# OPTN Kidney & Pancreas Transplantation Committee Continuous Distribution Workgroup
## Meeting Summary
## January 29, 2021
## Conference Call

**Silke Niederhaus, MD, Chair**
**Rachel Forbes, MD, Vice Chair**
**Vince Casingal, MD, Chair**
**Martha Pavlakis, MD, Vice Chair**

### Introduction

The Kidney & Pancreas Transplantation Committee Continuous Distribution Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 01/29/2021 to discuss the following agenda items:

1. Welcome & Review of Project Goals
2. Recap of January 15th Meeting
3. Overview of Pediatric Priority in Kidney Allocation Policy
4. Discussion: Pediatric Specific Data Request
5. Next Steps

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

### 1. Welcome & Review of Project Goals

The Workgroup reviewed the goals of the Continuous Distribution project as well as the Workgroup's next steps, including the second phase of the project (assigning values to attributes) and the development of a concept paper summarizing the identification and categorization of attributes.

Summary of discussion:

The Workgroup had no comments or questions.

### 2. Recap of January 15th Meeting

The Workgroup reviewed highlights from their January 15th meeting. During that meeting, the Workgroup reviewed the attributes that were identified and categorized and then began the second phase of the project assigning values to the attributes. The Workgroup discussed and developed a data request for Calculated Panel Reactive Antibodies (CPRA) and blood type.

Summary of discussion:

One member asked if the Kidney Donor Profile Index (KDPI) would continue to be used to stratify donors. Staff clarified that while it was likely KDPI would remain, the Workgroup will further discuss and consider how KDPI is used in the Continuous Distribution model. The member noted that some literature points to KDPI as a poor predictor of transplant outcomes for pediatric patients compared to adult patients.

The Chair of the Pediatric Committee added that pediatric concerns should not only be addressed as a patient access issue, but within each individual attribute, such as medical urgency and candidate biology. A Workgroup Chair agreed, noting that many of these attributes overlap each other and pediatric concerns, and that pediatric priority should have a place in Continuous Distribution.

### 3. Pediatric Priority in Kidney Allocation Policy

The Workgroup reviewed pediatric priority in the circle-based kidney allocation policy, including match run examples.

Data summary:

The Kidney circle-based allocation policy has mechanisms that define pediatric patients both at time of match and at time of registration.

Pediatric kidney candidates are only prioritized donor kidneys with KDPIs in the ranges 0-20 percent and 21-34 percent. Pediatric candidates are only preceded in priority by 100 percent CPRA highly sensitized candidates and prior living donors. Within the pediatric classifications, candidates are sorted by medical urgency status, total time at medically urgent status (for currently medically urgent candidates only), total points, and date and time of candidate's registration. Candidates registered under the age of 18 begin collecting waiting time from time of registration, regardless of clinical criteria or start date of administered dialysis. If the candidate is between 0 and 10 years old, they receive 4 additional points. Candidates between 11 and 17 years of age receive 3 additional points. All candidates receive proximity points.

Pancreas and kidney-pancreas allocation systems do not currently prioritize pediatric patients.

Summary of discussion:

A Workgroup Chair clarified that the proposal worked on by the Kidney Pediatric Access Workgroup aimed to address pediatric organs donors who, due to size, were often allocated in higher KDPI sequences and therefore not as accessible to pediatric candidates. This proposal was delayed to be built into Continuous Distribution.

### 4. Discussion: Pediatric Specific Data Request

The Workgroup reviewed pediatric waitlist data for pediatric Kidney, Pancreas, and Kidney-Pancreas candidates, as well as a list of potential descriptive data for pediatric candidates, pediatric waitlist outcomes, preferred donors for pediatric candidates, and transplant recipients. The Workgroup discussed what data would be necessary and/or helpful to support rating attributes for the Continuous Distribution Model.

Data Summary:

Current waitlist data, as of January 2021:

- Of 91,403 kidney candidates, 1,114 are pediatric
- Of 891 pancreas candidates, 47 are pediatric
- Of 1696 kidney-pancreas candidates, 2 are pediatric

2020 transplant data:

- Of 22,817 kidney transplants, 710 were to pediatric recipients
- Of 135 pancreas transplants, 18 were to pediatric recipients
- Of 827 kidney-pancreas transplants, 5 were to pediatric recipients

Potential Descriptive Data (Kidney, Pancreas, and Kidney-Pancreas):

- Pediatric Candidate Characteristics
    - Age (any categorization to look at? ex.: under 12 vs 12-17, or under 11 vs 11-17)
    - Race/Ethnicity
    - Diagnosis
    - Multi-Organ
- Pediatric Waiting List Outcomes
    - Transplant rate
    - Waitlist mortality
    - Stratifications by characteristic (ex.: age)
- Pediatric Transplant Recipient Characteristics
    - Age
    - Race/Ethnicity
    - Diagnosis
    - Multi-Organ
- Characteristics of Donors Used by Pediatric Transplant
    - Age
    - Race/Ethnicity
    - KDPI

Summary of discussion:

The Chair of the Pediatric Committee referred to the 2014 *Ethical Considerations of Pediatric Organ Allocation* white paper as precedent justification for pediatric priority. A Workgroup Chair responded that most pediatric priority has been given by moving allocation classifications, and that both ethical principles and data pointing to the benefits of pediatric priority will be important to quantify and describe pediatric priority in the Continuous Distribution model.

