

OPTN Patient Affairs Committee

Meeting Summary

August 23, 2021

Conference Call

Garrett Erdle, M.B.A., Chair

Molly McCarthy, Vice Chair

Introduction

The Patient Affairs Committee met via Citrix GoToMeeting teleconference on 08/23/2021 to discuss the following agenda items:

1. Opening Remarks and Welcome
2. Regional Meeting Debrief and Discussion
3. Ethics Committee Presentation: Ethical Considerations of Continuous Distribution in Organ Allocation
4. Day 1 Debrief and Closing Remarks

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

1. Opening Remarks and Welcome

The Committee Chair introduced the Committee's leadership team and members provided a brief introduction. UNOS staff gave a quick overview of what to expect in the meeting and encouraged participation.

2. Regional Meeting Debrief and Discussion

UNOS staff provided a quick overview of the regional meetings and encouraged members to share their experience and feedback.

Summary of discussion:

Members shared their experience attending both in person and virtual regional meetings. Members gave advice about what to expect at a regional meeting, encouraged new members to make connections, and emphasized the unique patient voice and encouraged peers to feel empowered to speak up and engage in the conversation.

Next steps:

There are seven remaining regional meetings. UNOS staff encouraged members to attend and feel comfortable joining a different regional meeting if they are unable to attend their own.

3. Ethics Committee Presentation – Ethical Considerations of Continuous Distribution in Organ Allocation

Andrew Flescher, the OPTN Ethics Committee Vice Chair, presented the white paper *Ethical Considerations of Continuous Distribution in Organ Allocation*. A Committee member provided feedback from their workgroup to initiate the conversation.

Summary of discussion:

A Committee member initiated the conversation by sharing the feedback from the designated review group. The review group agreed with the vast majority of the content in the white paper and had additional questions about the maintenance, revision, and oversight of this new type of allocation framework. The presenter added that the Ethics Committee expresses concern in the paper over their role as the primary voice of ethical values and encouraged patients to share these concerns.

A member emphasized the importance of transparency in communicating this new allocation system in a manner that can be understood by the patient. However, another member disagreed stating that they feel better equipped to understand their place in continuous distribution than they did in a classification-based system.

A member inquired about the timing of this paper and why it was not released ahead of the Lung Committee's continuous distribution policy proposal. The presenter responded that additional time was necessary in order to provide a very thoughtful and robust analysis of the ethical considerations.

There was also a suggestion to include additional background on how the OPTN has gotten to this point. UNOS staff responded that through the white paper's intensive review process it was determined that the background was sufficiently provided at a general level without going into more organ specific scenarios as this white paper is meant to be a guidance document for all organ specific committees.

A member commented that gaming the system occurs when patients have financial resources that allow them to list at multiple centers therefore causing an issue of equity. The presenter agreed with this point and identified the greater issue is that this type of manipulation is allowable practice within the system.

A member emphasized the goal of transplanting as many patients as possible without geographic limitations and. The presenter responded that this focus on utility has both a cost and benefit, which needs balancing by equity based prioritizations.

A member highlighted the increased confidence they felt in continuous distribution from reading the Ethics Committee's white paper, but expressed concern on how the community will know if this system is successful and how it will be modified if it is not successful. The presenter shared that the Ethics Committee issued some critique of incrementalism but also understood its role in allowing changes to be made after the fact. A member countered that since the organ specific committees are having the correct discussions and modeling shows an improvement it is difficult to provide a critique of a system before implementation and data analysis.

Next steps:

UNOS staff will compile the feedback from today's conversation to develop the official public comment for the committee. If members have any additional questions or comments on the proposal, please reach out to UNOS staff.

4. Day 1 Debrief and Closing Remarks

Committee members provided advice on ways to engage in the meeting and the conversations going on in the chat. Other members shared their feedback from the meeting and identified potential gaps in understanding, such as historical relevance and national impact. Members shared some resources to assist each other and continued a dialogue on importance issues facing the patient population.

Upcoming Meetings

- August 24, 2021
- September 21, 2021
- October 19, 2021
- November 16, 2021
- December 21, 2021

Attendance

- **Committee Members**
 - Anita Patel
 - Betsey Brada
 - Chris Yanakos
 - Christopher Woody
 - Darnell Waun
 - David Skinner
 - Diego Acero
 - Earl Lovell
 - Eric Tanis
 - Garrett Erdle
 - James Sharrock
 - Julie Ice
 - Julie Spear
 - Kenny Laferriere
 - Molly McCarthy
 - Sarah Koochmaraie
 - Sejal Patel
- **HRSA Representatives**
 - Jim Bowman
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Abby Fox
 - Eric Messick
 - Kristina Hogan
 - Laura Schmitt
 - Lindsay Larkin
 - Sara Rose Wells
 - Susan Tlusty
- **Other Attendees**
 - Andrew Flescher