

**OPTN Patient Affairs Committee
Meeting Minutes
September 17, 2019
Conference Call**

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

Introduction

The Patient Affairs Committee (PAC) met via Citrix GoTo teleconference on 09/17/2019 to discuss the following agenda items:

1. Appropriate Terminology Use in Transplantation: Continued Discussion
2. Patient Affairs Committee Charge: Update
3. OPTN Research Orientation
4. OPTN Policy Oversight (POC): Update

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

1. Appropriate Terminology Use in Transplantation: Continued Discussion

UNOS staff gave a brief update regarding the "terminology to be used in transplantation" project. This project was briefly discussed during the in-person interview, whereby there was support for pursuing a guidance document or white paper. However, in order to ensure that PAC does not duplicate their efforts with Donate Life America (DLA), UNOS staff has reached out to DLA for further information.

2. Patient Affairs Committee Charge: Update

UNOS staff gave a brief update regarding the update to the PAC charge required as part of the new OPTN contract. There was discussion at the PAC in-person meeting, whereby it was decided to replace UNOS to OPTN, and specify both living and deceased donors. The updated PAC charge was submitted to the Executive Committee (ExCom) for review, and feedback is expected from them within the next month.

Summary of discussion:

One member asked when the last time the Committees reviewed their charge. In response, UNOS staff clarified that it had been a while since the charge was revised (perhaps since first created), and that the push to have charges reviewed stems from the new OPTN contract. Under the new contract, ExCom wants to make sure that the charges are in alignment with the purpose, charter or scope of the Committee. As of yet, ExCom has not done a thorough review of the PAC charge, which may be done offline. A Committee member requested that the updated charge be circulated to the Committee members prior to their call in October.

Next steps:

UNOS staff will send out the revised PAC charge to the Committee for their review.

3. OPTN Research Orientation

UNOS staff provided an overview of how OPTN research staff support project development and how this differs from the support provided by the Scientific Registry of Transplant Recipients (SRTR).

Summary of discussion:

UNOS staff went into detail about how data reports are requested, and how the data analysis is utilized by OPTN Committees (such as with pediatric priority in pancreas allocation). Such data requests will focus on identifying a problem, and then finding solutions to address these issues (such as through policy or via the creation of visualization tools). Staff reiterated however the most important aspect of the data request is investigating the issue, whether that is recipient or donor characteristics. Staff also clarified that they are actively pursuing ways in which to describe the data and terminology used throughout the data analysis, such as “patient years”. The goal is to present data in such a way as so everyone is able to understand the analysis and conclusions.

One Committee member asked whether there would be a charge for requested data not intended for OPTN or Committee use. Though staff said there can be a charge, typically data requests submitted through the online website are provided at no cost. Another member was advised that they could submit a data request to specifically look at the impact of 500NM on kidney allocation for populations located on the East Coast versus West Coast.

4. OPTN Policy Oversight (POC): Update

The Vice Chair of the PAC gave a brief update regarding the recent discussions at the OPTN Policy Oversight Committee, including the selected themes: continuous distribution, more efficient donor/recipient matching to increase utilization and improved equity for multi-organ and single organ candidates.

Summary of discussion:

There was a good deal of discussion about the POC selected themes and the PAC members’ views of how these were address at regional meetings. Several members voiced concerns that more efficient donor/recipient matching and the idea of continuous distribution was not a topic of discussion or brought up by anyone at the regional meetings. Most PAC members also viewed their regional meetings as contentious, and that the meetings lacked a “patient-centered focus”. A few members whom had attended previous regional meetings noted that this year, the patient’s voice was not heard at any of the Fall 2019 regional meetings they had attended. UNOS staff stated that they would bring these concerns and feedback back to policy leadership for further evaluation and consideration.

Upcoming Meeting

- October 15