

**OPTN Pediatric Transplantation Committee
Meeting Summary
October 15, 2019
Chicago, Illinois**

**George Mazariegos, MD, Chair
Evelyn Hsu, MD, Vice Chair**

Introduction

The OPTN Pediatric Transplantation Committee (the Committee) met in Chicago, Illinois on 10/15/2019 to discuss the following agenda items:

1. Committee Charge Update
2. Policy Oversight Committee (POC) Update
3. SRTR Annual Data Report
4. Pediatric Heart Allocation Project Update
5. Liver Allocation Update – Pediatric Perspective
6. Kidney-Pancreas Allocation Update – Pediatric Perspective
7. Collaborative Improvement Project Update
8. Bylaws Education Feedback
9. Ethical Principles of Pediatric Organ Allocation
10. New Project Discussion

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

1. Committee Charge Update

All OPTN Committee are being asked to review their current charges and update if necessary. The Committee reviewed their charge.

Summary of discussion:

The Chair suggested adding language to highlight the unique needs of pediatric patients. The Committee agreed with the proposed change.

A formal vote was taken regarding: do you support sending the updated charge to the Board of Directors for approval?

Results were as follows: 16 (100%) Yes; 0 (0%) Abstain; 0 (0%) No

Next steps:

The charge will be sent to the Board for final approval during their December meeting.

2. Policy Oversight Committee (POC) Update

The Vice Chair provided an update on the work of the POC.

Summary of discussion:

The Vice Chair provided an overview on the strategic policy priorities that have been developed by the POC. The Chair asked if the POC discussed improving long-term outcomes after transplant as a potential

theme. The Vice Chair stated that they primarily focused on themes related to access to transplant. UNOS staff outlined how the POC decided on the three final strategic priorities. A Committee member noted that Committees can still pursue projects that do not fit into one of the strategic policy priorities.

Next steps:

The Committee will consider the strategic policy priorities when discussing new projects.

3. SRTR Annual Data Report

The Committee requested to review pediatric outcomes metrics prior to new project discussion. The Scientific Registry of Transplant Recipients (SRTR) representative presented data on pediatric waitlist mortality from the SRTR Annual Data Report (ADR).

Summary of discussion:

The SRTR representative presented high-level data on pre-transplant mortality for pediatric candidates across organ types (kidney, liver, heart, intestine, and liver-intestine).

The Committee discussed the potential reasons for the improvement in pre-transplant mortality for pediatric heart candidates with idiopathic cardiomyopathy (CM). The Committee also discussed the impact of ventricular assist devices (VADs). The data presented did not include results of changes to heart allocation in 2018.

The Committee agreed that it would be beneficial to include data on pre-transplant mortality by diagnosis for organs other than heart. The Committee also suggested adding the counts of the patients included in the cohort for each figure in the ADR. The Committee suggested also including:

- Changes in waitlist status for heart candidates
- Referrals (or some form of access to transplant, especially by socioeconomic status)
- Pre-transplant mortality by race for all organs
- Re-transplants
- Degree of sensitization
- Multi-organ combinations
- Comparison to expected mortality for the population

The Vice Chair suggested comparing the US outcomes data to the data in other countries. A Committee member commented that very young kidney candidates often must wait to be transplanted until they are grown to a sufficient size and this could be a factor in pre-transplant mortality for this cohort.

The Committee agreed to submit an abstract using the data to the American Transplant Congress (ATC).

A Committee member suggested more consistent review of pediatric programs when poor outcomes occur.

Next steps:

The SRTR representative and UNOS staff will coordinate synthesizing the additional requested data and the Committee will explore an abstract submission.

4. Pediatric Heart Allocation Project Update

The OPTN Thoracic Organ Transplantation Committee is sponsoring a project to create a national pediatric heart review board. Pediatric Committee members have participated in the work group with Thoracic Committee members. The project is slated to go out for public comment in spring 2020.

