

Meeting Summary

OPTN Patient Affairs Committee
Meeting Summary
January 21, 2020
Conference Call

Darnell Waun, MSN, Chair Garrett Erdle, MBA, Vice Chair

Introduction

The Patient Affairs Committee (PAC) met via Citrix GoTo teleconference on 1/21/2020 to discuss the following agenda items:

- 1. OPTN Policy Making Process
- 2. Public Comment Review Assignments
- 3. Ethics Committee Covert Factors Workgroup

The following is a summary of the Committee's discussions.

1. OPTN Policy Making Process

The Committee reviewed the OPTN policy making process including:

- The OPTN's policy governance including NOTA, the Final Rule, OPTN Contract and OPTN Bylaws
- Policy development process and cycles
- Public comment
- Committee review and feedback

Summary of discussion:

The Chair reminded committee members they can provide feedback as individuals in addition to contributing to committee feedback.

One committee member asked how the PAC relates to UNOS Ambassadors. It was clarified the PAC is an OPTN Committee and comments on public comment items as a group. UNOS Ambassadors are individuals and are not asked to comment on OPTN policy items as a group.

Next steps:

Committee members are encouraged to attend upcoming public comment webinars and regional meetings in their area.

2. Public Comment Review Assignments

The Committee reviewed the small-group strategy the PAC has used in the past to provide feedback on public comment proposals. Committee members were assigned to review groups, one to review the Kidney Committee's *Medical Urgency* proposal and another to review the Minority Affair Committee's *Socioeconomic Data Collection* proposal. Committee members were encouraged to review both proposals and any other public comment documents.

Next steps:

Committee members will review their assigned proposals and submit feedback to their group leads by January 31. The group leaders will compile the feedback to present to the full committee at the February 20 meeting in Chicago.

3. Ethics Committee Covert Factors Workgroup

The Committee was informed the Ethics Committee is forming a workgroup to work on a project to provide patients with information that should be considered to help make informed decisions relating to donation and transplantation. The Ethics Committee is asking for some PAC members to join the workgroup.

Next steps:

Interested committee members will be forwarded to the Ethics Committee Point of Contact for followup.

Upcoming Meeting

• February 20, 2020 - Chicago, IL