic Committee
- 10. Review of HLA Tables (2016) Histocompatibility Committee
- 11. Revisions to Pediatric Emergency Membership Exception Pediatric Committee

The Executive Committee discussed these two of the proposals that the POC had recommended be release for public comment:

- Revise White Paper Addressing Financial Incentives for Organ Donation Ethics Committee
- Enhancing Liver Distribution Liver Committee

The Executive Committee approved the consent items for release for public comment. After considering the POC's recommendations to the Exec Comm that both of the discuss items go out for public comment, the Executive Committee ultimately voted that the Ethics Committee white paper should *not* be released for public comment, while the Liver proposal was released for public comment.

Several POC members expressed concern over the Executive Committee's decision to not release the Ethics Committee's white paper and questioned the POC's role in the process. Specifically, a member questioned why, if the POC's role is to manage resources and the Committee had decided that a substantial amount of resources had already been expended to develop this white paper, the Executive Committee would go against the POC's vote at this point in the process? Several expressed concern that this was a poor use of volunteer time spent developing the paper and then additional time spent reviewing the project, and ultimately the public comment proposal, only to have it pulled at this late point in the process. There seemed to be a general concern that the Executive Committee simply wanted a "rubber stamp" on the proposals and that the expertise of the POC (and expenditure of time) was not really necessary. Specifically, the POC members expressed the need to figure out as an organization how to ensure that this does not happen again.

The Chair then reported that the Executive Committee approved all three of the new projects that the POC had recommended to move forward in the Evidence Gathering status, as shown below:

- 1. Update Guidance for ABO Subtyping Organ Donors for Blood Groups A and AB (Operations and Safety)
- 2. Extra vessels: Reducing reporting burdens and clarifying policies (Operations and Safety)
- 3. Informed Consent Clarification (DTAC)

#### SRTR Visiting Committee (SVC) Update

The Chair then gave an update on her recent participation with the SRTR Visiting Committee (SVC). She provided a detailed overview of the new key initiatives and SRTR updates that are available to the community, including:

- "New Reports" Public & Internal
- Improvements to Beta Site
- Waiting List Mortality & Transplant Rate Ratio & Tiers
- Patient Input
- Decision Aid for Kidney Recipients
- Pediatric Outcomes Reports
- Liver Models
- OPO Yield Models

The update included information about the development of a decision aid for kidney recipients and the patient input provided, including the involvement of 6 kidney focus groups with 19 patients and 4 family members as well as a patient survey distributed to 3 Advocacy Groups (NKF, TRIO, Transplant Families).

### Proposal/Project Review Metrics

The Chair also briefly reported back to the Committee about the results of their previous discussion regarding project and proposal review metrics. The discussion resulted in guidelines for the appropriate workload when POC member must complete project or public comment proposal reviews. She reported that going forward, review assignments would be no more than 4 proposals or projects to review per person, and that a minimum of seven days would be provided to complete the reviews. She also reported that the POC liaison and research liaison were working on creating the survey in REDCap to add functionality that would make it easier to stop mid-review and complete the survey later. POC members had expressed frustration in not being able to figure out where they had stopped when coming back to the survey after stopping mid review with the current Survey Monkey tool.

The meeting adjourned at 4:30 pm.

#### **Upcoming Meetings**

- Friday, September 15, 2017, 3:00 PM ET, conference call
- Friday, October 6, 2017, 8:30 AM 3:30 PM CENTRAL, In-person, CHICAGO, IL
- Wednesday, October 18, 3:30 PM ET, conference call
- Friday, November 17, 3:00 PM ET, conference call
- Wednesday, December 20, 3:30 PM ET, conference call