Summary of discussion:

The Pediatric Committee members who have participated in the work group gave an update on the work thus far. The two main goals of the project are to provide guidance for when exceptions are appropriate for cardiomyopathy patients and the formation of a pediatric national review board for status exceptions. A Committee member noted that after a recent policy change, which made the Status 1A requirements more stringent, the number of Status 1A exceptions has increased but waitlist mortality has not changed. Committee members agreed that there is a need for better guidance on when exceptions are appropriate for cardiomyopathy patients. A Committee member noted that many pediatric exception cases are reviewed by adult clinicians.

Committee members noted that adolescent heart candidates are being transplanted quickly under the new allocation system. A Committee member commented that the project was a good first step but the statuses may not be the best system for ordering candidates and suggested moving towards a system like the lung allocation score (LAS).

Next steps:

The work group members will keep the Committee updated on the work of the work group.

5. Liver Allocation Update – Pediatric Perspective

The Vice Chair provided an update for the Committee on the pediatric community perspective regarding recent implementations and proposed changes in liver allocation.

Summary of discussion:

The Vice Chair presented data on the first few months of the National Liver Review Board (NLRB). Under the NLRB, there has been a 14% decrease in pediatric transplants. The percent of pediatric exceptions cases that are approved also decreased. The Pediatric Committee was concerned that there would continue to be poor outcomes for pediatric patients until the new allocation system is implemented. The Vice Chair presented the results of a survey on the NLRB completed by the Society of Pediatric Liver Transplantation (SPLIT). Many of the respondents to the survey stated that they would like more detailed guidance for pediatric exceptions. The Vice Chair informed the Committee of a letter drafted by members of the pediatric community to improve pediatric liver transplant outcomes. The Vice Chair also provided information on the pediatric end-stage live disease (PELD) score and how it could be improved to more accurately reflect medical urgency.

The Pediatric Committee agreed to share the results of the SPLIT survey with the Liver Committee and will collaborate with Liver Committee on future updates to the NLRB guidance documents. The Pediatric Committee discussed the Appeals Review Team (ART) and agreed that there should be more pediatric expertise on the ART.

The Chair asked UNOS staff to provide more information on the performance of the pediatric NLRB, especially the number of pediatric transplants and the median exception score granted. The Committee noted that pediatric candidates actually compete with adult candidates for offers under the current system.

The Committee discussed if it would be possible to review the exception reviews and asked to be kept up to date on this effort of the NLRB Subcommittee.

Next steps:

Interested Committee members will take part in ongoing NLRB conversations. Committee members will present the results of the SPLIT survey to the NLRB Subcommittee. UNOS staff will discuss the possibility of a pediatric-specific ART.

6. Kidney-Pancreas Allocation Update – Pediatric Perspective

Committee members provided the Committee with an update on the pediatric community perspective on proposed changes in kidney-pancreas allocation.

Summary of discussion:

A Committee member provided an overview on the proposed changes to kidney-pancreas allocation. The Committee member noted that the projected increase in pediatric transplants was due to broader sharing and not the increased pediatric priority. The Committee member also commented that there is the potential for increased delayed graft function due to the broader sharing. The Committee member also noted that kidney-pancreas candidates are prioritized ahead of pediatric candidates, which could disadvantage pediatric candidates in areas with an active kidney-pancreas program. The Committee member commented that pediatric candidates do not have sufficient access to pediatric donors. The Committee member noted that the kidney donor profile index (KDPI) score was not calculated using pediatric donors to pediatric recipients so KDPI may not be a good representation of the quality of pediatric donors. As a result, many of these donors have high KDPI, which pediatric candidates do not have access to. The Committee agreed that pediatric candidates should have better access to pediatric donors. They were also concerned that kidney-pancreas priority could disadvantage pediatric candidates.

The Committee discussed ways to get better access to pediatric donors for pediatric recipients. A Committee member noted that many pediatric donor families would prefer pediatric donors are offered to a pediatric candidate. The Vice Chair asked if it would be preferable to re-calculated KDPI or advocate for allocation changes to give pediatric candidates more access to donors with KDPI > 35. A Committee member also suggested moving pediatric donors with KDPI > 35 to Sequence B, where pediatric candidates already have priority. The SRTR representatives agreed that re-calculating KPDI could be a good option.

