OPTN Pediatric Transplantation Committee
Meeting Summary
February 17, 2021
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 2/17/2021 to discuss the following agenda items:

1. Organ Procurement and Transplantation Network (OPTN) Governance Presentation
2. Liver Committee Public Comment Proposal: Calculate Median MELD at Transplant (MMaT) around the Donor Hospital & Update Sorting within Liver Allocation
3. Liver Committee Public Comment Proposal: Update National Liver Review Board Guidance Documents & Policy Clarification
4. Continuous Distribution Update

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

1. Organ Procurement and Transplantation Network (OPTN) Governance Presentation

The Committee received a training on Organ Procurement and Transplantation Network (OPTN) Governance that aimed to help members understand the 4 governing structures of the OPTN (National Organ Transplant Act (NOTA), OPTN Final Rule, OPTN Contract, and OPTN Policies & Bylaws) and how these structures impact their role as a committee member.

Summary of discussion:

There were no questions or discussion.

2. Liver Committee Public Comment Proposal: Calculate Median MELD at Transplant (MMaT) around the Donor Hospital & Update Sorting within Liver Allocation

The Committee reviewed the Liver Committee's public comment proposal and provided feedback.

The proposal will calculate the median MELD at transplant (MMaT) for each donor hospital based on transplants performed within 150 nautical miles (NM) of the donor hospital and assign exception scores to exception candidates on the match run relative to the MMaT for the donor hospital where the match is run. These exception candidates will then be ranked against each other based on the time since submission of earliest approved exception.

The proposal will also update the sorting of liver allocation, so lab candidates (ranked by time at score or higher) will now be ranked ahead of exception candidates of the same MELD/PELD score and blood type compatibility.

Summary of discussion:

A member inquired whether this proposal applies to adult and children candidates or just adult candidates. The presenter stated that this only applies to adults. Staff clarified that the new MMaT calculation would apply to the 12-17 year olds candidates who have MELD exceptions scores.

A member mentioned that, while it is true that babies are the ones with higher exception scores, he or she suspected the adolescents tend to have lower exception scores, so they may be disfavored with this change in sorting. The Chair stated that one third of the adolescents need organs from adult donors and have lower exception scores. Adolescent candidates have MELD scores so their MELD exception scores will vary based on the MMaT of the donor hospital. Adolescent exception candidates would be ranked behind adult lab candidates of the same MELD or PELD score and blood type compatibility. The presenter countered by inquiring if adolescents with MELD exceptions are worse off than adults with lab MELD scores, other than being ranked behind the lab candidates for that MELD score.

A member noted that a larger proportion of adolescent candidates are listed with an exception score so the proposal to rank exception candidates behind candidates with a lab score of the same MELD/PELD and blood type compatibility would disproportionately impact adolescent candidates. The presenter explained that, with adults, lab candidates have higher waitlist mortality than exception candidates and that might not necessarily be the case with pediatrics.

A member stated that the reason exception candidates have lower waiting list mortality is due to hepatocellular carcinoma (HCC), which has some ability to withstand longer periods of time; however, adolescents receive exceptions for different reasons, the same assumption about mortality rates for exception candidates cannot be made. The presenter continued by stating that the data doesn't show that pediatric candidates are unfairly disadvantaged by this.

The Chair stated that the Committee's concern is that the pediatric perspective wasn't considered when deciding this proposal and it doesn't cite any pediatric data. The Chair expressed concern that the MMaT score will change, assuming it won't cause a problem for pediatric candidates, without doing the data modeling that normally precedes an allocation change like this.

The Chair suggested considering whether adolescents should have PELD scores and exception scores assigned relative a median PELD at transplant, instead of a MMaT, but it takes a long time to understand the impact on adolescents because the number of adolescent candidates are small.

The presenter stated that the Liver Committee will have to monitor the effects this proposal has on adolescent MELD exception candidates and asked if the Committee had any suggestions on how to account for the one-third of adolescents that may be disadvantaged. The Chair suggested considering all pediatric scores as lab scores, since it's the ranking of candidates with a lab score ahead of candidates with an exception score when the MELD and PELD and blood type compatibility are the same that is concerning. The Chair explained that a concern with this suggestion is figuring out the time at score, but suggested using the time at the exception score instead of the time since submission of earliest approved exception.

3. Liver Committee Public Comment Proposal: Update National Liver Review Board Guidance Documents & Policy Clarification

The Committee reviewed the Liver Committee's public comment proposal and provided feedback.

This proposal will increase equity and efficiency in granting exception requests. It will include the following changes:

- Cholangiocarcinoma (CCA) exception criteria

- Adult Other Diagnosis Guidance: neuroendocrine tumors and primary sclerosing cholangitis
- Pediatric Guidance
    - Complications of portal hypertension, including ascites and gastrointestinal (GI) bleeding
    - Growth failure or nutritional insufficiency
    - Metabolic liver disease
    - Conclusion section

Summary of discussion:

The Chair stated that this is a great example of collaboration since some of the wording for this proposal that applies to pediatrics was developed within the joint Liver and Pediatric Committee.

4. Continuous Distribution Update

The Workgroup received an update that the Kidney & Pancreas Continuous Distribution Workgroup had submitted a data request in order to inform their weights and rating scales for pediatric prioritization. The data request will be presented to the Kidney & Pancreas Continuous Distribution Workgroup in the spring of 2021.

The data request included the following:

- Pediatric Candidate/Recipient Characteristics
    - Age
    - Race/Ethnicity
    - Diagnosis
    - Multi-organ
- Pediatric Waitlist Outcomes
    - Transplant Rate
    - Waiting List Mortality
    - Wait Time
    - Stratified by candidate/recipient characteristics
- Characteristics of Donors Used By Pediatric Transplant
    - Age
    - Race/Ethnicity
    - Kidney Donor Profile Index (KDPI)

Summary of discussion:

There were no questions or comments. The meeting was adjourned.

Upcoming Meetings

- March 17, 2021 (Teleconference)
- March 30, 2021 (Virtual In-Person)

Attendance

- **Committee Members**
  - Emily Perito
  - Abigail Martin
  - Brian Feingold
  - Caitlin Shearer
  - Douglas Mogul
  - Johanna Mishra
  - Regino Gonzalez-Peralta
  - Sam Endicott
  - Shellie Mason
  - William Dreyer
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
- **SRTR Staff**
  - Chris Folken
  - Jodi Smith
- **UNOS Staff**
  - Matt Cafarella
  - Rebecca Brookman
  - Betsy Ganz
  - Julia Foutz
  - Leah Slife
  - Lloyd Board
  - Matt Prentice
  - Rebecca Murdock
- **Other Attendees**
  - James Pomposelli
  - Joseph Hillenburg
  - Rachel Engen
  - Sharon Bartosh