

## **OPTN Pediatric Transplantation Committee**

### **Meeting Summary**

**August 18, 2021**

**Conference Call**

**Evelyn Hsu, MD, Chair**

**Emily Perito, MD, Vice Chair**

### **Introduction**

The OPTN Pediatric Transplantation Committee (the Committee) met via Citrix GoToMeeting teleconference on 8/18/2021 to discuss the following agenda items:

1. Public Comment Presentation: Update on OPTN Regional Review Project, Executive Committee
2. Public Comment Presentation: Establish Continuous Distribution of Lungs, Lung Committee
3. Public Comment Presentation: Enhance Transplant Program Performance Monitoring System, Membership & Professional Standards Committee (MPSC)

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

#### **1. Public Comment Presentation: Update on OPTN Regional Review Project, Executive Committee**

The Committee reviewed the Update on Organ Procurement and Transplantation Network (OPTN) Regional Review Project proposal from the OPTN Executive Committee.

The following is the purpose of the proposal:

- OPTN, donation and transplant community, and organ allocation policies have undergone significant change since OPTN Regions were created
- Purpose of the review is to evaluate the structure, processes, performance, and effectiveness of Regions
- Review considers current and future needs of the nation's donation and transplant community

The following are three proposed options for the new structural model:

- Communities of Common Interest
  - Eliminate geographic Regions and organize members into like-interested communities
- Repurposed Regions
  - Resize and re-draw geographic Regions, with members grouped by a combination of factors (population size, number of transplant centers, geographic proximity)
- Hybrid Cohorts
  - Organize membership into cohorts using a hybrid approach
    - Geographic proximity for procurement and transplantation organizations
    - Like-interests for other stakeholders

#### Summary of discussion:

The Chair mentioned that geography continues to be really important and the issues that affect patients are relevant from a geographic standpoint as well.

A member stated that there needs to be an additional factor in the regional structure, instead of just the communities of interest model, because OPTN committees already provide a similar communities of interest structure. The member emphasized that, in their experience, the really important pediatric discussions arise from the impact the non-pediatric policies have on children, so they would want to keep an open forum for discussions between members who have pediatric expertise and those who don't.

A member expressed concern about the communities of interest model in regards to pediatrics since it would put members with the same opinions together instead of encouraging discussions among members with different priorities or interests. A member agreed and also mentioned that the communities of interest model would make it more difficult for pediatric practitioners to advocate for their patients if they weren't able to have these discussions and hear the opinions of adult practitioners.

The presenter inquired if Committee members thought the current regional structure and regional meetings were working well to represent the pediatric perspective or if there is still some opportunity for improvement. A member stated that, from their experience in the larger regional meetings, it seems specific people are doing a lot of the talking, especially those with technical expertise or experience, and they are more concerned that members with a patient perspective may not feel as comfortable speaking. The member noted that the new virtual format has been helpful with allowing more people to share their opinions.

A member mentioned that they feel like there's a good amount of pediatric representation during the regional meetings.

## **2. Public Comment Presentation: Establish Continuous Distribution of Lungs, Lung Committee**

The Committee reviewed the Establish Continuous Distribution of Lungs proposal from the OPTN Lung Committee.

The following is the purpose of the proposal:

- Part of larger effort to align all organs in a smarter allocation system
- Align lung allocation with community, ethical, and regulatory goals and medial advancements
- Move from classification groups with hard boundaries to considering individual candidates holistically
- Based on feedback provided from community earlier this year

The following was the proposed attributes and their corresponding weight:

- Waiting list Survival – 25%
- Post-Transplant Survival – 25%
- Candidate Biology – 15%
  - ABO – 5%
  - Calculated panel reactive antibodies (cPRA) – 5%
  - Height – 5%
- Patient Access – 25%
  - Pediatric – 20%
  - Prior Living Donor – 5%
- Efficiency – 10%
  - Travel Efficiency – 5%
  - Proximity Efficiency – 5%

### Summary of discussion:

The Chair stated that that this proposal is a really great start in the transition to continuous distribution for lungs. The Chair asked the presenter the following questions:

1. How did these conversations go with the OPTN Lung Committee, from the presenter's view as a pediatrician?
2. Does this proposal adequately address waitlist mortality, especially since lung transplant waitlist is among the highest for all pediatric candidates?