One member remarked that most of the pediatric pancreas data were likely part of a multi-organ or multi-visceral listing, and that priority for these patients would be driven by pediatric access for their main organ listing, such as a heart or liver. The member continued that pediatric pancreas alone patients and pediatric kidney-pancreas alone patient data should be used to provide accurate analysis. Another member agreed, adding that it would be important to understand how long pediatric candidates typically wait for isolated pancreas or kidney-pancreas, and what kinds of donors are typically accepted for these patients. A Workgroup Chair noted that an extended wait time for these patients could be attributed to the wait time for an ideal donor. A member mentioned that his center performed an analysis of the SRTR database, and only found 22 cases of pediatric (defined in his study as under age 16) pancreas alone transplants over 20 years. The member continued that the rarity of pediatric pancreas alone listings and transplants will make significant analysis difficult, and that pediatric priority will need to be determined outside of that. A Workgroup Chair remarked that pediatric pancreas transplants only occurred in special scenarios, such as within one-center organ procurement organizations or that pediatric surgeons will coordinate with other centers on an ideal donor match run to essentially organize pediatric priority for their patient. The Workgroup Chair added that this means wait time data would not accurately reflect the current allocation system, but that the rarity of pediatric pancreas transplants does not negate the need for pediatric priority for pancreas alone and kidney-pancreas candidates. The Chair of the Pediatric Committee agreed that the clinical stories and situations belie a need to establish pediatric priority in the absence of large-sample data.

A member asked to include data on the number of pediatric donor kidneys allocated to pediatric recipients. A Workgroup Chair agreed that this would be a good opportunity to examine pediatric donation to pediatric recipients, including experiences in donor size, quality, and age matching. Another member added that pediatric donors generally have high KDPIs due to their size, which often precludes pediatric candidates from accessing pediatric donor organs. The member continued that any data on pediatric donor KDPIs, recipients of pediatric donor organs, and pediatric organ performance in pediatric recipients will be critical to developing pediatric priority appropriately in Continuous Distribution.

A Workgroup Chair asked if the pediatric transplant community shared a sentiment that most candidate-donor matches should have three or fewer antigen mismatches, citing the large volume of offer declines for pediatric candidates as an opportunity to improve efficiency. Another member responded that a number of factors influence the offer decline rate at pediatric programs, including a belief that higher KDPI kidneys – such as those in 20-34 percent range – are not as high quality kidneys, dependent on adult and pediatric donor. The member continued that while some centers are willing to accept pediatric donor kidneys, many centers are more conservative and opt to reduce rejection risk over transplanting candidates earlier. The member also shared that many adolescent recipients are known to have problems with compliance in post-transplant care. A Workgroup Chair agreed that many pediatric programs have high turn down rates, as they can afford to wait for more ideal donors. The Workgroup Chair remarked that it would be important to preserve pediatric patient access while minimizing offers to transplant centers that they will not take.

A member noted that it may be worth looking at the impact of improved pediatric priority on living donation. A Workgroup Chair pointed out that they also examined that data when pediatrics first began receiving priority.

After the workgroup reviewed potential descriptive data, a member suggested examining pediatric donors and what kinds of candidates receive those kidneys. Another member recommended including CPRA in analysis. A Workgroup Chair suggested incorporating Human Leukoctye Antigen (HLA) mismatch.

A Workgroup Chair recommended looking at age of listing, noting that some patients are listed as pediatric and transplanted as adults, and that any data around that transition period may be helpful. The Workgroup Chair clarified that the pediatric boundary generates very different transplant experiences for young patients aged 18 and older, and that this may be a patient population that could be more appropriately served and addressed in Continuous Distribution. Any data on where these patients are listed and how they transition to adult programs could smooth that boundary.

The Chair of the Pediatric Committee questioned how age in recipients and candidates would be categorized. A member pointed out that it would be helpful to look at younger patients, using either age 5 or 1 as a boundary. Another member shared that the SRTR used ages 11-17, 6-10, 1-5, and less than 1 for kidney, although kidney patients under age 1 are unusual. The member continued that it would be important to categorize age groups such that current pediatric policy may be examined. The Workgroup agreed to evaluate with age groups 11-17, 6-10, and 0-5.

**5. Next Steps**

The Workgroup will continue discussions to develop the data request, with focus at the upcoming meeting on HLA matching.

**Upcoming Meetings**

- February 12, 2021 (Teleconference)

**Attendance**

- **Committee Members**
  - Abigail Martin
  - Arpita Basu
  - Caitlin Shearer
  - Cathi Murphey
  - Evelyn Hsu
  - Jeffery Steers
  - Martha Pavlakis
  - Parul Patel
  - Peter Kennealey
  - Rachel Forbes
  - Raja Kandaswamy
  - Silke Niederhaus
  - Tarek Alhamad
  - Vincent Casingal
  - Jodi Smith
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
  - Raelene Skerda
- **SRTR Staff**
  - Ajay Israni
  - Bryn Thompson
  - Jonathan Miller
  - Nick Salkowski
- **UNOS Staff**
  - Alison Wilhelm
  - Amanda Robinson
  - Ben Wolford
  - James Alcorn
  - Jen Wainright
  - Joann White
  - Joel Newman
  - Julia Foutz
  - Kayla Temple
  - Kerrie Masten
  - Lauren Motley
  - Leah Slife
  - Lindsay Larkin
  - Matt Cafarella
  - Melissa Lane
  - Nang Thu Thu Kyaw
  - Rebecca Brookman
  - Ross Walton