

**OPTN Pediatric Transplantation Committee
Meeting Summary
September 21, 2022
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 09/21/2022 to discuss the following agenda items:

1. Public Comment Presentation: *Continuous Distribution of Liver and Intestines Concept Paper*
2. Public Comment Presentation: *Continuous Distribution of Kidneys and Pancreata Update*
3. Public Comment Presentation: *Transparency in Program Selection*
4. Know Before You Go

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

1. Public Comment Presentation: *Continuous Distribution of Liver and Intestines Concept Paper*

The Committee heard a presentation from the OPTN Liver and Intestinal Organ Transplantation Committee on their concept paper out for summer 2022 public comment, *Continuous Distribution of Liver and Intestines Concept Paper*.

Summary of discussion:

The Chair noted the importance of providing appropriate priority for pediatric candidates within the new points-based framework. The Chair continued by stating that individuals with pediatric expertise must be involved in the development of continuous distribution so that the pediatric perspective is appropriately considered. A member spoke about the need to advocate for policy considerations that could lead to an increase in split liver transplants, which are especially impactful for the pediatric population.

A member pointed out that sometimes there is an inflation of points for sicker individuals. The member expressed concerns that if inflation of points occurs due to an aging or sicker population, there should be something in place to ensure children are maintaining their priority. The presenter agreed and stated that there needs to be a way to compare medical urgency between adults and pediatric candidates within continuous distribution.

One member commented on the need for creating standardized split liver policies and procedures across the country. The Committee member noted that some centers are more willing to split livers and asked if this could be factored into the new allocation system. Another Committee member stated that there should be a rigorous policy evaluation after implementation that will allow the OPTN to correct any unintended consequences.

Another member pointed out that it is important to follow patients before and after continuous distribution to ensure that the implemented changes were beneficial to the pediatric population.

Next steps:

The Committee's feedback will be summarized and posted on the OPTN website.

2. Public Comment Presentation: *Continuous Distribution of Kidneys and Pancreata Update*

The Committee heard a presentation from the OPTN Kidney Transplantation Committee and the OPTN Pancreas Transplantation Committee on their Committee Update out for summer 2022 public comment, *Update on Continuous Distribution of Kidneys and Pancreata*.

Summary of Discussion:

The Committee appreciated the OPTN Kidney Transplantation and the OPTN Pancreas Transplantation Committees' dedication to pediatric candidates in the update.

A member asked if a candidate registered before turning 18 who turns 18 on the waitlist is able to maintain pediatric priority. The presenter replied this is correct. The Committee supported the use of age at the time of registration to assign pediatric priority in the allocation system.

Next steps:

The Committee's feedback will be summarized and posted on the OPTN website.

3. Public Comment Presentation: *Transparency in Program Selection*

The Committee heard a presentation from the OPTN Ethics Committee on their white paper out for summer 2022 public comment, *Transparency in Program Selection*.

Summary of Discussion:

A member described the consent process at his or her center. The member stated that they present families with the Scientific Registry of Transplant Recipients (SRTR) data about their institution and encourage families to review information available on the SRTR website to ensure the program is the right fit for them. Another member stated that transplant programs should be transparent about their ability or willingness to perform a split liver transplant, as this can impact pediatric liver transplant candidates' access to transplant. The Committee member also commented that there are significantly fewer pediatric transplant programs and these centers are more geographically diverse, which can create additional challenges when choosing a transplant program for pediatric candidates.

Next steps:

The Committee's feedback will be summarized and posted on the OPTN website.

4. Know Before You Go

The Chair reminded the Committee about the upcoming in-person meeting in Chicago on October 6th and provided important info regarding travel and the meeting.

Upcoming Meeting

- October 6, 2022

Attendance

- **Committee Members**
 - Abigail Martin
 - Neha Bansal
 - Brian Feingold
 - Caitlin Peterson
 - Dan Carratturo
 - Daniel Ranch
 - Emily Perito
 - Gonzalo Wallis
 - Kara Ventura
 - Meelie DebRoy
 - Rachel Engen
 - Geoffrey Kurland
 - Shellie Mason
- **HRSA Representatives**
 - Shelley Tims Grant
- **UNOS Staff**
 - James Alcorn
 - Betsy Gans
 - Joann White
 - Laura Schmitt
 - Susan Tlusty
 - Tamika Watkins
 - Samantha Weiss
- **Other Attendees**
 - Rachel Forbes
 - Keren Ladin
 - Melissa McQueen