

**OPTN Patient Affairs Committee
Meeting Summary
December 17, 2019
Conference Call**

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

Introduction

The Patient Affairs Committee (PAC) met via Citrix GoTo teleconference on 12/17/2019 to discuss the following agenda items:

1. Board of Directors Wrap-up
2. Review Proposal At-A-glance
3. Public Comment Process Review
4. Discuss Patient Information Letter

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

1. Board of Directors Wrap-Up

The PAC Chair gave an update on the discussions and decisions made at the Board of Directors (BOD) meeting from December 2nd – 3rd, 2019.

Summary of discussion:

The Chair informed the Committee that the BOD passed all the proposals that PAC contributed to. In terms of potential opportunities for PAC involvement, there were discussions during the Chair dinner about how PAC can contribute to the work of other OPTN Committees. It was acknowledged that there may be an opportunity for the PAC to work with the Ethics Committee on a potential white paper regarding a candidate's understanding of organ transplantation. Also, there may be an opportunity to look at clinical guidance regarding immunizations for transplant patients. There was interest from DTAC leadership about PAC's involvement with revisions to the PHS increased risk requirements. It was noted that there are four PAC members who have volunteered for this initiative. Last, the BOD approved the newly- modified PAC charge without any further changes.

2. Review Proposal At-A-Glance

The Committee discussed a revised version of the proposal at-a-glance based on a template from the recently approved kidney proposal (removing DSA and region by adding nautical mile distance). There have been further revisions to the proposal at-a-glance based on feedback from the PAC and UNOS Ambassadors earlier this year. Some of these recommendations can be easily made, but others will take more time to develop.

Summary of discussion:

Overall, the Committee thought that the newly revised proposal at-a-glance was better and easier to read. One Committee member noted the need to be careful in the "Terms you need to know" section. The terms outlined in this section need to be made clearer in order for the public to understand them. Another member was also concerned regarding the reading level of this document, and stated that the

reading level should be more basic. To this point, a member reminded the Committee that this document should just be an overview, and only preview the details within a public comment document.

One Committee member thought that this new document was a step in the right direction. This member asked questions regarding who would be developing and writing the documents. Because it is currently UNOS staff developing the documents for each proposal, this member suggested that the donor or patient representative from each OPTN Committee help write the proposals at-a-glance. However, there were concerns regarding the logistics of having each patient or donor representative write the proposals at-a-glance, especially since each proposal tends to undergo multiple revisions.

UNOS staff also shared that the OPTN glossary can be found on the OPTN website. One PAC member suggested moving the glossary in each abstract to the top of the page so that this it is predominately featured.

Another Committee member stated that the OPTN should get better at distributing webinar information to the PAC so that those members interested can attend. UNOS staff encouraged feedback on how best to improve this communication with the PAC.

Next Steps

Staff will continue to gather feedback from the PAC, and utilize this feedback to further revise the proposal at-a-glance.

3. Public Comment Process Review

The PAC Chair and UNOS staff gave an overview of the OPTN public comment cycle. Discussion revolved around past practices for gathering and developing PAC feedback on certain proposals, and new platforms for collaboration.

Summary of discussion:

The Chair discussed the small-group strategy PAC has used in the past to provide feedback on public comment proposals. Since Basecamp will no longer be used, the Committee discussed what new methods of collaboration or platforms can be used. Most Committee member agreed that SharePoint is not a great collaboration tool, and acts more as a depository for documents.

A Committee member suggested LinkedIn Groups, because other OPTN Committees are using this platform. Another Committee member suggested using Microsoft teams. There was some discussion about licensing and whether Microsoft teams would be secure. Clarification was provided that other organizations use Microsoft teams because it is protected and in compliance with their organizations' privacy laws. Also, if an organization has access to Microsoft Office suite, then they should already have licensing for this product.

Other suggestions included creating email groups, holding conference calls, or providing feedback via comments in Sharepoint documents. There was not a lot of support for conference calls, unless it was used to facilitate discussion and feedback. However, email groups may result in long email chains and threads, and can therefore be cumbersome.

Next steps:

Staff will look further into the PAC's suggestions for new platforms or methods of collaboration prior to Spring 2020 public comment.

4. Discuss Patient Information Letter

As a result of the new OPTN contract, the OPTN has asked PAC to approve branding changes to the patient information letter sent by transplant hospitals. Some PAC members have already offered feedback on how to improve this patient information letter. The Committee discussed this feedback and made suggestions for improving the letter.

Summary of discussion:

Committee members suggested to simplify the letter, improve readability with bullet points, and reorder the content. Most Committee members agreed with those suggestions, and that the modified patient information letter would be far better and easier to comprehend. However, Committee members agreed that more revisions might be necessary and that they have not had enough time to review the letter. The Chair noted if there was a need for more substantive revisions from PAC, the PAC would need more time to make such revisions. The Committee agreed with the Chair, and that the content needs to be worked on for improved readability.

A suggestion was made to add the patient information letter as a cover letter for each booklet that a patient receives. Clarification was provided that current OPTN policy requires transplant hospitals to provide the patient information letter under certain circumstances. One Committee member working as a coordinator stated that they had not received any negative feedback on the patient information letter currently being used.

Next steps:

For now, the patient information letter will be sent for internal UNOS review and to HRSA for approval. The PAC will continue to work on this letter at their in-person meeting in February 2020.

Upcoming Meeting

- January 21, 2020