

OPTN Pediatric Transplantation Committee

Meeting Summary

March 27, 2025

Conference Call

Rachel Engen, MD, Chair

Neha Bansal, MD, Vice Chair

Introduction

The Pediatric Transplantation Committee (the Committee) met via WebEx teleconference on 3/27/2025 to discuss the following agenda items:

1. HRSA Update
2. Open Forum

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

1. HRSA Update

During its March meeting, the OPTN Pediatric Transplantation Committee welcomed a representative from the Health Resources and Services Administration (HRSA) to provide an update on the progress of the OPTN Modernization Initiative and to engage with committee members on related topics, including OPTN governance, transparency, and patient and family engagement.

Summary of discussion:

No decisions were made.

A member asked whether recent federal staffing changes, including reported layoffs at HHS, would affect HRSA's capacity to support ongoing OPTN modernization efforts. The HRSA representative responded that while there are administrative changes, including the upcoming transition to the Administration for Healthy America, there is bipartisan support for modernization, and HRSA's core operations remain intact.

The Chair inquired about the impact of limited resources, noting that the Pediatric Committee has been informed OPTN Committees are maintaining the current volume of work and meetings overall. The HRSA representative stated they would work to better understand these resource limitations. The HRSA representative noted that OPTN modernization is entering a new phase, including a change in funding structure where HRSA will soon directly collect listing fees, which may provide greater financial flexibility.

Discussion turned to patient safety and transparency. The HRSA representative described ongoing patient safety investigations and the launch of a new "critical comment" page on the HRSA website. He stated that while MPSC remains the primary body for performance review, HRSA will now more actively respond to safety concerns raised directly. A member expressed concern about transparency and how the results of these investigations are shared with the public. The HRSA representative agreed that transparency is essential to restoring public trust and emphasized that trust must be earned.

Members also asked about the decision to disallow former Board members from serving on the new Board if they served in the past ten years. A member noted that this has caused distress among patient and family representatives who have served in elected roles. The HRSA representative acknowledged the concern and emphasized that the decision was based on recommendations from the Transition Nominating Committee and aimed at resetting governance in response to congressional oversight. The HRSA representative stated the move is not personal and reiterated HRSA's commitment to a patient-centered system.

A caregiver and current Board member shared concerns about patient and family voices being marginalized, particularly in light of the transition to a new Board. The visiting Board member noted that a letter sent by patient and family members had not received a response. The HRSA representative acknowledged the concern, apologized for the distress caused, and said that a formal response is planned. The representative emphasized that modernization is being done for the patients and reiterated HRSA's desire to restore trust.

Several members shared frustrations about perceived lack of follow-through on committee work, citing examples where major initiatives such as continuous distribution and multi-organ allocation seemed to stall despite years of input. One member said, "Perfect is the enemy of good," and called for more actionable outcomes from committee work. Another added that minority populations, particularly pediatric patients, often face barriers in advancing priorities due to underrepresentation on work groups. Members urged more intentional inclusion of voices representing small patient populations and expressed concern that "pediatric representation" comes from individuals whose primary focus is adult care.

The HRSA representative asked for feedback on how to improve communication and coordination between committees and between committees and the Board. One member noted that while inter-committee collaboration can be effective, the follow-through to policy implementation seems inefficient. Another highlighted "comment fatigue," noting a pattern where public comments are solicited but feedback may not be incorporated into the final policy decisions.

Finally, a member asked about the lack of publicly accessible archives documenting the history of OPTN policy development. The HRSA representative expressed interest in creating a public-facing policy archive and agreed that OPTN data analyses used to inform policy should be made more widely available.

Next steps:

Committee members are encouraged to reach out to the HRSA representative with any additional feedback or questions.

2. Open Forum

There were no open forum speakers.

Upcoming Meeting

- TBD

Attendance

- **Committee Members**
 - Rachel Engen
 - Neha Bansal
 - Emily Perito
 - Aaron Wightman
 - Gonzalo Wallis
 - Meelie Debroy
 - Daniel Ranch
 - Shawn West
 - Gonzalo Wallis
 - Namrata Jain
 - Reem Rafaat
 - Ryan Fischer
 - Jennifer Vittorio
 - Jill McCardel
 - JoAnn Morey
 - Melissa McQueen
- **HRSA Representatives**
 - Ray Lynch
 - Kersten Smith
- **SRTR Representatives**
 - Avery Cook
- **UNOS Staff**
 - Leah Nunez
 - Matt Cafarella
 - Betsy Gans
 - Susan Tlusty
 - Dzhuliyana Handarova
 - Niyati Upadhyay