

**OPTN Patient Affairs Committee
Meeting Minutes
October 28, 2019
Conference Call
Darnell Waun, MSN, Chair
Garrett Erdle, MBA, Vice Chair**

Introduction

The Patient Affairs Committee (PAC) met via Citrix GoTo teleconference on 10/28/2019 to discuss the following agenda items:

1. Transplant Terminology Review: Update
2. Patient Affairs Committee Charge
3. PAC Task Force

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

1. Transplant Terminology Review: Update

The PAC was given a brief update regarding the project to modify transplant terminology. Donate Life America (DLA) had suggested that PAC utilize finalized transplant nomenclature in OPTN communications, policy, and guidance. The Committee discussed next steps for this project and how best to collaborate with DLA moving forward.

Summary of discussion:

Overall, Committee members voiced approval that a document detailing appropriate transplant terminology and nomenclature would be an excellent resource for OPOs, since there are many different words being used amongst OPOs and volunteers working with OPOs. There was discussion about how these changes are communicated to the public, specifically to physicians. One member was adamant that despite there being older generations of physicians using improper terms, all physicians should adopt appropriate terminology. The general sense from this member was that change and impact in the field of transplantation begins with physicians. By this means, some on the Committee discussed that the focus should be on how the PAC may utilize this document publically, not just for internal OPTN use. The HRSA representative did comment that HRSA also maintains a list of glossary terms separate from the OPTN, though there may be discrepancies between these two glossaries and DLA's glossary.

Next steps:

UNOS staff will reach out to DLA for an update from them, including possible next steps.

2. Patient Affairs Committee Charge

The Committee reviewed an updated version of the PAC charge, and provided feedback. The modified PAC charge will be submitted for approval to the Board of Directors in December 2019.

Summary of Discussion

The Chair reviewed the updated PAC charge with the Committee. Most members agreed that they liked the proactive tone and alignment with the strategic goals. One member asked whether the PAC needed to define "educational content". Many members agreed to leave this term broad in case opportunities

arise in which the PAC can be charged to lead such initiatives. There was concern from one member that the PAC does not develop educational content, but members stated that they have in the past. SRTR commented that they are keen in developing patient educational materials in conjunction with the OPTN and PAC. Another member opined that the term “patient groups” is quite narrow, and that saying “patient groups” can be more inclusive. This member suggested that since the PAC wants OPTN content to affect people who are not only patients, that “patient and patient groups” be deleted and replaced with “patient perspective”.

The members voted unanimously to approve the charge in its modified state as shown below:

All OPTN activities impact transplant patients either directly or indirectly. The OPTN Patient Affairs Committee advises the OPTN Board of Directors and engages with its committees from the perspectives of transplant candidates, recipients, living and deceased donors, and families. The Committee works independently, or with other Committees, to develop initiatives and policy proposals of significant importance to patients, including transplant access, outcomes, and safety. The Committee develops and provides patient perspective on OPTN educational content.

3. PAC Task Force

The Committee discussed how to deploy teams of PAC members onto other OPTN Committees. The intent of the teams would be to attend conference calls as able, and to represent the patient perspective on these calls. The teams would also receive feedback and bring this back to the PAC for consideration. However, this would not be an appointment to another Committee, and would not replace any patient members on those Committees.

Summary of Discussion

Members began submitting their preferences for which Committees they would like to attend. There was concern from PAC leadership though that PAC members do not overstep their purview when attending other OPTN Committee calls since these Committees already have patient representatives.

Next Steps

Committee members will reach out to staff to indicate their preference for which OPTN Committee they would prefer to listen to. PAC leadership will also reach out to the leadership of these other Committees in order to convey the nature of PAC’s involvement when attending their conference calls. UNOS staff will collect an updated calendar of when other Committees are meeting and the call information.

Upcoming Meeting

- November 19, 2019

Attendance

- **Committee Members**
 - Diego Acero
 - Garrett Erdle
 - Sarah Koohmaraie
 - Marvin Lim
 - Beth Rubinstein
 - Jim Sharrock
 - William Tribett
 - Darnell Waun
 - Phil Williams
 - Chris Yanakos
- **HRSA Representatives**
 - Melanie Deal
 - Janet Kuramoto-Crawford
- **SRTR Staff**
 - Katie Audette
 - Allyson Hart
- **UNOS Staff**
 - Hannah Byford
 - Chris Wholley
 - Sara Rose Wells
- **Other Attendees**
 - Valinda Jones