

## **OPTN Pediatric Transplantation Committee**

### **Meeting Summary**

**November 21, 2024**

### **Conference Call**

**Rachel Engen, MD, Chair**

**Neha Bansal, MD, Vice Chair**

## **Introduction**

The Pediatric Transplantation Committee met via WebEx teleconference on 11/21/2024 to discuss the following agenda items:

1. Project Idea: Pediatric Loss to Follow-up
2. Open Forum

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

### **1. Project Idea: Pediatric Loss to Follow-up**

The Committee decided to move forward with a project proposal to address problems related to pediatric loss to follow-up (LTF) during the in-person meeting on September 17, 2024. On October 24, 2024, the Committee refined the scope of the project proposal.

#### Summary of discussion:

There was a brief review of past Committee work related to pediatric LTF and transfers of care, including the OPTN Guidance Document on Pediatric Transitions and Transfers. Insights from analyses incorporated into the guidance document were reviewed.

#### *The problem*

The Committee reviewed the problems they wish to address with this project proposal. The Committee would like to target the lack of standardization surrounding recipient LTF. Recipient LTF may be reported inconsistently in the OPTN data system. There is an existing process in the OPTN data system for reporting recipient LTF that is not codified; current OPTN policy does not provide criteria for LTF. Additionally, LTF designations result in loss of pediatric outcomes data needed to inform allocation policy and clinical decision-making.

The Committee will also target the inability to define the scope of pediatric LTF, due to a lack of granular data collection surrounding LTF and transfers of care. In May 2023, the option to discretely capture "transfer to a non-OPTN provider" was removed from the organ-specific transplant recipient follow up (TRF) form. Multiple factors may contribute to LTF reporting to the OPTN, such as insurance, geography and difficulty obtaining health information from a non-OPTN provider. There is no required data collection on LTF designations. Thus, recipients at risk of graft loss/failure due to non-adherence or insurance issues cannot be distinguished from those who transferred to a non-OPTN provider. New data collection on LTF could help the community quantify the number of recipients LTF that may be at risk of graft loss/failure. Additionally, there are 100+ pediatric programs sharing a hospital code with adult programs at the same institution. With no distinction between pediatric and adult programs in the OPTN data system, there is no way to track the transfer from pediatric to adult care.

### *Transfer of care component*

There was some discussion surrounding the utility of capturing when/at what age the transfer to adult care occurs. There is no national level data on recipient LTF or pediatric transfers of care. Given the link between suboptimal transition and transfer of care for pediatric transplant recipients and LTF, it would be helpful to begin collecting discrete, national-level data. The Chair noted that there are some single transplant hospital-level studies and multi-hospital studies that suggest delaying transition and transfer may be beneficial, but national data is needed to provide more definitive recommendations on transfer age. A member commented that capturing age at transfer would allow for comparison of LTF rates at various ages or between age groups.

There was some discussion of transition and transfer resources and guidelines available, or in development, outside of the OPTN. Analyses of age at transfer and LTF rates insight could inform future updates to OPTN guidance and external resources/tools aimed at improving pediatric transfer.

Additionally, there was an interest in exploring the rate of LTF after transfer to adult care. Members reported that adult care environment may lack the structure necessary to support pediatric recipients after transfer.

There was a suggestion to consider collecting information on whether hospitals have institutional transition policies, to see whether certain practices decrease the likelihood of LTF and improve health outcomes. However, a wide variety of factors, such as developmental concerns and mental health status, may contribute to poor outcomes in pediatric transplant recipients. This adds complexity to interpretation of such data.

#### Next steps:

OPTN Contractor staff will develop a project proposal on behalf of the Committee.

## **2. Open Forum**

There were no open forum speakers.

### **Upcoming Meeting**

- January 23, 2024, teleconference, 4-5 PM ET

## Attendance

- **Committee Members**
  - Aaron Wightman
  - Daniel Ranch
  - Gonzalo Wallis
  - Jennifer Vittorio
  - Jill McCardel
  - JoAnn Morey
  - Katrina Fields
  - Meelie DebRoy
  - Melissa McQueen
  - Namrata Jain
  - Neha Bansal
  - Rachel Engen
  - Reem Raafat
  - Shawn West
  - Woodlhey Ambroise
- **HRSA Representatives**
  - None
- **UNOS Staff**
  - Leah Nunez
  - Kaitlin Swanner
  - Dzhuliyana Handarova
  - Susan Tlusty
  - Laura Schmitt