

# **Meeting Summary**

# OPTN Kidney & Pancreas Transplantation Committee Continuous Distribution Workgroup Meeting Summary July 16, 2021 Conference Call

Rachel Forbes, MD, Chair Oyedolamu Olaitan, MD, Vice Chair Martha Pavlakis, MD, Chair Jim Kim, MD, Vice Chair

#### Introduction

The Kidney & Pancreas Transplantation Committee Continuous Distribution Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 7/16/2021 to discuss the following agenda items:

- 1. Welcome & Review of Project Goals
- 2. Project Approach
- 3. Review: Results of Pediatric Data Request
- 4. Rating Scale Recommendation
- 5. Discussion: Pediatrics Literature Review
- 6. Wrap Up

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

#### 1. Welcome & Review of Project Goals

The Workgroup reviewed the scope of the Continuous Distribution project, which is to change allocation from a classification-based system to a points-based system. The Workgroup is currently in the second phase of the project where they will be assigning values to the kidney and pancreas attributes and developing a concept paper.

#### **Summary of discussion:**

There was no discussion.

#### 2. Project Approach

The Workgroup received an overview of the second phase of the project and what it means to develop rating scales and weights.

The following is the chronological process of the second phase:

- 1. Attribute
  - a. Discuss each attribute individually
  - b. Ex: calculated panel reactive antibody (cPRA)
- 2. Rating Scale
  - a. Determine rating scale for each attribute
  - b. Ex: Workgroup decides this should be a steep non-linear scale
- 3. Weight
  - a. Determine weight for each attribute compared to other attributes
  - b. Ex: Workgroup decides cPRA should count for 5% of total score

#### 4. Build & Adjust

- a. Use Workgroup's decisions to build draft framework and adjust as needed
- b. Ex: Upon review, Workgroup decides to adjust weight to 10% of total score

#### Summary of discussion:

There was no discussion.

#### 3. Review: Results of Pediatric Data Request

The Committee reviewed the results of the pediatric data request that was submitted in January.

#### Data summary:

- Pediatric transplant volume has been stable post-Kidney Allocation System (KAS), while adult transplant volume has increased
- Pediatric kidney recipients tend to be older than pediatric kidney-pancreas and pancreas recipients
- Few pediatric patients need a kidney-pancreas or pancreas transplant, and many need additional organs
- Pediatric kidney patients under six years old have longer waiting times, potentially due to challenges with size matching

#### Summary of discussion:

A member inquired if the number of pediatric deceased donor pancreas transplant recipients were just pancreas alone transplants or if that included multi-visceral transplants. Staff explained that it does include multi-visceral transplants. The member stated that most of those pediatric pancreas transplants were probably multi-visceral.

A Scientific Registry for Transplant Recipients (SRTR) representative stated that there are three categories when looking at pediatric pancreas transplants: (1) pancreas transplant alone, which is at least one transplant; (2) multi-visceral transplant – there was a medical reason to transplant the pancreas; and (3) multi-visceral transplant – the pancreas was transplanted for technical reasons only.

Staff explained that, since so many of the pediatric pancreas recipients are also receiving livers and/or intestines, these organs aren't getting allocated off of the kidney-pancreas match run. This will need to be a point of discussion during the Liver Transplantation Committee's transition to continuous distribution.

An SRTR representative mentioned that, considering there were three kidney-pancreas transplants and two pancreas transplants alone, there are small numbers of highly selective pediatric patients that receive pancreas or kidney-pancreas transplants, not part of multi-visceral. The representative stated that since it's such a small number it could be argued that not much needs to be done about it or argued that, since it won't affect the overall burden of the system, priority should be granted for these pediatric patients.

A member inquired if there is data on discard rates for pediatric donors by age. Staff explained that the data isn't included in what was presented, but they have looked at it and it was single digits. A member noted that it depends on how discard is defined because, for these really young donors, the kidneys may not even be procured because the organ procurement organization (OPO) hasn't found an interested candidate. The member mentioned that the more interesting data point would be the number of kidneys that are procured based on the number of donors.

A member agreed and continued by stating that, in regards to size matching, there are many surgeons who aren't comfortable using small donor kidneys because the vasculature is so much smaller if they are transplanted as a single organ. The member mentioned that some small donor kidneys actually carry a higher risk than kidneys from older donors with a decent body size.

A member suggested that it would be interesting to look at who these small donor kidneys do get allocated to, if they are not prioritized for pediatric candidates. A member noted that they would want to consider those small donor kidneys (young donor age, high kidney donor profile index (KDPI)) for pediatric patients because the KDPI may be inaccurately allocating these kidneys to older candidates when they might be appropriate for pediatric candidates.

A member noted that there is huge potential in training surgeons to recover those pediatric kidneys and use them well. The member emphasized the importance of having the right recipient for these pediatric kidneys. The member also suggested a special allocation consideration given to kidneys from donors, who are less than two years old or less than 20 pounds, and they should go to low-weight, low body mass index (BMI), non-hypertensive recipients. If they were allocated in that way, some surgeons would be more likely to risk doing those transplants, utilize those organs, and shorten wait times for some specific patient groups.

