

## **OPTN Pediatric Transplantation Committee**

### **Meeting Summary**

**May 17, 2023**

**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 05/17/2023 to discuss the following agenda items:

1. Welcome
2. Working Session: Monitoring Report Reference Document Project
3. Policy Oversight Committee Update
4. Discussion: Pediatric National Heart Review Board Improvement Ideas

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

#### **1. Welcome**

Committee leadership welcomed the Committee members to the meeting.

#### **2. Working Session: Monitoring Report Reference Document Project**

Staff summarized the previous Committee discussions on this project and used the current version as a working document for the meeting.

#### Summary of Discussion:

##### *Multi-Organ Transplants*

Staff asked members if it was important to include multi-organ transplant data within each organ specific report. For example, include liver-kidney data in both the liver and kidney reports. A member responded that since liver policy also affects liver-kidney patients it would be important to see the pediatric outcomes and counts for liver alone, kidney alone, and liver-kidney.

A member added that with the changes to heart policy it would be important to know the counts for heart-liver, heart-kidney, and heart-lung even though the numbers are small.

A member commented that every policy change that affects the kidney should be reviewed for transplant rates and outcomes. She added that even though there are smaller numbers of multi-organ transplants, there is a chance that adult multi-organ transplants could take organs away from pediatric candidates, such as the case with kidney-pancreas. A member suggested evaluating how many pediatric candidates were on an adult multi-organ match run and include pediatric kidney transplant rates.

##### *Heart*

Research staff asked the members if the current age stratifications, such as 6-11 and 12-15, were acceptable. Members agreed that for consistency the age stratifications are acceptable although one member noted that a major concern with outcomes exists for younger pediatric patients. This member suggested that the age categories 0-1 and 2-5 remain separate.

Research staff asked members if candidate status at listing and waitlist removal is acceptable or if it should be presented differently. For example, if there should be more specific information about Status 7 (inactive) candidates. A member commented that sometimes it is difficult to explain why there are extended periods of time at Status 7. This member added that children might periodically improve so their status will change and recommended monitoring how long candidates are listed at Status 7. It was noted that if candidates are inactive for an extended period there might be a need for a second evaluation, depending on the insurance carrier requirements. Lastly, this member added that there are implications for the families as well if their child is inactive but then suddenly gets reactivated.

The Vice-Chair noted that it might be important to evaluate if policy changes affect how long certain patients are listed at Status 7 and further added that this issue could potentially be a future committee project.

### *Lung*

Members agreed to collect the same information for Status 7 lung patients as noted with heart.

Members agreed that the age stratifications for lung were appropriate and recognized that the number of lung transplants in the 0-1 age group is small. A member added that the reasons for transplant in the 0-1 age group is different than the 6-10 and 12 and over age groups, however the committee might consider combining it into a 0-5 age category to increase the numbers.

A member asked if the status at listing and at transplant is still important with the new lung allocation system. For example, with continuous distribution the allocation score is subject to change with every donor. The Chair added that this entire document might look different as each of the organ systems move to continuous distribution.

### *Kidney*

The Vice-Chair agreed that the categories for weight are acceptable but noted that the number of transplants for patients under 10 kilograms are low due to physiological reasons. The Vice-Chair recommended combining the smaller weight categories into a “less than 10 kilograms” category.

The Chair asked about height and whether it will inform something different than just age and weight, because what we are interested in is the high-risk categories. A member responded that if there is interest in linear growth, it would be great if the Scientific Registry of Transplant Recipients (SRTR) collected more information. However, currently this data does not affect allocation policies.

A member added that transplants for children less than 10 kilograms do happen in emergency situations if they are running out of dialysis options. Therefore, it would be nice to know how often that is occurring and which centers are performing the transplants. This member added that the 10-25 kilograms range is too broad because the highest risk patients are those in the 10-15 kilograms range and suggested that a range of 10-20 kilograms might be more appropriate. Another member suggested 10-20 kilograms and 20-25 kilograms weight ranges.

The Vice-Chair commented that while it is important to know how many “under 10 kilograms” transplants are occurring and what the outcomes are, it is something that should be in the SRTR reports and not the OPTN monitoring reports and added that a lot of research studies reference under 15 kilograms as a high-risk category.

The Chair suggested evaluating less than 10 kilograms, 10-20 kilograms, and over 20 kilograms. The Vice-Chair noted that kids over 20 kilograms have less risk factors.

