

**OPTN/UNOS Pediatric Transplantation Committee**  
**Meeting Minutes**  
**October 17, 2018**  
**Conference Call**

**George V. Mazariegos, M.D., Chair**  
**Evelyn K. Hsu, M.D., Vice Chair**

## **Introduction**

The Pediatric Transplantation Committee met via teleconference on 10/17/2018 to discuss the following agenda items:

1. Guidance on Pediatric Transplant Recipient Transition and Transfer
2. Public Comment – Eliminate the Use of DSAs and Regions From Liver Distribution

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

### **1. Guidance on Pediatric Transplant Recipient Transition and Transfer**

The Committee reviewed the feedback received during the recent public comment period and discussed amendments to the guidance document.

#### Summary of discussion:

The Committee's guidance document on *Pediatric Transplant Recipient Transition and Transfer* was out for public comment from August 3, 2018 to October 1, 2018. The proposal received 274 comments from OPTN regions and committees, transplant societies, and individuals. Many of these comments not only shared support, but also recommendations for enhancements. These recommendations focused on the following two areas:

- Suggestions to enhance recommendations in the guidance document
- Desire for OPTN policy requirement for transplant hospitals policies or procedures on recipient transition and transfer, and benchmark comparison

#### Suggestions to enhance recommendations in the guidance document

These included:

- formalizing transition processes at pediatric transplant hospitals and early engagement with the recipient and their family
- the need for recipient-focused approach that considered the cultural practices of the family
- expanded detail on content for a robust transition care plan and detailed information sharing between programs
- the need for standardization in the transfer process and diligent engagement with involved adult medical care teams

The Committee agreed with many of these recommendations and amended the guidance accordingly.

#### OPTN Policy Requirement for Transplant Hospitals on Recipient Transition and Transfer, and Benchmark Comparison

The idea of an OPTN policy requirement for transplant hospitals to have policies or procedures on recipient transition and transfer, and the development of benchmarks for lost to follow-up designation were included in several comments. Though outside the scope of this proposal, the

Committee feels these ideas are important. Any future policy requirement will need to include mechanisms for objectively evaluating program performance and addressing situations when outlier transplant programs are identified, either through process improvement or a peer-review process. The Committee will have future project discussions with the OPTN/UNOS Membership and Professional Standards Committee (MPSC) on these ideas.

#### Other Feedback Received

Feedback was also received in the following areas:

- Explore a way to “disincentivize” transplant programs from inappropriately using lost to follow-up designation on TRF forms
- Monitor the impact of the guidance on providers’ existing workloads
- Develop a mechanism between electronic medical record (EMR) platforms and OPTN systems for data submission
- Observed lack of survey engagement with recipients or their families

The Committee discussed this input, noting that the first three ideas extended outside the scope of this project. The Committee will have future discussions on the concept of a policy requirements for transition and transfer policies and procedures. The first three bullet points above will be important considerations in this potential project.

Regarding the lack of survey engagement with recipients and their families, the Committee members affirmed their belief that the primary focus of a transplant teams’ efforts is to treat a patient with end-stage organ failure and promote the optimal outcome possible. Feedback in support of this guidance was received from transplant recipients, and the OPTN/UNOS Patient Affairs Committee. However, the OPTN’s position is that guidance documents are targeted to transplant professionals as resources to address real time operational challenges. Whether, or the degree to which, a transplant program chooses to use the resource is a decision best left to the individual program and their judgement what may help individual patients. Efforts on patient-centered guidance are best led by other organizations and groups.

After considering the feedback in-total, the Committee approved the changes to the guidance document, and recommended consideration by the OPTN/UNOS Board of Directors at their December 2018 meeting (Yes – 12, No – 0, Abstain – 0).

#### Next steps:

UNOS staff will prepare the necessary materials for the Board meeting.

The Chair will be in attendance at the Board meeting to provide updates and answer questions from Board members. A Board debriefing will be shared during the Committee’s December 2018 conference call.

## **2. Public Comment – Eliminate the Use of DSAs and Regions from Liver Distribution**

The Chair of the OPTN/UNOS Liver and Intestine Transplantation Committee shared a presentation on policy changes regarding liver distribution.

#### Summary of discussion:

The Liver Committee has been diligently developing a proposal to amend OPTN policies pertaining to distribution of livers from deceased donors. The Committee was previously apprised of this project in July 2018, and members have been participating on Liver Committee calls to provide insight and advice from the pediatric liver transplant perspective.

The Committee understands the impetus of this proposal is to ensure liver distribution policies are in compliance with the OPTN Final Rule. As a result, the development timeline was short and opportunities for collaboration existed only in real-time. The Chair and Vice Chair verbalized their appreciation for the early and ongoing collaboration with the Liver Committee over the last several weeks.

The Liver Committee chair carefully explained the proposal, with particular focus on the impacts to pediatric liver transplantation. At the conclusion of the presentation, the Chair opened the floor for discussion:

- It is routine practice for pediatric liver transplant teams to travel the 500-600 mile distances outlined in the proposal. Frequently, pediatric liver teams travel beyond these distances to recover livers from deceased organ donors. The Committee supports wide sharing of deceased donor livers over either 500 or 600 nautical miles (nm). The Committee would support an allocation distance for livers from pediatric deceased donors up to 1,000 nm.
- The complexities of liver disease and the potential for precipitous decompensation in pediatric liver transplant candidates differ widely from adult liver transplant candidates. As a result, the Model for End-Stage Liver Disease (MELD) or Pediatric End-Stage Liver Disease (PELD) scores may not accurately reflect their severity of disease or risk of dying on the waiting list. Exception scores are often required to accurately reflect pediatric liver candidates' morbidity or mortality risk. The Committee fully supports the concept in the proposal of no cap on MELD or PELD exception scores for pediatric liver transplant candidates.

Regarding the request for feedback from the Liver Committee in two areas:

- What is your opinion of this proposal of broader 2-circle sharing at 32 threshold? Do you prefer one of the other models, such as the acuity based model?
  - The Committee felt the acuity (AC) model appears to result in greater gains in transplant count for pediatric liver transplant candidates. Broader sharing (B2C) benefits pediatric candidates and will likely lead to increased utilization as well (e.g.: transplanting two small pediatric liver candidates with one larger donor organ).
- What is your opinion of the MELD/PELD sharing threshold? Is 32 appropriate, or would you prefer 29? Or 35?
  - The Committee felt a lower MELD/PELD sharing threshold would have the potential for broader sharing to candidates waiting for a liver transplant. This will serve to benefit pediatric liver transplant candidates.

Though the development time line for this proposal was short, the members shared their desire to critically examine a further breakdown of transplant outcomes and waitlist mortality for both the AC and B2C models across pediatric age ranges and candidate diagnoses. This additional breakdown would aid members' understanding to the appearance of slightly increased waiting list mortality for pediatric liver candidates under either model, despite the expected increased transplant rates and lower median MELD or PELD score at the time of transplant.

Members also requested in regular post-implementation updates examining transplant counts, waitlist mortality, and waitlist removals for pediatric liver transplant candidates and recipients by candidate age, status or score, and diagnosis.

The Chair thanked members and the Liver Committee Chair for the engaging discussion.

Next steps:

UNOS staff will draft a formal response from the Committee and share with the Chair and Vice Chair for review. Thereafter, the response will be posted on the OPTN website and shared with the Liver Committee.

With no other business to discuss, the conference call was adjourned.

**Upcoming Meetings**

- 3rd Wednesday of every month, 4-5 pm EST
- March 19, 2019, in-person meeting in Richmond