

**OPTN Patient Affairs Committee
Meeting Summary
January 18, 2022
Conference Call**

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

Introduction

The Patient Affairs Committee (the Committee) met via Citrix GoToMeeting teleconference 01/18/2022 to discuss the following agenda items:

1. OPTN Board of Directors December Meeting Update
2. Continuous Distribution of Kidneys and Pancreata AHP Prioritization Exercise Review
3. Preview of *Establish Eligibility Criteria and Safety Net for Heart-Kidney and Lung-Kidney Allocation*
4. Recap and Discussion of TRAIPEG Call

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

1. OPTN Board of Directors December Meeting Update

The Chair presented on the OPTN Board of Directors meeting, and provided some updates to the Committee about the Board's decisions. They noted that all proposals had passed, including the first round of Continuous Distribution proposals.

2. Continuous Distribution of Kidneys and Pancreata AHP Prioritization Exercise Review

Analytical Hierarchy Process (AHP) is a psychosocial theory that enables people to prioritize and evaluate "tangible and intangible factors" that seem impossible to quantify in a decision. AHP is being used to help develop weighting characteristics for candidates' points in the Continuous Distribution framework.

Data review:

Continuous Distribution (CD) will switch allocation from a classification-based system, in which candidates must meet specific criteria in order to achieve points or status, to a points-based system, in which all characteristics of a candidate are quantified and compiled together to create an overall score. The AHP exercise helps determine how characteristics should be weighted by asking the participant to compare two theoretical candidate profiles.

The kidney and pancreata AHP exercise has been made more concrete following feedback from the lung AHP exercise, and will be more directly comparing two distinct candidates instead of aspects of their profile. UNOS Staff briefly walked the Committee through the registration process for the AHP exercise, as well as the type of question the exercise will ask.

Summary of discussion:

A Committee member inquired as to whether there would be any attempt to create consistency in scoring across organs, as they worried there would be potential for inequity if different organs used different CD points weighting. The subject matter expert (SME) for the AHP exercise responded that

long-term usability was one of the factors that was required to be considered in making the CD framework. Consequently, while some organs do not consider factors that others do and therefore will have no weighting assigned to them, the “null value” weights will still be present within that organ’s framework. This will allow the committees to review these values to determine exactly whether or not any points weighting should be given to them as they review the results, or whether they were initially correct to omit them.

A second member also wondered why each organ for CD was being done sequentially, rather than concurrently. The SME replied that it is a combination of each organ being at a different readiness for CD, resource constraints, and ensuring the community is eased into the new system. This will allow time to analyze what does and does not work.

The Vice-Chair also inquired as to what security surrounded the survey, as they were disclosing private health information into it. In addition, were responses weighted differently depending on how they identified their relation to the transplant community (i.e surgeon, coordinator, recipient, general public, etc.). It was noted that the survey is done through RedCap, a survey tool often used in clinical studies and has the appropriate security to contain private health information. In addition, while names are used to distribute the accounts, the accounts themselves only carry a unique numerical identifier. To the second question, the sponsoring committees were most interested in the differences between responses depending on perspective. Rarely, it was then added, did the sponsoring committee look at the responses as an aggregate whole.

A third member was interested in why this proposal was using the AHP exercise when other policy proposals did not use a similar tool to gather feedback. The SME responded that, when developing the CD framework, they realized they had a value-based question that required community input, rather than a precision-based question, that could be solved with better algorithms. In this case, to address the value-based question, the AHP exercise was adopted.

It was also proposed that, once the new system is in place, there could be a retrospective review done by the Scientific Registry of Transplant Recipients of the past years of allocation to understand how CD would have allocated differently in contrast to the old system. The SME responded that they did intend to review not just how allocation could have looked in the CD system adopted, but also with different weightings for CD.

Next steps:

The Committee members will receive an email containing the account they should use in the AHP exercise.

3. Preview of *Establish Eligibility Criteria and Safety Net for Heart-Kidney and Lung-Kidney Allocation*

The Committee heard a presentation on the proposal *Establish Eligibility Criteria and Safety Net for Heart-Kidney and Lung-Kidney Allocation*. The proposal will create guidelines that determine when a candidate will receive a kidney in a multiple organ transplant. This was the second time the Committee had heard a presentation on this topic from the ad hoc Multi-Organ Transplant (MOT) Committee.

Data review:

The proposal has been in development since the creation of the MOT Committee and is the first proposal submitted for public comment from them. The proposal will use kidney function as justification for a transplant, as well as protect access for kidney alone candidates in cases when a kidney is not justified for multi-organ transplant.

The proposal uses the same justification from simultaneous liver-kidney and extends it to establish justification for heart and lung-kidney allocation. The presenter did note that pediatric candidates are excluded from eligibility requirements, as they are eligible just by being register for both organs.

Summary of discussion:

There was no discussion surrounding this topic.

4. Recap and Discussion of TRAIPEG Call

The Chair discussed the Transplant Recipients and Immunocompromised Patient Advocacy Group (TRAIPEG) call they attended. They expressed that the TRAIPEG group had not seen significant organizational guidance surrounding COVID-19 information in immunocompromised individuals.

Summary of discussion:

A member present on the call explained that the TRAIPEG group came out of a university's study to determine vaccine effectiveness in immunocompromised individuals. Most of the members are immunocompromised individuals looking for guidance surrounding COVID-19 precautions.

Another member shared their experience contracting COVID-19 twice, and their difficulty understanding the Centers for Disease Control and Prevention (CDC) guidance when it appears to be different for health professionals and members of the general public. The Vice-Chair agreed and commented on a lack of consistent communication coming from transplant programs surrounding COVID-19 and vaccination information. A second member did add that the CDC guidance is updated almost daily, which consequently makes it more difficult for programs to maintain a consistent message. In addition, the member theorized that programs may be hesitant to create guidance because of a fear of a lawsuit if their information does not align with CDC recommendations in the future.

Upcoming Meeting

- February 15, 2022

Attendance

- **Committee Members**
 - Garrett Erdle
 - Molly McCarthy
 - Betsy Brada
 - Sarah Koochmaraie
 - Kenny Laferriere
 - Earl Lovell
 - Anita Patel
 - Sejal Patel
 - Justine van der Pool
 - Kristen Ramsay
 - James Sharrock
 - Julie Spear
 - Eric Tanis
 - Darnell Waun
 - Justin Wilkerson
 - Christopher Yanakos
- **HRSA Representatives**
 - James Bowman
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - James Alcorn
 - Isaac Hager
 - Eric Messick
 - Tina Rhoades
 - Laura Schmitt
 - Kaitlin Swanner
 - Susan Tlusty
 - Sara Rose Wells
 - Joann White