

**OPTN Pediatric Transplantation Committee
Meeting Summary
December 16, 2020
Conference Call**

**Evelyn Hsu, MD, Chair
Emily Perito, MD, Vice Chair**

Introduction

The OPTN Pediatric Transplantation Committee (the Committee) met via Citrix GoToMeeting teleconference on 12/16/2020 to discuss the following agenda items:

1. Bylaws Implementation Monitoring Update
2. Kidney Pediatric Working Group Manuscript
3. Pediatric Kidney-Alone vs. Multi-Organ Data Request
4. Mortality Manuscript
5. Liver PELD/Status 1B Project Update

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

1. Bylaws Implementation Monitoring Update

The Committee reviewed the following metrics that will be monitored during the implementation phase of the Pediatric Bylaws:

- Maps of approved programs by organ type
- Counts of pediatric transplants by program and organ compared to pre-policy
- Counts of reasons for removal (transplant, death or too sick to transplant, still waiting) by organ compared to pre-policy
- Counts of cases where programs without an approved pediatric component listed a candidate less than 18 years old; of those cases, how many registered using the emergency exception

These metrics will be updated 6 months, 1 year, 2 years, and 3 years post-implementation.

Summary of discussion:

A member mentioned that this monitoring plan looked good and inquired if the Board of Directors (BOD) had any feedback on this implementation. A member explained that there wasn't much discussion because this wasn't considered controversial. The member suggested that the enforcement aspect of this monitoring plan may need to be re-examined.

A member inquired if a final tally of programs that had been approved or opted out had been presented during the BOD meeting. Staff explained that a list of these programs can be accessed through the member directory on the Organ Procurement and Transplantation Network (OPTN) website.

A member noted that all of the candidates who were listed at programs that no longer had an approved pediatric component would be notified.. The Committee asked if it would be possible to know if these patients were listed at another program. Staff informed the Committee that there were only a few

candidates listed at programs that do not have an approved pediatric component, and they are temporarily inactive. Currently, there are no applications via the emergency exception pathway.

2. Kidney Pediatric Working Group Manuscript

The Committee was reminded that the Policy Oversight Committee (POC) recommended the work of the Kidney-Pediatric Workgroup, which was focused on increasing pediatric priority among Sequence C donors, be rolled into the efforts of continuous distribution due to sequencing and resources.

Staff informed the Committee that the Kidney Pancreas Continuous Distribution Workgroup tentatively plans to release a concept paper for community feedback in Fall 2021.

Summary of discussion:

A member, who had attended the first Kidney Pancreas Continuous Distribution Workgroup meeting, mentioned that the Workgroup was in the early stages of identifying and categorizing attributes for kidney-pancreas to include in the continuous distribution model. The member continued by stating that both kidney and pancreas continuous distribution workgroups had listed pediatric priority as an attribute that they wanted to consider.

The Committee Chair mentioned that there will need to be constant reiteration of a need for pediatric priority during the Kidney Pancreas Continuous Distribution Workgroup calls in order for it to be included in the continuous distribution model.

The Committee Chair reiterated that the Committee can provide support to their representatives on the Kidney Pancreas Continuous Distribution Workgroup. For example, the Committee Chair expressed concern, from a liver perspective, about stratifying pediatric age groups because it's the adolescents that will be disadvantaged and lose valuable time.

The Committee Chair suggested that it would be beneficial for members to write a possible publication encompassing their experience working on the Kidney-Pediatric Workgroup and the data that was reviewed. Some members agreed this would be a good idea.

3. Pediatric Kidney-Alone vs. Multi-Organ Data Request

Staff presented the results of the data request, which will help the Committee understand if prioritization of multi-organ candidates over pediatric kidney-alone candidates adversely affects pediatrics.

Data Summary:

The results of the data request concluded the following:

- Kidney-pancreas, liver-kidney, and heart-kidney transplants increased in recent years; a very small portion were pediatric transplants
- About 1 in 5 pediatric kidney-alone and kidney-pancreas transplants were from pediatric donors
- The majority of pediatric kidney-alone and kidney-pancreas transplants were kidneys with a Kidney Donor Profile Index (KDPI) greater than 35%
- One year graft survival was significantly lower for liver-kidney and heart-kidney transplants compared to other organ combinations
- The next candidate on the kidney-alone match run analysis found 447 cases out of 3,955 where the kidney-alone recipient was less than 18 years of age at transplant, indicating a high

probability a pediatric candidate would have accepted the second kidney had it been offered to them on the kidney match run

- If a pediatric recipient received the single kidney, it was common for the next candidate on the match run to be less than 18 at listing
- Many of the next candidates on the match run did go on to receive a transplant; however, many are still waiting

Summary of discussion:

A member inquired about the number of kidneys going to Simultaneous Liver Kidney (SLK) candidates compared to the number of kidneys going to candidates that would fall into the SLK Safety Net. The member continued by explaining they wanted to know how many kidneys are given to candidates that may first receive a liver transplant and then a kidney transplant later, through the safety net, compared to the candidates that receive a SLK transplant. Research Staff explained that they would look in the SLK monitoring report for the answer to this.

