

OPTN Pediatric Transplantation Committee

Meeting Summary

November 20, 2019

Conference Call

George Mazariegos, MD, Chair

Evelyn Hsu, MD, Vice Chair

Introduction

The OPTN Pediatric Transplantation Committee (the Committee) met via teleconference on 11/20/2019 to discuss the following agenda items:

1. Pediatric Heart Review Board Update
2. Proposed Project: Assess for Disadvantaged Patients in the Allocation System
3. Proposed Project: Liver
4. Proposed Project: Improving Access for Pediatric Recipients in Kidney Allocation
5. Collaborative Improvement Project Update

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

1. Pediatric Heart Review Board Update

The OPTN Thoracic Transplantation Committee is planning to sponsor a public comment proposal to establish a national pediatric heart review board. The Committee previously heard a presentation about the project and Committee members participated in the work group that helped design the review board.

Summary of discussion:

The Thoracic Committee Chair presented the proposal to the Committee. The Thoracic Committee Chair noted that the intent is to have the operational guidelines and policy language for the proposal out for public comment in the spring and the guidance for specific diagnoses out for public comment in the fall. Despite the different public comment cycles, the entire review board would be implemented at the same time.

The Thoracic Committee Chair then provided an overview of the proposed policy and guidelines. Each pediatric heart program would be able to appoint a primary and alternate reviewer for a one year term. Reviewers can renew their terms after one year and can also be removed if they are not responsive. Exception cases would be randomly assigned to nine reviewers who have three days to respond. If there is no vote submitted after 24 hours, the alternate would be able to vote. An exception case would be approved if five reviewers vote to approve. If there are not five votes submitted by the sixth day, then the case is based on the majority of the votes submitted and if there is a tie, then the case is approved.

The first appeal would go to the same group of nine reviewers. The second level of appeal would go to a work group of Pediatric and Thoracic Committee members.

The Committee discussed the number of pediatric heart programs and supported the suggestion that each case should have diverse regional representation within the reviewers.

A Committee member suggested that the Thoracic Committee be sure to engage and educate parent and patient stakeholder organizations in the public comment process.

Committee members discussed the early experience with the national liver review board (NLRB) and suggested that the Thoracic Committee carefully consider any potential unintended consequences. Specifically, the Committee suggested that the guidance include language noting that a diagnosis not included in the guidance can still be considered for an exception and to carefully monitor transplant rates and pediatric exception scores.

Next steps:

The Committee will provide additional specific feedback on the proposal during public comment.

2. Proposed Project: Assess for Disadvantaged Patients in the Allocation System

The Committee previously reviewed data from the Scientific Registry of Transplant Recipients (SRTR) on pediatric waitlist outcomes. The Committee discussed drafting an abstract using the data and submitting it to the American Transplant Congress (ATC).

Summary of discussion:

The Chair presented high-level data on pediatric waitlist outcomes. The Chair also presented data on deaths per waitlist year for pediatric candidates stratified by specific risk factors and compared them to data for adult candidates. The Chair noted that the intent of the data is to show where there are particularly poor waitlist outcomes and where to focus future policy initiatives. The Committee agreed that using data to find the specific waitlist characteristics most associated with waitlist mortality was important for determining future policy work.

Committee members suggested comparing pediatric candidates and adults candidates of similar statuses and further stratifying the pediatric population by age.

A Committee member noted that the data focused primarily on mortality but pediatric patients are also effected by developmental delays.

Next steps:

The Committee will work on drafting an abstract submission for the ATC using the data provided.

3. Proposed Project: Liver

The Committee has previously discussed ways to work with the Liver Committee to improve the NLRB and pediatric waitlist outcomes.

Summary of discussion:

The Chair provided an update on the proposed liver projects. The Chair noted that Committee members are planning to join an upcoming NLRB Subcommittee call to present the results of the Society for Pediatric Liver Transplantation (SPLIT) survey that the Committee previously reviewed. The Chair also noted that the Liver Committee supported the ideas to create a pediatric specific Appeals Review Team (ART) and add Pediatric Committee members to the Status 1A/1B Review Subcommittee.

The Chair stated that the Liver Committee is also on board with working to update PELD and Status 1B criteria and that they are going to move forward with forming a work group. The Chair suggested that the project should also examine the feasibility of including factors outside or mortality risk when allocating organs to pediatric candidates.

Next steps:

The Committee will move forward with the project to re-do PELD and Status 1B criteria.

4. Proposed Project: Improving Access for Pediatric Recipients in Kidney Allocation

The Committee previously discussed ways to improve access for pediatric candidates in kidney allocation.

Summary of discussion:

The Committee was informed that the Kidney Committee would be open to considering a project to improve pediatric access to kidneys, but the project would need to come after the Kidney Committee wraps up their current geography proposal.

A Committee member noted that the Committee has discussed multiple ways to improve pediatric access and they all should be discussed with the Kidney Committee leadership.

Next steps:

The Committee will continue to work with the Kidney Committee to improve access for pediatric candidates.

5. Collaborative Improvement Project Update

The UNOS Collaborative Improvement (CI) team has been working on a project to improve pediatric organ offer acceptance.

Summary of discussion:

The Chair informed the Committee of the current progress on the CI project. The Chair noted the criteria used to select the practice model organizations. The Chair noted that the project is evolving and is an iterative process. The Chair also provided some of the feedback that was presented to the CI team.

Next steps:

The Committee will continue to receive periodic updates on the CI project.

Upcoming Meetings

- December 18, 2019
- January 15, 2020

Attendance

- **Committee Members**
 - Amira Al-Uzri
 - Sharon Bartosh
 - Samantha Endicott
 - Regino Gonzalez-Peralta
 - Joseph Hillenburg
 - Evelyn Hsu
 - Jennifer Lau
 - George Mazariegos
 - Melissa Nugent
 - Emily Perito
 - Meghan Potis
 - Khashayar Vakili
 - Priya Verghese
 - Rachel White
 - Warren Zuckerman
 - Jodi Smith
- **HRSA Representatives**
 - Jim Bowman
 - Marilyn Levi
- **SRTR Staff**
 - Katie Audette
 - Nick Salkowski
- **UNOS Staff**
 - Lloyd Board
 - Betsy Gans
 - Julia Foutz
 - Matt Cafarella
- **Other Attendees**
 - Ryan Davies