

**OPTN/UNOS Patient Affairs Committee  
Meeting Minutes  
February 21, 2017  
Conference Call**

**Kristie Lemmon, MBA, Chair  
Darnell Waun, MSN, RN, Vice Chair**

**Introduction**

The Patient Affairs Committee (PAC) met via Citrix GoToTraining teleconference on 02/21/2017 to discuss the following agenda items:

1. Policy Oversight Committee Update
2. Public Comment Primer
3. Other Significant Items

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

**1. Policy Oversight Committee Update**

The Vice Chair provided an update on projects recently approved by the Policy Oversight Committee (POC).

Summary of discussion:

There were no questions.

Next steps:

The Vice Chair will provide an in-depth update at the next PAC meeting.

**2. Public Comment Primer**

Committee leadership requested more education on OPTN policies and related OPTN topics for PAC members. As a result, the Committee is engaged in a monthly policy learning series to ensure they are comfortable with OPTN policies and are able to contribute informed feedback when reviewing other OPTN Committee proposals. This month's topic was on public comment.

Summary of discussion:

UNOS staff informed the PAC of the importance of public comment, the process, and how to get patients more involved. The OPTN/UNOS rarely received feedback from candidates, recipients, donor families, living donors, recipient parents or other members of the general public. There may be proposals in which the only patient feedback the sponsoring Committee receives is from PAC. The PAC was reminded that they represent the general public, so sponsoring Committees really value their feedback. UNOS staff reviewed the policy development process and where public comment fits in.

The following barriers were identified as to why patients might not participate in OPTN/UNOS public comment:

- Patients don't know about public comment
- Proposals are not written at a level patients understand
- How should patients comment? What feedback are we looking for from patients?
- People may not know who UNOS/OPTN are
- General public may feel intimidated or overwhelmed
- Not empowered or knowledgeable enough to respond

- Patient population may not know outcome of proposals-were their comments considered? Did the proposal go out for another round of pc?
- Controversial proposals can be intimidating to provide feedback on
- Many patients might not feel connected enough to the process (or understand the process) to participate
- Proposals might come across biased; patients might not consider what cons might be
- Patients unaware of timeline to make and implement changes
- We may not be reaching patients effectively
- Donor families don't have much of a voice-OPTN policy touches procurement, but not really interaction with donor families

UNOS staff shared tips on how to prepare to provide comment during Committee public comment proposal reviews:

- Read the proposals
- Ask liaison context or policy questions, definitions or acronyms you do not understand
- Be considerate of opposing viewpoints, but challenge each other
- If you do not agree with PAC's decision to support/oppose a proposal, your voice can still be heard. Post a comment as an individual
- Challenge the presenters-ask questions

UNOS staff suggested questions members could ask when evaluating proposals that would be relevant to the patient perspective:

- Are patients going to be directly impacted?
- Who will benefit from this proposal?
- Who will be disadvantaged?
- What alternatives did the Committee consider?
- Has the Committee considered unintended consequences?
- How urgent is this issue?
- How will the transplant community educate patients about the changes?

### **3. Other Significant Items**

The PAC discussed logistical details for the upcoming in-person meeting March 13<sup>th</sup> in Chicago, IL.

#### **Upcoming Meeting**

- March, 2017