

OPTN Pediatric Transplantation Committee

Meeting Summary

July 12, 2023

Conference Call

Emily Perito, MD, Chair

Rachel Engen, MD, Vice Chair

Introduction

The OPTN Pediatric Transplantation Committee (the Committee) met via Citrix GoToMeeting teleconference, on 07/12/2023 to discuss the following agenda items:

1. Welcome
2. New Member Orientation

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

1. Welcome

Committee leadership welcomed the Committee members to the meeting.

2. New Member Orientation

The Chair and Vice Chair presented an orientation to the OPTN and to the work of the Committee for new members.

Presentation Summary:

The Chair explained the OPTN governance structure. The OPTN is governed by the Board of Directors. It has both Operating Committees and Committees of the Board. The OPTN Pediatric Transplantation Committee is one of the OPTN Policy Governance Committees, an Operating Committee.

The OPTN Policy Oversight Committee is an Operating Committee and advises the Board of Directors and the Executive Committee on the following:

- Developing strategic policy priorities
- Prioritizing and coordinating policy and committee projects
- Evaluating policy and committee proposals prior to public comment
- Assessing impact of implemented policy proposals
- Ensuring OPTN Committees justify proposals in compliance with policy development requirements

Committee leadership introduced themselves and introduced all other members on the Committee and their roles. Special attention was devoted to the patient and donor affairs representatives on the Committee, who help elevate the patient voice in the OPTN policy development process and provide unique and critical feedback on proposed policy changes.

The Chair noted that the Committee also receives support from the Health Resources and Services Administration (HRSA), staff members, and representatives from the Scientific Registry for Transplant Recipients (SRTR). An SRTR representative introduced themselves on the call and their role for the

Committee to help provide modeling and data analysis. The Chair introduced staff members and their role for the Committee to coordinate and facilitate Committee operations.

The Chair and Vice Chair provided some information on the difference between the OPTN and the Contractor. The OPTN is the entity tasked with managing the national registry for organ matching. The OPTN is limited in function by statute, regulation, contract, and its own policies and bylaws. The Vice Chair noted that the work that occurs in this Committee is OPTN work, and any policies that it develops or collaborates on are OPTN policies. The Contractor is the non-profit contracted to operate the OPTN. Its private work is limited only by its own policies and bylaws.

The Vice Chair introduced the regional meeting schedule and the role of Committee members at regional meetings.

The Vice Chair explained the policy development process steps¹:

1. Gather ideas
2. Problem analysis
3. Project approval
4. Evidence gathering
5. Public comment approval
6. Public comment
7. Pending board approval
8. Board approval
9. Implementation
10. Post-implementation review

All projects are required to align with one or more of the following OPTN Strategic Goals: increase the number of transplants, provide equity in access to transplants, promote living donor and transplant recipient safety, and improve waitlisted patient, living donor, and transplant recipient outcomes.

The Vice Chair gave some examples of recent Committee projects that are pending implementation or have been implemented, including *Expand ABO-Incompatible Eligibility to All Pediatric Status 1A and 1B Heart and Heart-Lung Candidates* (Board approved June 2023, full target implementation November 2023), *Pediatric Candidate Pre-Transplant Human Immunodeficiency Virus (HIV), Hepatitis B (HBV), and Hepatitis C (HCV) Testing* (Board approved June 2022, implemented July 2023), and *Improving Liver Allocation: Model for End-Stage Liver Disease (MELD), Pediatric End-Stage Liver Disease (PELD), Status 1A, and Status 1B* (Board approved June 2022, implemented July 2023).

The Chair introduced some of the Committee's recent new project ideas, including to improve the National Heart Review Board (NHRB) function for reviewers and programs, and investigate and potentially modify the functional status variables for pediatric candidates and recipients. The Committee will continue to brainstorm new ideas in future meetings.

Some initiatives of other OPTN Committees were also shown, including:

- Continuous Distribution of Kidney and Pancreas, Liver and Intestine, and Heart (respective organ-specific Committees, in various stages of development)
- Modify Offer Acceptance Limits (OPTN Organ Procurement Organization Committee)
- Identify Priority Shares in Kidney Multi-Organ Allocation (OPTN Ad-Hoc Multi-Organ Transplantation Committee)

¹ <https://optn.transplant.hrsa.gov/policies-bylaws/policy-development/>

- Modification of Kidney Donor Profile Index (KDPI) to Remove Race and HCV (OPTN Minority Affairs Committee, and a cross-committee workgroup)

The Chair explained that participation in cross-Committee workgroups is encouraged and helps to ensure that the pediatric perspective is well-represented.

The site where Committee members can access meeting agendas, materials, and project documents was demonstrated. Additional resources are available to members on the OPTN website.

The Chair also explained the expectations of Committee members, including attendance, reviewing materials, and roles and responsibilities at regional meetings. If a member is contacted by the media or press, they are recommended to contact staff for assistance in scheduling and talking points for support.

Summary of Discussion:

Because this meeting focused on orientation, there were no relevant decisions made.

The Vice-Chair encouraged members to share their ideas for new projects via email.

A member asked if the Committee's focus was on solely 0-18 year old patients, and the Chair responded that the OPTN defines a pediatric candidate as someone who is 0-18 years old, so this age range is the focus of the Committee. However, the Committee sometimes does get involved with candidates older than 18, such as collaboration on a project to ensure that candidates who are listed before the age of 18 but are not transplanted until after age 18 retain their pediatric priority. The Vice-Chair stated that making policy is a collaborative effort, so if any member recognizes a problem but it does not directly fit into the Committee's scope, other OPTN Committees can help to tackle the issue.

The Vice-Chair also stated that a project idea the Committee could look into is tracking pediatric transition to adult care.

Upcoming Meeting

- August 18th, in-person

Attendance

- **Committee Members**
 - Emily Perito
 - Rachel Engen
 - Aaron Wightman
 - Carol Wittelib-Weber
 - JoAnn Morey
 - Katrina Fields
 - Sonya Kirmani
 - Neha Bansal
 - Geoffrey Kurland
 - Shantavia Edmonds
 - Reem Raafat
- **HRSA Representatives**
 - Jim Bowman
- **SRTR Staff**
 - Simon Horslen
- **UNOS Staff**
 - Kieran McMahon
 - Besty Gans
 - Laura Schmitt
 - Dzhuliyana Handarova
 - Susan Tlusty