OPTN/UNOS Pediatric Transplantation Committee
Meeting Minutes
August 15, 2018
Conference Call

George Mazariegos, M.D. – Chair
Evelyn Hsu, M.D. – Vice Chair

Introduction

The Pediatric Transplantation Committee met via teleconference on August 15, 2018 to discuss the following agenda items:

1. Project Report – *Guidance on Pediatric Transplant Recipient Transition and Transfer*
2. Task Force Reports
3. Basecamp Onboarding

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

1. Project Report – Guidance on Pediatric Transplant Recipient Transition and Transfer

UNOS staff provided an update on the Committee's guidance document that is out for public comment.

Summary of discussion:

UNOS staff reported the current public comment period began on August 3, 2018 and will conclude on October 3, 2018. Feedback on the Committee's guidance document, *Pediatric Transplant Recipient Transition and Transfer*, was being sought. To-date:

- National webinar with ~100 participants
- Forthcoming presentations to two OPTN committees
- Outreach to external stakeholder groups has occurred

The Committee will have an opportunity to consider the comments received during their October 19, 2018 conference call and vote whether to recommend the guidance to the OPTN/UNOS Board of Directors during their December 2018 meeting.

Next steps:

UNOS staff will keep the Committee apprised of comments received.

UNOS staff will facilitate future presentation requests.

2. Task Force Reports

Task Force members provided updates from the Kidney/Pancreas Working Group, and Liver & Intestine and Thoracic Committees.

Summary of discussion:

In July 2018, the Chair requested members form informal "Task Forces" to ensure pediatric representatives were engaged with the policy development discussions pertaining to amendments to organ allocation policies that use Donation Service Areas (DSAs) or regions for organ distribution. Members verbalized their interest in this concept and committed to being engaged with the Kidney/Pancreas Working Group, and Liver & Intestine and Thoracic Committees in the coming months. An update from the respective Task Forces appear below:

a) Liver Task Force:

Four committee members have been engaged with the Liver & Intestine Committee's discussions. Early discussion favored replacing instances where DSA or region are used in liver distribution with one of two fixed distance models using 500/600 nautical miles (nm) then national allocation (acuity circles), or 500 nm then national allocation (laddered circles). Members noted they were pleased with the progress to-date, which included broader sharing of livers from deceased pediatric donors, and support from the Liver Committee that these organs should be prioritized to liver candidates less than 18 years old. The Chair shared that implementation of the recently approved National Liver Review Board (NLRB) would be on-hold for a short period. Also, the role of a "cap" or score just below the median score at transplant for pediatric MELD/PELD exceptions was discussed. It was decided that a cap or "median score minus points" may disadvantage pediatric candidates and the Liver Committee is no longer considering these ideas. Future discussions will address simultaneous liver/kidney, intestine, and liver/intestine allocation.

The Committee appreciated the update and members commented on the importance of MELD or PELD exception scores to get pediatric liver candidates transplanted. Members asked, what would be the role of the NLRB? The Chair mentioned these concerns were brought up with the Liver Committee. The future pediatric liver review board was intended to, and will continue to, be composed entirely of pediatric liver specialists. This is seen as a substantial improvement over the current system. Also, review board guidelines previously established clinical criteria for exceptions and will continue to allow a transplant program to advocate for an appropriate score for their candidate. Members supported the idea of <u>not</u> having a score cap as discussed by the Liver Committee and Task Force members.

Committee members are encouraged to share comments and questions with their colleagues on the Liver Task Force.

This project is on an accelerated timeline:

- Liver Simulation Allocation Modeling (LSAM) due back from the Scientific Registry of Transplant Recipients (SRTR) at the end of September 2018
- A special public comment period in October 2018
- Board consideration in December 2018

b) Kidney Task Force:

Four committee members have been engaged with the Kidney/Pancreas Working Group's discussions. Members shared the Working Group reviewed data on acceptance practices and distance of the current system, and were committed to a solution in compliance with OPTN Final Rule. Early discussion favored replacing instances where DSA or region are used in kidney distribution with one of two fixed distance models using 75/150/350 nm, or 350/500/800 nm. The Working Group acknowledged the current timeline may limit the distribution model considered to the fixed distance model, but there was interest in one of the more complex models in the future.