Research staff asked about the dialysis status and whether it needs to be identified by living versus deceased donors. The Vice-Chair agreed that the distinction is important.

Research staff asked members if donation after circulatory death (DCD) donors need to be identified by pediatric versus adult or overall DCD donors. The Vice-Chair noted that most pediatric kidney candidates (less than 10 years of age) receive lower kidney donor profile index (KDPI) kidney offers so kidneys from DCD donors would increase the KDPI. The Vice-Chair also noted that future kidney continuous distribution policies could change that. Another member also noted that KDPI might also change in the future because there are discussions about removing hepatitis C as part of the calculation.

Research staff asked for clarification about whether hepatitis C and human immunodeficiency virus (HIV) kidneys refer to the donor or recipient. The Vice-Chair suggested evaluation for both donors and recipients even though it is very uncommon in pediatrics and added that the SRTR could track trends over time.

Research staff asked for clarification about “size” when referring to delayed graft function stratified by age, size, and donor type. Members confirmed that it was referring to weight.

#### *Pancreas*

Research staff noted that pancreas has its own section because some of the kidney metrics won't apply. Currently there are only age stratifications for pancreas. Staff requested members send an email if there are any pancreas specific information that needs to be added to the monitoring report.

#### *Liver*

Research staff confirmed with members that the age stratification changes to ages 7-11 and 12-17 were acceptable.

Members had previously discussed including exception information for liver and intestine. Research staff asked if members were interested in seeing exception information for other organs as well. A member suggested collecting how often centers successfully apply for an exception. Research staff confirmed that the plan is to look at waitlist removal by exception status – for example, no exception, standard exception, or non-standard exception. Staff noted that review board functions might also be part of a separate monitoring report.

A member commented that they serve on the liver review board as a pediatric representative and the goal is to collect granular information about exception scores and transplant versus lab MELD<sup>1</sup> scores at transplant. A member added that it would be important for future development. Staff noted that as all organ systems move to continuous distribution they are creating or updating review boards and those efforts will have their own monitoring reports.

The Committee had no further comments or questions.

### **3. Policy Oversight Committee Update**

The Vice-Chair provided an update on the work of the Policy Oversight Committee.

#### Presentation summary:

The presentation included the POC's role in the policy development process, including the following:

- New project review

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<sup>1</sup> Model for End-Stage Liver Disease

- Pre-public comment review
- Policy priorities
- Benefit scoring
- Post-implementation monitoring

Summary of discussion:

The Vice-Chair commented that it is promising to see that equity is an important part of the POC discussions.

**4. Discussion: Pediatric National Heart Review Board Improvement Ideas**

Staff noted that the plan is to introduce this topic to the committee and allow members time to have discussions with their community. Additional information will be brought back to the committee for discussion at a future meeting.

Presentation Summary:

A member provided information about concerns from the community regarding how heart review boards are operating and how improvements can be made to the process. This includes the following:

- Narratives in the exception requests often do not provide enough information for the reviewers.
- When a majority decision has been reached and the case closes, should there still be an opportunity for reviewers to vote and provide feedback on the exception request. Commenters recognize the importance of not delaying the approval of the exception request while also noting that additional comments might be useful.
- Reviewers having the ability to see their own previously submitted comments on exception requests. Comments were that it would not bias the existing reviewers but would refrain from sharing other reviewer's comments.

The member agreed to consolidate additional comments from the community and bring the information back to the Pediatric Committee during a future call.

Summary of Discussion:

The Committee had no comments or questions.

**Upcoming Meeting**

- June 21, 2023 (Teleconference)

## Attendance

- **Committee Members**
  - Emily Perito
  - Rachel Engen
  - Caitlin Peterson
  - Caitlin Shearer
  - Daniel Ranch
  - Neha Bansal
  - Gonzalo Wallis
  - Jennifer Lau
  - Namrata Jain
  - Katherine Fields
  - Melissa McQueen
  - Meelie Debroy
  - Geoffrey Kurland
  - Shelley Mason
  - Reem Raafat
  - Sonya Kirmani
- **HRSA Representatives**
  - Marilyn Levi
  - Jim Bowman
- **SRTR Staff**
  - Simon Horslen
- **UNOS Staff**
  - Kieran McMahon
  - Amy Minkler
  - Eric Messick
  - Laura Schmitt
  - Dzhuliyana Handarova
  - Robert Hunter
  - Susan Tlusty
- **Other Attendees**
  - JoAnn Morey