OPTN Pediatric Transplantation Committee
Meeting Summary
August 17, 2022
Conference Call

Emily Perito, MD, Chair
Rachel Engen, MD, Vice Chair

Introduction

The OPTN Pediatric Transplantation Committee (the Committee) met via Citrix GoTo teleconference on 08/17/2022 to discuss the following agenda items:

1. Review of Pediatric EPTS Data Request Recommendation
2. Public Comment Presentation: Continued Review of National Liver Review Board Guidance
3. Public Comment Presentation: Revise Lung Review Board Guidelines, Guidance, and Policy for Continuous Distribution

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

1. Review of Pediatric EPTS Data Requestion Recommendation

The Committee reviewed their recommendation for the Evaluating Predictive Ability of Estimated Post-Transplant survival (EPTS) in Pediatric Kidney Recipient's data request.

Summary of discussion:

A Committee member asked if EPTS scores used for adults are more accurate than EPTS scores used for pediatrics, and if so, how much more accurate.

A member replied that the c-statistic for EPTS in adults is about a .65 - .68 range more accurate than EPTS scores used in pediatrics.

A member further explained that EPTS does not currently apply to all children. Sometimes, the online calculator will not generate a value when attempting to use an online calculator to determine a candidate's EPTS score. In the current allocation system, adults with EPTS less than twenty percent are expected to have more prolonged post-transplant survival and are given priority for certain kidney groups.

A member stated that EPTS cannot predict pediatric post-transplant survival; therefore, if EPTS is used in adults, then kids should have the most favorable EPTS score to use as a part of their priority since the EPTS score is not as accurate for them.

A member suggested publishing the results of the data request.

Next steps:

UNOS staff will present the data request results at an upcoming Committee meeting.

2. Public Comment Presentation: Continued Review of National Liver Review Board Guidance

The Committee heard a presentation on the OPTN Liver and Intestinal Organ Transplantation Committee's public comment proposal titled: Continued Review of National Liver Review Board Guidance.

Summary of discussion:

The Committee agreed with the proposed guidance, specific to pediatric candidates with CFLD. The Committee recognizes that the current standard exception was written in reference to lung-liver candidates, not liver-only candidates. Offering the liver alone may improve lung function, and once lung function declines past a certain point, the candidate requires a liver-lung transplant.

The Committee suggested clarifying the wording of this guidance since there was confusion as to whether it applied to lung-liver or liver candidates.

A member asked how to differentiate growth failure from liver disease in the context of cystic fibrosis (CF) from other potential causes of growth failure in CF patients.

The presenter stated that the proposed language is meant to encourage those applying for an exception to justify that they have done everything possible to address growth failure.

A member asked about the rationale behind 70% for FEV1.

The Chair responded that it is based on the published literature showing that these candidates are moving towards more advanced lung disease, thus reducing their opportunity for a liver transplant.

Next steps:

Comments will be posted on behalf of the Committee on the OPTN website.

3. Public Comment Presentation: Revise Lung Review Board Guidelines, Guidance, and Policy for Continuous Distribution

The Committee heard a presentation from the OPTN Lung Transplantation Committee on their public comment proposal titled: Revise Lung Review Board Guidelines, Guidance, and Policy for Continuous Distribution.

Summary of discussion:

A Committee member asked how many review board members would review a pediatric case.

The presenter clarified that there are twelve reviewers on the board, nine of whom are assigned to a pediatric case, of which three are pediatric providers. The presenter further explained that there are only twelve pediatric lung transplant centers, and it is a lot to ask those centers always to have someone on the review board. Currently, the review board is predominately adult transplant provider.

Another member noted that it would be helpful to include guidance on requesting a priority 1 equivalent score.

The presenter explained that requesting a priority 1 equivalent score for pediatrics is specific to the criteria an individual would need to meet to be eligible to move from priority 2 to priority 1. The presenter noted that this is similar to pulmonary hypertension, which is that they have to have specific criteria, such as; right heart catheterization data with a pressure greater than 15, a cardiac index less than 1.5, etc, to be eligible for a priority. Similarly, a pediatric patient should be eligible for specific criteria to move from a priority 2 to a priority 1.

Another member noted that having evidence-based specific criteria within the guidance document is ideal if an individual considers requesting additional priority. Additionally, the member mentioned that exception requests would be more effectively reviewed when the transplant program includes all the needed information.

Another member asked if there is any flexibility to have a more pediatric-focused review board, three reviewers would be pediatrics, and two are adult providers.

The presenter responded that to remain consistent, cannot be any changes to the number of reviewers for each case. If this were the case, all the patients would need to be reduced to five reviewers. The presenter also clarified that there is a possibility that a pediatric provider will be asked to review an adult case; however, if it's a pediatric case, then all three pediatric representatives will be asked to review, as opposed to a random selection.

Another member suggested having an alternative pediatric center in case one of the review board's pediatric representatives could not vote on a pediatric case.

The presenter replied that there are limitations on what can and cannot be done. Having an alternative center not actively represented on the review board as one of the twelve members may not be an option.

Another member asked how many pediatric cases with priority 2 get raised to priority 1.

The presenter responded that less than ten pediatric cases are moved from a priority 2 to a priority 1 a year.

Next steps:

Comments will be posted on behalf of the Committee on the OPTN website.

Upcoming Meeting

- October 6, 2022

Attendance

- **Committee Members**
  - Evelyn Hsu
  - Emily Perito
  - Rachel Engen
  - Neha Bansal
  - Brian Feingold
  - Caitlin Peterson
  - Caitlin Shearer
  - Douglas Mogul
  - Geoffrey Kurland
  - Gonzalo Wallis
  - Jennifer Lau
  - Johanna Mishra
  - Kara Ventura
  - Meelie DebRoy
  - Namrata Jain
  - Reem Raafat
  - Shantavia Edmonds
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
- **SRTR Staff**
- **UNOS Staff**
  - Tamika Watkins
  - Matthew Cafarella
  - Rebecca Brookman
  - Kaitlin Swanner
  - Krissy Laurie
  - Lauren Mauk
  - Samantha Weiss

- **Other Attendees**
  - Erika Lease
  - Melissa McQueen