Members shared some difficulty sharing the pediatric perspective during the initial discussions. Much of this was likely due to the Working Group transitioning away from a DSA-based distribution model to an alternative approach. Members also shared that the potential allocation priorities for a new allocation system did not appear to be that different from the current system. Task Force members will share their concerns during a future call about the risk of longer cold ischemic time (CIT), and organ quality (noted by Kidney Donor Profile Index (KDPI)) for pediatric kidney candidates.

One member questioned the mileage distances being considered by the Working Group. To maximize the chance of a pediatric donor kidney being allocated to a pediatric candidate, perhaps a substantially larger fixed distance should be considered, e.g: up to 1,500 nm. He suggested reviewing graft and recipient outcome data for pediatric transplants performed at hospitals that would meet the new training and experience requirements approved by the Board in 2015. This may inform the decision regarding a fixed distance.

Members then discussed whether there may be openness with the Working Group to consider the concept of kidneys from deceased donors being prioritized to pediatric candidates. Some members felt there was not as much enthusiasm toward the concept with the Working Group as compared to with the Liver Committee. UNOS staff encouraged Task Force members to articulate their concerns and ideas with the Working Group.

The Kidney/Pancreas Working Group will continue to work towards modeling requests for SRTR. Committee members are encouraged to share comments and questions with their colleagues on the Kidney Task Force.

This project is on the following timeline:

- Kidney Simulation Allocation Modeling (KSAM) due back from the SRTR at the end of November 2018
- Public comment in January 2019
- Board consideration in June 2019

c) Thoracic Task Force:

Four committee members have been engaged with the Thoracic Committee's discussions. Members shared the Thoracic Committee reviewed data heart transplant ischemic times and distances travel by recovery teams. The Thoracic Committee favored replacing instances where DSA or region are used in heart distribution with a fixed distance model using 150/250/500 nm distances. Recovery cost concerns have been a central theme of the discussions.

Task Force members shared their initial assessment was there was not likely an adverse impact on pediatric heart transplant candidates. Members shared concerns about pediatric status 1B candidates with the Thoracic Committee and these will be considered during future calls. Members also shared the 500+ nm distance for recoveries was a frequent occurrence in the pediatric heart transplant community. Conversely, distances up this amount are typically not seen in the adult heart transplant practice. Members shared that adding a second fixed distance circle for pediatric heart distribution beyond 500 nm may add a level of complexity that did not add a corresponding level of benefit. UNOS staff encouraged Task Force members to articulate their concerns and ideas with the Thoracic Committee.

The Thoracic Committee will continue to work towards modeling requests for SRTR. Committee members are encouraged to share comments and questions with their colleagues on the Thoracic Task Force.

This project is on an accelerated timeline:

- Thoracic Simulation Allocation Modeling (TSAM) due back from the SRTR at the end of November 2018
- Public comment in January 2019
- Board consideration in June 2019

<u>Next steps:</u>

Committee leadership encouraged members to remain dutifully engaged in the respective Committee/Working Group discussions. It was critical for the pediatric voice to be considered

contemporaneously by these groups and not be an “after thought”. Task Force members were encouraged to post their feedback/concerns in the respective Check-in area on the Committee’s Basecamp site in order to keep members informed on these fast moving projects.

3. Basecamp On-boarding

UNOS staff provided some Basecamp basics to the Committee.

Summary of discussion:

UNOS staff shared instructions and helpful tips to facilitate members’ use of Basecamp. This included:

- Purpose of three key areas of Basecamp (Task Force Check-ins, Chat, Message Board, and Documents) and suggested content for each area.
- How to access user profile settings and notification management tips

Next steps:

UNOS staff will be available for Basecamp questions.

Upcoming Meetings

- Task Force members
    - Kidney/Pancreas Workgroup – Tuesdays 4-5 PM (Eastern)
    - Liver Committee – Tuesdays 5-6 PM (Eastern)
    - Thoracic Committee – Thursdays 5-6 PM (Eastern)
- Full Committee conference calls -- 3rd Wednesday of each month 4-5 PM (Eastern)
- November 6, 2018 (Chicago)
- March 19, 2019 (Richmond)