A member noted that they wanted to focus on the KDPI of 35-85% and the donor age group of 6-10 years old because those are the organs that pediatric candidates are not getting priority for and they would probably be used for those candidates in certain situations. A member noted that it's further complicated because many pediatric kidney programs are only considering and receiving offers on the less than 35% KDPI donors.

## 4. Rating Scale Recommendation

The Workgroup reviewed the following rating scale recommendations:

- Pancreas
  - Binary (Yes/No) scale
  - Candidates who are under the age of 18 at the time they are registered on the waiting list will receive the full benefit of pediatric points
- Kidney
  - Binary (Yes/No) scale conditional on donor factors
  - Candidates under the age of 18 would receive the full benefit of the pediatric points if specific donor criteria are met (ex. KDPI)

#### Summary of discussion:

A member inquired what the priority for pediatrics was before KDPI or KAS were implemented. Staff explained that prior to the kidney allocation changes in 2014, pediatric priority was based off of donor age and pediatric candidates received priority for donors under the age of 35.

A member stated that the recommendations make sense for pancreas, due to the small volume; however, the kidney recommendation could be up for discussion since the volume is greater. A member agreed and explained that, because the pancreas and kidney-pancreas volume in the pediatric population is extremely small and done for pancreatic function, those pediatric candidates should be able to pull whatever organ comes with the kidney offer.

The Workgroup agreed with the rating scale recommendations as proposed. The specific donor factors for kidney will be determined as part of future discussions.

#### 5. Discussion: Pediatrics Literature Review

The Workgroup received an overview of the pediatric literature that was shared with members, and held a discussion on the following questions:

- What donor factors should be considered?
- Independent of post-transplant survival, should there be other considerations to how pediatrics is prioritized?
- How does the Workgroup define pediatric priority? Are there distinct differences between kidney and pancreas?

#### Summary of discussion:

A member inquired if there was a sense in the pediatric community as to why they are not using some of those higher KDPI kidneys – is it because they aren't receiving the offers or would those in the pediatric community not use them even if they were getting offers? A member explained that it is complicated because they are not sure if every pediatric center understands the nuances, especially if they are only a pediatric center. The member noted that if a center would be willing to accept a higher KDPI kidney from a donor who is 6-10 years old, then the problem, under the current system, is that that center will be completely inundated with offers that they would not likely accept. This could be overwhelming for that center in terms of the workload.

A member noted that opening up Sequence C (KDPI 35-85%) to all pediatric candidates would be too much; however, there is a subset of those donors, primarily the younger donors who may have had acute kidney injury that caused their KDPI to increase, who could be teased out in order to prioritize those donors for pediatric candidates.

A member inquired about the upper limit of donor age for that consideration. A member stated that they were thinking thirty-five years old, but that had been under discussion. The member explained that, when looking at the KDPI calculation, it seems that younger donors who have a higher KDPI affects the KDPI calculation up until around age thirty-five.

A member stated that it could be possible to create an extra Sequence for the younger donors.. So, younger donors would be pulled out of Sequence C and that would allow a way to give the pediatric programs and recipients priority, without opening them up to all of the higher KDPI kidneys from the adult population.

A member stated that, when looking at the recipients under the age of five, a large number of those recipients have living donors; however, when looking at recipients aged 11-17, only 10% of those recipients receive living donor transplants. The member stated that the explanation has always been that the parents will let the pediatric recipient be high priority for the deceased donor transplant and then, subsequently, when those recipients become adults and need a second transplant, the parents will then be the living donor for their child. The member inquired if this is true and suggested that the Workgroup should still be encouraging living donation as opposed to receiving priority for a deceased donor, which is taking that organ away from someone else.

A member explained that they aren't sure if there is any data to support this explanation besides anecdotal data. The member also explained that it depends on the type of disease that the teenage candidates may have and the length of time that pediatric patients should stay on treatments, such as dialysis.

#### 6. Wrap Up

The Workgroup should provide their feedback on the following discussion questions, which will also be posed in the Kidney Pancreas Continuous Distribution Concept Paper going out during the August 2021 public comment cycle:

- Which kidneys should pediatric patients receive priority points for?
- Which kidneys should pediatric patients not receive priority points for?
- What are some alternatives to KDPI for directing organs to pediatric candidates?

# **Upcoming Meetings**

• July 30, 2021 (Teleconference)

#### **Attendance**

# • Workgroup Members

- o Martha Pavlakis
- Jim Kim
- Silke Niederhaus
- Abigail Martin
- o Amy Evenson
- o Beatrice Concepcion
- o Caitlin Shearer
- o Parul Patel
- o Pradeep Vaitla
- o Todd Pesavento

### • HRSA Representatives

- o Jim Bowman
- Marilyn Levi

#### SRTR Staff

- o Bryn Thompson
- Nick Salkowski
- Raja Kandaswamy

#### • UNOS Staff

- Joann White
- Rebecca Brookman
- Anne McPherson
- Lindsay Larkin
- o Kayla Temple
- Ross Walton
- o Alison Wilhelm
- Amanda Robinson
- James Alcorn
- o Joel Newman
- Kaitlin Swanner
- o Lauren Motley
- Leah Slife
- Matt Prentice
- Melissa Lane
- Nicole Benjamin
- Sarah Booker

# • Other Attendees

Emily PeritoEvelyn Hsu