

## OPTN Pediatric Transplantation Committee

### Meeting Summary

May 15, 2024

Conference Call

Emily Perito, MD, Chair

Rachel Engen, MD, Vice Chair

### Introduction

The Pediatric Transplantation Committee (Committee) met via WebEx teleconference on 05/15/2024 to discuss the following agenda items:

1. Pediatric Bylaws 3-year Monitoring Report
2. Proposal Overview: *Establish Code of Conduct & Whistleblower Protection Bylaws*
3. Pediatric Loss to Follow up discussion
4. Open Forum

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

### 1. Pediatric Bylaws 3-year Monitoring Report

In December 2020, *Establish pediatric training and experience*<sup>1</sup> updated OPTN Bylaws to establish requirements for pediatric components of the following transplant program types: kidney, liver, pancreas, heart, lung. On April 17, 2024, the Committee began discussing the 3-year monitoring report<sup>2</sup> for this bylaw implementation.

#### Data summary:

Data analysis compared the pre-implementation period (December 14, 2017-December 14, 2020) to the post-implementation period (December 15, 2020-December 15, 2023).

Pediatric transplant volume:

- Total number of pediatric transplants decreased by 8
- Pediatric heart and kidney transplant volume increased slightly
- Pediatric liver and pancreas transplant volume decreased slightly
- Number of pediatric lung transplants decreased from 119 to 70
- Median distance from recipient zip code to transplant program remained similar
- Since last annual report, 2 cases in which bylaw requirements were not met/emergency exceptions were not approved

#### Summary of discussion:

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<sup>1</sup> *Establish pediatric training and experience*, OPTN Pediatric Transplantation Committee, December 2020, [https://optn.transplant.hrsa.gov/media/2074/policynote\\_20151201\\_pediatric\\_training\\_experience.pdf](https://optn.transplant.hrsa.gov/media/2074/policynote_20151201_pediatric_training_experience.pdf) (accessed May 13, 2024).

<sup>2</sup> OPTN Descriptive Data Request. "Pediatric Bylaw Change 3 Year Monitoring Report." Prepared for OPTN Pediatric Transplantation Committee Conference Call, April 17, 2024.

No decisions were made.

One member from a kidney transplant program felt like pediatric candidates were receiving fewer offers in the last 2-3 years and questioned whether there might be differences in the data by region. The Chair mentioned that some of the data by region may be available via the Scientific Registry of Transplant Recipients (SRTR) [website](#).

The Vice Chair asked members if the Committee should be involved in ongoing reviews of whether pediatric programs meet bylaw requirements. The Committee previously agreed that membership reviews were the charge of the OPTN Membership and Professional Standards Committee. No members expressed concerns about the previous decision.

## **2. Proposal Overview: *Establish Code of Conduct & Whistleblower Protection Bylaws***

The *Establish Code of Conduct & Whistleblower Protection Bylaws* proposal, sponsored by the OPTN Executive Committee, was available for public comment from April 17, 2024 to May 17, 2024. The Committee heard an [overview of this proposal](#).

Summary of discussion:

No decisions were made.

The presenter, a visiting member of the OPTN Board of Directors and Code of Conduct Workgroup, emphasized that this proposal is intended to formalize expectations (e.g. respectful dialogue, attend meetings, etc.) that are standard across many organizations. The presenter also highlighted the goal of protecting OPTN members and volunteers while reporting and addressing potential wrongdoing. The Chair encouraged Committee members to provide individual feedback on the proposal. If approved by the OPTN Board of Directors, members will be asked to sign OPTN Code of Conduct attestations by July 1, 2024.

## **3. Loss to Follow up discussion**

On December 13, 2023 and February 2, 2024, the Committee reviewed data and discussed the issue of recipient loss to follow up (LTF) during the course of transplant follow up care. Pediatric recipients may be particularly vulnerable to LTF during the transition and transfer from pediatric to adult care. A recipient may be designated as lost to follow up in the OPTN Computer System because of transfer to a non-OPTN provider; loss of contact; recipient not being under provider care. Current data collection lacks granularity, making it difficult to understand the scope of the problem. The Committee has discussed project ideas to address pediatric LTF including data collection opportunities to inform potential solutions. A project may include:

- Establishing a formal definition for loss to follow up
- Adjustments to drop-down options on TRF form regarding pediatric transfer from transplant programs
  - Specifically, returning the “Transfer to non-OPTN center” to the Transplant Recipient Follow up (TRF) form
- Updating transplant program codes to distinguish pediatric programs from adult programs at the same hospital

Summary of discussion:

The Committee confirmed their interest in pursuing a project to address LTF.

The Committee confirmed their interest in pursuing a project to address LTF. Members voiced their support for exploring this project idea and felt it was well-aligned with the work and needs of the pediatric transplant community. There was interest in the ideas listed above, however, establishing a formal definition for loss to follow up and updating transplant program codes were prioritized above adjustments to the drop-down options on the TRF. Some members stated more options on the TRF would be the least helpful. The need to capture more detail on the transition of care when aging out of pediatric programs was emphasized.

Next steps:

The Committee will continue to discuss this topic at upcoming meetings.

**4. Open Forum**

The Committee received from a member of the community a request to submit a comment for the Committee's consideration.

The community member summarized a recent occurrence at their program in which a highly sensitized pediatric kidney candidate missed the opportunity to receive a rare offer. The kidney was offered first to a kidney-pancreas candidate, which was initially accepted and later declined. Ultimately, the kidney was allocated out of sequence to another candidate. The community member highlighted the need for policy changes to protect vulnerable populations, such as pediatric and highly sensitized candidates.

Summary of discussion:

The Committee thanked the community member for sharing this experience. The Chair said it will be important to remain vigilant of data surrounding allocations out of sequence; there is significant concern that this is increasing for kidney and liver candidates. The Vice Chair summarized the OPTN Ad Hoc Multi-Organ Transplantation Committee's current work towards prioritizing certain candidates. The community member was encouraged to participate in public comment periods and attend regional meetings. There was a suggestion to share this with the Kidney and Pancreas community.

**Upcoming Meetings**

- June 26, 2024, 4 PM ET, conference call

## Attendance

- **Committee Members**
  - Emily Perito
  - Rachel Engen
  - Neha Bansal
  - Aaron Wightman
  - JoAnn Morey
  - Jodi Smith
  - Sonya Kirmani
  - Melissa McQueen
  - Reem Raafat
  - Ryan Fischer
  - Carol Wittlieb-Weber
  - Katrina Fields
  - Gonzalo Wallis
  - Namrata Jain
  - Daniel Ranch
- **HRSA Representatives**
  - James Bowman
- **SRTR Staff**
  - Avery Cook
- **UNOS Staff**
  - Leah Nunez
  - Kaitlin Swanner
  - Susan Tlusty
  - Dzhuliyana Handarova
  - Betsy Gans
  - Laura Schmitt
  - Houlder Hudgins
- **Other Attendees**
  - Melissa McQueen
  - Jen Lau
  - Meredith Barrett
  - Woodlhey Ambroise
  - Shawn West