

**OPTN Patient Affairs Committee
Meeting Summary
April 20, 2021
Conference Call**

**Darnell Waun, R.N., M.S.N., Chair
Garrett Erdle, M.B.A., Vice Chair**

Introduction

The Patient Affairs Committee met via Citrix GoToMeeting teleconference on 04/20/2021 to discuss the following agenda items:

1. Update and Discussion – OPTN Regional Review Project

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

1. Update and Discussion – OPTN Regional Review Project

Matthew Weiss, MD, MBA, from Ernst & Young (EY) consulting firm presented on the existing eleven region structure that comprises the OPTN. EY has been charged with investigating what the current state of the regions are, what are they doing well, where are they falling short, and if alternative structures could better accomplish their goals. EY requested the PAC's feedback on the current state of the region system and how the structure could be improved.

Data summary:

EY identified five guiding principles in developing an alternative governance model as maximize benefits, accountability and effectiveness, community engagement, inclusive participation, and allocation equity.

Preliminary research, including the OPTN Regional Review Feedback in Summer 2020, revealed gaps within the four primary functions of the OPTN which are representation, communication and feedback, operations, and data analysis.

Summary of discussion:

A member inquired about the 480 OPTN members that were depicted in the presentation, the primary concern was that the OPTN represents a vast community beyond the 480 members. PAC members felt encouraged by a system that allowed greater participation from more than just the existing 480 OPTN members.

While not a result of the regional structure, a member noted that the regional meetings discuss complex policy and clinical implications that create a barrier to patients. Another member echoed that the majority of their time is spent trying to look up acronyms in order to understand what is going on as opposed to being able to contribute the patient perspective. Members shared that these meetings can be overwhelming, especially since the majority of medical professionals already know each other so patients sometimes struggle trying to find a way to fit in and contribute in a meaningful manner.

The Vice Chair identified that providing patients with a louder voice would only be a positive. It was suggested to take time during the Regional Meetings to discuss a topic of importance to patients and led by patients. Furthermore, it was viewed that the OPTN should be able to ensure consistent best practices around patient communication across transplant centers, regardless of region.

A member expressed that the regional platform should be utilized as a place to communicate amongst members and was concerned that if there were less regions then it is possible that voices could be lost. This member was supportive of a broad regional structure and against one that was too centralized or top down.

Alternatively, it was suggested to emphasize patient participation in the OPTN earlier to gain experience patients can use in Committee participation. The Committee Chair praised the UNOS Ambassadors program for its ability to engage the community and identified that this program would be a stepping stone to engage more patients in the OPTN prior to joining a Committee and participating actively in the regional structure.

Additionally, members expressed frustration over inconsistent listing criteria from transplant centers. Members shared that the metrics of small transplant centers would be more heavily impacted from a possible bad outcome whereas larger transplant centers could take more risk in listing patients. While this issue would not be adjudicated through a different regional structure, members would like to see a system that is consistent across regions.

Members discussed the challenges associated with equity and accessibility for people to participate in the regional structure, especially in more rural communities. This called to question if the OPTN needs representation based on population density, similar to the House of Representatives, or if policy decisions would be better made through modifications to the existing system.

A member praised the virtual environment of the recent regional meetings because it allowed members to attend more than just their regional meeting and gain a better understanding of concerns elsewhere in the country. Alternatively, another member missed the ability to connect in person and dive further into discussion with members of the community.

Next steps:

If members have any additional comments or concerns they would like to be heard, please email UNOS staff and it will be shared directly with EY.

Upcoming Meetings

- May 18, 2021
- June 15, 2021

Attendance

- **Committee Members**
 - Darnell Waun, Chair
 - Garrett Erdle, Vice Chair
 - Chris Yanakos
 - David Skinner
 - Diego Lovell
 - Eric Tanis
 - James Sharrock
 - Julie Ice
 - Julie Siegel
 - Kenny Laferriere
 - Molly McCarthy
 - Sarah Koohmaraie
 - Stephanie Little
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Abby Fox
 - Chelsea Haynes
 - Kaitlin Swanner
 - Laura Schmitt
 - Pete Sokol
 - Sara Rose Wells
- **Other Attendees**
 - Betsey Brada
 - Julie Spear
 - Justine Van Der Pool
 - Matthew Marolla
 - Matthew Weiss