The Committee Chair inquired about how many transplants would be done if every pediatric candidate received a transplant each year. The Committee Chair explained that it looked like 11% of the list was still waiting, so around 300 more transplants each year. Research Staff mentioned that they could pull data from the end of November to see the amount of pediatric candidates still waiting.

The Committee Chair asked what would happen if pediatric kidney-alone candidates were put ahead of kidney-pancreas (KP) candidates and suggested that this is what will need to be discussed. A member mentioned that the majority of adult SLK candidates with renal disease are still getting dual organs due to the SLK Safety Net. These adult SLK candidates can pass on the kidney and just get a liver transplant; however, they still have a year to be re-listed for an isolated kidney. The member explained that the adult SLK candidates receive some priority points, but that priority is below that of children. A member countered by stating the adult KP candidate group is the group that's taking the quality kidneys children need.

Members agreed that this data should be published.

A member inquired if pancreas programs are using pancreata from pediatric donors because they are better quality and if that is why the majority of pediatric kidney donors are going to KP candidates. The member inquired if there is any data on kidney donor quality related to age. A member stated that they thought it had more to do with the KDPI than the age of the kidney. The member explained a fair number of the pediatric donors don't necessarily have a great KDPI and maybe part of the reason they are going to the adult KP candidates is because of the slightly higher KDPI and the pediatric kidney programs are not accepting them. A member stated that this reinforces that KDPI, at least for pediatric donors, is not a great indicator of the quality of that kidney.

A member inquired whether it would be possible to look at the KDPI of the pediatric kidneys that went to KP candidates. A member explained that OPOs are required to offer to the KP candidate if both the kidney and pancreas are available for transplant based on candidate age less than 50 and body mass index (BMI) less than 30. OPOs also have the choice to continue down the KP list or switch to the kidney list and offer the pancreas separately. The member stated that the issue for OPOs is that they are measured on how many organs get transplanted and there are twice as many KP candidates as there are pancreas candidates; so, when switching over to the pancreas list, the chance of placing that pancreas is cut in half.

4. Mortality Manuscript

The Committee was reminded that this manuscript wanted to describe pre-transplant mortality in children across organs and that a previous Committee member is leading the process of writing this manuscript.

Summary of discussion:

There were no questions or comments.

5. Liver PELD/Status 1B Project Update

The Committee was informed that the PELD Derivation Request has been sent to Scientific Registry of Transplant Recipients (SRTR) and considered the following characteristics:

- Age
- Bilirubin
- Albumin
- INR
- Growth Failure
- Sodium
- Modified Schwartz calculation of eGFR (or serum creatinine)
- SRTR will also explore including a PELD trajectory variable

After deriving a new PELD, SRTR will calibrate a new PELD score so that children's mortality risk will better compare to the age-standardized mortality rate of adults.

The Committee also reviewed the age-adjusted mortality factors that predict mortality in children, but are not currently collected by the OPTN.

Summary of discussion:

There were no questions or comments.

Upcoming Meetings

- January 20th, 2021 (Teleconference)
- March 30th, 2021 (Tentatively In-Person)

Attendance

- **Committee Members**
 - Evelyn Hsu
 - Emily Perito
 - George Mazariegos
 - Abigail Martin
 - Andy Bonham
 - Brian Feingold
 - Caitlin Shearer
 - Douglas Mogul
 - Jennifer Lau
 - Johanna Mishra
 - Kara Ventura
 - Sam Endicott
 - Shellie Mason
 - Walter Andrews
 - Warren Zuckerman
 - William Dreyer
- **HRSA Representatives**
 - Jim Bowman
 - Marilyn Levi
 - Raelene Skerda
- **SRTR Staff**
 - Chris Folken
 - Jodi Smith
- **UNOS Staff**
 - Kiana Stewart
 - Matt Cafarella
 - Betsy Gans
 - Julia Foutz
 - Kelsi Lindblad
 - Leah Slife
 - Lloyd Board
- **Other Attendees**
 - Sharon Bartosh
 - Joseph Hillenburg