The presenter stated that there was a lot of discussion around pediatrics and the OPTN Lung Committee was very open to the weight of 20% for pediatric priority. The presenter noted that giving a larger weight to pediatric priority than 20% doesn't make much difference based off of the modeling.

The Chair stated that obviously children will benefit from the height points, the pediatric priority points, and probably to some degree the biological disadvantages and inquired if those benefits will negate the fact that the lung allocation score (LAS) doesn't work well for children under the age of 12. The presenter believed it will because LAS was still based on waiting time and priority status. The presenter also noted that children under the age of 12 is a unique group due to the fact that most organs will be allocated to them because of the organ size needs they have.

A member inquired if all candidates less than 12 years old will receive the same LAS score or if there is a calculation for children. Staff explained that candidates under 12 years old on the wait list will receive a set score based on their priority; however, they all receive the same post-transplant outcomes score. A member suggested that the post-transplant outcomes score should be re-evaluated over time, since it will be the same score for all lung recipients under 12 years old.

### **3. Public Comment Presentation: Enhance Transplant Program Performance Monitoring System, Membership & Professional Standards Committee (MPSC)**

The Committee reviewed the Enhance Transplant Program Performance Monitoring System from the OPTN Membership & Professional Standards Committee (MPSC).

The following is the purpose of the proposal:

- Develop a holistic review of member performance throughout all phases of transplant
  - Current performance monitoring evaluates only 1-year post-transplant patient and graft survival
- Identify real-time patient safety issues
- Provide support and collaboration to transplant programs for identified opportunities for improvement
- Evaluate and modify any system of review to ensure maximum support for increasing the number of transplants, promoting equitable access to transplantation and fostering innovation

This project proposes the following:

- Four metrics to evaluate multiple aspects of transplant program performance
- Performance review process
  - MPSC intervention or "red" zone – inquiry and interaction with MPSC
  - Performance improvement or "yellow" zone – notice and offer of assistance, if desired
- Separate criteria for adult and pediatric transplants
- New peer visit section codifies current process
- Administrative revisions to bylaw definitions

- Does not relate to or have an effect on the Scientific Registry of Transplant Recipients (SRTR) public website

Summary of discussion:

A member inquired if there were discussions surrounding split liver transplants and living donors and how the outcome metrics would be adjusted in those situations. Staff explained that the MPSC will continue to include living donors in combination with deceased donors in the post-transplant metrics.

A member inquired if this would be data that is required as part of the evaluation form, similar to how the one year outcomes are required to be shared with candidates during evaluation. Staff explained that there is no requirement by the OPTN that these metrics be communicated. Some members on the MPSC felt like it would be helpful to provide educational resources to programs, if they intended to discuss these metrics with their patients.

A member noted that graft and patient survival is a Centers for Medicare & Medicaid Services (CMS) requirement and mentioned it would be interesting to see how that would change with this proposal.

The Chair stated that they are appreciative of the collaborative work the MPSC has done to focus on transplant outcomes while being respectful of program size.

There was no further discussion.

**Upcoming Meetings**

- September 23, 2021 (Virtual)

## Attendance

- **Committee Members**
  - Evelyn Hsu
  - Emily Perito
  - Abigail Martin
  - Caitlin Peterson
  - Caitlin Shearer
  - Dan Carratturo
  - Douglas Mogul
  - Kara Ventura
  - Johanna Mishra
  - Rachel Engen
  - Regino Gonzalez-Peralta
  - Shellie Mason
  - Warren Zuckerman
  - William Dreyer
- **HRSA Representatives**
  - Jim Bowman
  - Raelene Skerda
- **SRTR Staff**
  - Jodi Smith
- **UNOS Staff**
  - Rebecca Brookman
  - Matt Cafarella
  - Betsy Gans
  - Elizabeth Miller
  - Kaitlin Swanner
  - Katrina Gauntt
  - Krissy Laurie
  - Leah Slife
  - Sara Rose Wells
  - Sharon Shepherd
- **Other Attendees**
  - Melissa McQueen
  - Marc Schechter
  - Zoe Stewart Lewis