Next steps:

The Committee will continue to advocate for more access for pediatric candidates and will collaborate with the Kidney Committee on future changes.

7. Collaborative Improvement Project Update

The UNOS Organizational Excellence Department is working on a Collaborative Improvement (CI) project looking at organ offer acceptance rates for pediatric programs.

Summary of discussion:

UNOS staff provided an update on the project. The Pediatric Committee offered to provide input on scoping the project and how to measure good organ offer acceptance.

Next steps:

UNOS staff will continue to update the Committee on the status of the project.

8. Bylaws Education Feedback

The application period for the pediatric component applications closes on December 3, 2019. The community has expressed a desire for additional education regarding the bylaws and the UNOS Member Quality Department is working on developing a podcast to provide more information.

Summary of discussion:

A Committee member suggested more education on the bylaws for the general public. Other Committee members suggested including detailed information on the applications in the podcast. A Committee member also suggested providing additional communications to OPOs who may be asked for procurement records.

Next steps:

UNOS staff will update the Committee when the podcast is posted.

9. Ethical Principles of Pediatric Organ Allocation

The Vice Chair of the OPTN Ethics Committee presented the principles of pediatric organ allocation that were included in a white paper in 2014.

Summary of discussion:

The Ethics Committee Vice Chair presented the ethical principles included in the white paper in 2014. The Ethics Vice Chair noted that there are arguments that would prioritize adults ahead of pediatric candidates, as there are always contradictory arguments to be made. The Committee discussed different ethical aspects of pediatric organ allocation, including social value and instrumental value of potential transplant recipients.

The Chair stated that the ethical principles of pediatric organ allocation are not well known. The Committee agreed that the principles should be better publicized, especially so that other committees utilize the document in their discussions. The Committee agreed to work with the Ethics Committee on educating the community and publishing a peer reviewed paper with the principles. The Committee also noted that there should be a consistent approach to considering pediatric allocation in the policy development process.

The Committee discussed completing a gap analysis on the application of the ethical principles in current organ allocation.

The Committee also discussed ways to ensure that organ-specific committees are properly considering pediatric prioritization in allocation changes moving forward.

Next steps:

The Committee will collaborate with the Ethics Committee on a project regarding the use of the ethical principles of pediatric allocation.

10. New Project Discussion

The Committee has previously discussed potential next projects but has not decided what to work on next.

Summary of discussion:

The Committee reviewed a list of potential next projects that they previously compiled. They discussed each of the projects on the list. They removed projects that were no longer relevant and added new projects that they may want to pursue. After the initial review, the Committee decided to further discuss the following projects.

1. Assess for Disadvantaged Patients in the Allocation System
2. Increase Use of Domino Transplant
3. Re-doing PELD
4. Improving Access for Pediatric Candidates in Kidney Allocation
5. Organ and Offer Acceptance Practices

6. Increase Participation of Pediatric Kidney Programs in Kidney-Paired Donation (KPD)
7. Update Recipient Follow-up Data Collection
8. Peer Review Publication on Gaps in Application of Ethical Principles of Pediatric Allocation

The Committee then split into two groups to discuss the projects listed above. For each project, the groups were asked with providing responses to the following items:

- POC Strategic Policy Priority
- Strategic Theme
- Problem Statement
- Evidence
- Type of Project
- Effort

The two groups then re-convened, shared their responses, and discussed which projects to pursue. After the discussion, Committee members took an unofficial vote on the projects to prioritize for future work. As a result of the vote, the Committee will prioritize the following projects:

- Assess for Disadvantaged Patients in the Allocation System
- Peer Review Publication on Gaps in Application of Ethical Principles of Pediatric Allocation
- Re-doing PELD
- Improving Access for Pediatric Candidates in Kidney Allocation

Those projects not prioritized will still be recorded for future consideration.

Next steps:

The Committee will move forward with the projects listed above.

Upcoming Meetings

- November 20, 2019 – Teleconference
- December 18, 2019 - Teleconference