

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

**Garrett Erdle, M.B.A., Chair
Molly McCarthy, Vice Chair**

Introduction

The Patient Affairs Committee met via Citrix GoToMeeting teleconference on 07/20/2021 to discuss the following agenda items:

1. New Member Welcome
2. Public Comment Orientation
3. Board of Directors Meeting Recap
4. Continuous Distribution – Where we started and where we're headed
5. Closing Remarks

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

1. New Member Welcome

The Chair welcomed the new members to the first Committee meeting of their three-year term and outlined leadership's goals for the upcoming year. UNOS staff introduced the Committee Leadership, Regional Representatives, At-Large Representatives, and Visiting Board Member.

2. Public Comment Orientation

UNOS staff provided an introduction to the new member orientation process, starting with an overview of the OPTN policy development process and highlighting public comment. The Summer Public Comment Cycle begins on August 3, 2021 and runs until September 30, 2021. Each region will have an in person regional meeting to review and discuss the policy items out for public comment.

Summary of discussion:

The chair highlighted the work of Committee members in providing feedback to the Executive Committee's *2021-2024 Strategic Plan* proposal that resulted in substantial improvements to the proposal. A member noted that there were measures added to the plan that were a direct result of feedback PAC provided.

The Vice Chair identified the complexity of public comment proposals but reassured members that their point of view is still valid and to not be discouraged when working through the public comment proposals. UNOS staff added that each proposal will have a video presentation associated with them on the OPTN website and encouraged members to reach out to UNOS staff with questions or requests for additional resources.

A member inquired about the process for submitting individual public comment versus the formal PAC public comment. UNOS staff explained that the Committee will review a handful of public comment items as small groups and share that feedback to facilitate a greater conversation within the full

Committee. A final public comment will be formulated that captures both the feedback from the small group and the conversation from the full Committee and submitted on behalf of the Committee.

Next steps:

UNOS staff encouraged members, and their networks, to participate and submit their comments on the OPTN website.

3. Board of Directors Meeting Recap

The past Chair provided an overview of the June 2021 Board of Director's meeting and the impact that the PAC had on these proposals during public comment. All of the proposals submitted during public comment were passed by the Board of Directors.

4. Continuous Distribution – Where we started and where we're headed

UNOS staff presented an overview of continuous distribution and how organ allocation has evolved into this new framework and why it was needed. This presentation is meant to be an introduction to further conversations and policy development surrounding continuous distribution.

Summary of discussion:

Members praised the presenter for sharing an overview of continuous distribution in a very patient friendly and consumable manner. The Chair recognized this framework for its ability to get organs to the patient most in need. The Chair inquired how this framework and example match run could be amended at a quicker rate than in the existing system? UNOS staff responded that the flexibility of this system allows for the specific organ systems to customize the inclusion and prioritization of factors once the framework has been built out. In its development and implementation, continuous distribution will be a more customizable system than what is current in place.

A member asked if there's a specific target for equity of access in this framework, in alignment with the Strategic Plan and emphasis on patient equity. UNOS staff responded that the goal of this first round of implementation is to not worsen the situation of any population, especially vulnerable populations. The Scientific Registry of Transplant Recipients (SRTR) has provided modeling for that shows positive improvements for every population and this will allow for ongoing monitoring and improvement.

A member inquired if the definition of pediatric candidate varied by organ system, thus impacting the prioritization a younger recipient could have compared to an adult. UNOS staff responded that in developing continuous distribution to be a more consistent framework across the OPTN, it has identified discrepancies and created opportunities to align policy when possible. For this scenario, the OPTN has categorized pediatric candidates as under the age of 18.

A member inquired what the oppositions to this framework and proposal are. UNOS staff responded that due to the length of the proposal, the main concern is that everything necessary has been addressed appropriately when developing this framework. Since continuous distribution will completely replace the current policy it is necessary to consider modeling that shows the potential impact of these changes. The next most important concern is to ensure that this policy reflects the thoughts and feedback of the entire transplant community.

An attendee asked how continuous distribution will impact the role of the regions moving forward. UNOS staff responded that at this point the regions are not used for allocation but instead for Committee and Board representation, organization of in person meetings, and analytical purposes. Separate from continuous distribution, the regional system currently under review with the assistance

from an external contractor. The Executive Committee will have a request for feedback during the upcoming public comment cycle asking the community what the role of regions should be.

Next steps:

Three continuous distribution projects will be out for public comment during the summer cycle. The OPTN Lung Transplantation Committee has a policy proposal to develop and implement continuous distribution. The OPTN Kidney Transplantation and OPTN Pancreas Transplantation Committees are co-sponsoring a concept paper and request for feedback. The OPTN Ethics Committee has a white paper analyzing the ethical considerations of continuous distribution.

5. Closing Remarks

UNOS staff shared the dates and locations for each in person Regional Meeting. Virtual components will be available for each of these meetings. At the request of members, UNOS staff will follow up with regional representatives with information about the regional meetings.

The PAC In Person meeting will be held on August 24 from 9:00 am to 3:00 pm Central Time at the Chicago O’Hare Hilton. The Chair urged all members to attend if possible. UNOS Meeting Partners will reach out to members to arrange travel for Committee members.

The Committee Chair thanked the Patient and Donor Representatives who joined today’s call from other OPTN Committees.

Upcoming Meetings

- August 24, 2021 – In Person Meeting, Chicago Hilton O’Hare
- September 21, 2021
- October 19, 2021
- November 16, 2021
- December 21, 2021
- January 18, 2022
- February 15, 2022
- March 15, 2022
- April 19, 2022
- May 17, 2022
- June 21, 2022

Attendance

- **Committee Members**
 - Anita Patel
 - Betsey Brada
 - Chris Yanakos
 - Darnell Waun
 - David Skinner
 - Earl Lovell
 - Eric Tanis
 - Garrett Erdle
 - James Sharrock
 - Julie Ice
 - Julie Spear
 - Kristen Ramsay
 - Marvin Lim
 - Molly McCarthy
 - Sarah Koochmaraie
 - Sejal Patel
- **HRSA Representatives**
 - Jim Bowman
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Abby Fox
 - James Alcorn
 - Laura Schmitt
 - Lindsay Larkin
 - Sara Rose Wells
 - Tina Rhoades
- **Other Attendees**
 - Kelly Willenberg
 - Laurel Avery
 - Merry Smith
 - Paige Oberle
 - Peter Matthews