

OPTN/UNOS Pediatric Transplantation Committee
Meeting Minutes
June 20, 2018
Conference Call

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

Introduction

The OPTN/UNOS Pediatric Transplantation Committee met via teleconference on June 20, 2018 to discuss the following agenda items:

1. Tracking Pediatric Transplant Outcomes Following Transition
2. Project updates
3. Update from OPTN/UNOS Board of Directors Meeting
4. Chair's Remarks

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

1. Tracking Pediatric Transplant Outcomes Following Transition

The Committee discussed the final draft of the guidance document on *Tracking Pediatric Transplant Outcomes Following Transition* and considered whether to recommend the guidance to the OPTN/UNOS Policy Oversight Committee (POC) for public comment.

Summary of discussion:

The Transition Subcommittee Chair shared an overview of the latest draft of the guidance. This draft reflects a more direct approach with less reliance on describing background reasoning. References are provided to support the summary statements about adolescent development, challenges with adolescent transplant recipients, etc... Background information was also amended to:

- Delineate transition vs transfer & explain linkage
- Show impact of normal adolescent development & complications to complex medical conditions
- Highlight three prevalent models of transfer for recipients
- Highlight responsibility of OPTN form submission
- Themes identified in the on-line survey

The guidance also highlights recommendations for pediatric transplant programs and adult providers that will accept transplant recipients. The guidance closes with a small number of references on transition and transfer and an appendix including supporting tables. The Subcommittee Chair thanked staff for the update and for their substantial assistance getting the project to the next stage.

The Chair thanked members for the update and opened the floor for discussion. Members verbalized their support for the document and commented on the valuable content contained within the guidance. The Committee briefly discussed the concept of a hybrid model of transfer; where an unaffiliated provider has primary responsibility for ongoing medical care and another transplant program is responsible for periodic following. Members felt this model reflected innovative thinking to improve recipient plan of care adherence, though the discussion did not reflect it was a common practice. UNOS staff reported feedback on this model could be sought during public comment.

UNOS staff then profiled the timeline for the project:

- Public comment – August to October 2018
- Committee discussion of public comment – November 2018
- Board consideration – December 2018

At the conclusion of the discussion, UNOS staff noted that a quorum of voting members was not present on the conference call. As a result, the Committee was not able to recommend the project to the POC. Members on the call verbalized their support for the guidance, but understood the need for quorum.

Next steps:

UNOS staff will proceed with an email vote of members whether to move forward to public comment. A short conference call will also be scheduled as a back-up.

2. Project updates

Committee members updated the Committee on two projects in the “analyzing the problem” status.

Summary of discussion:

Improve Pediatric Kidney Transplant Access

The Working Group met by conference call on June 14, 2018. The focus of this call was a discussion on two relevant articles on pediatric kidney transplantation and the Kidney Allocation System. The first discussion was on an AJT Letter to the Editor on pediatric kidney candidate priority. At the conclusion of the summary, working group members shared several points:

- The general desire to get all pediatric kidney transplant candidates transplanted.
- Potential of and the unclear degree of impact from the recent En-bloc Kidney policy change re: deceased kidney donors less than 18 kilograms.

The Working Group then discussed a viewpoint article that KAS does not appropriately stratify risk of pediatric deceased donor kidneys. At the conclusion of the summary, working group members shared several points:

- The concern of waiting times shortening for some adult candidates and waiting time for pediatric candidates remained unchanged after KAS implementation.
- KAS appeared to match organs for better longevity in adult candidates. KAS does not appear to perform the same for pediatric candidates.
- Diversity of opinions whether it was realistic to interpret long term outcomes based on three year KAS data.

At the conclusion of the working group call, members supported looking at a small set of additional data to help arrive at the point of a modeling request to the Scientific Registry of Transplant Recipients (SRTR).

The Chair thanked members for the update and opened the floor for discussion. Some members felt there was good progress being made by the working group, and others verbalized the desire to move quickly to SRTR modeling. UNOS staff expressed the modeling would likely commence soon, but it was important to diligently explore the issues in order to avoid the need to correct policy changes in the future. UNOS staff then reported future working group calls are scheduled in July and August 2018.

Reduce Pediatric Liver Waiting List Mortality

The working group held their first conference call on June 19, 2018 with colleagues from the OPTN/UNOS Liver and Intestine Transplantation Committee. The call included discussions on administrative matters (group leaders from both committees, reoccurring conference calls), a short review of the data that compelled the Committee to move forward with the project, and a short discussion of the contemporaneous discussions related to geographic distribution of organs.

The working group then discussed what data elements would be useful to understand which candidates on the waiting list are dying, and what was their experience on the waiting list. This included:

- Liver candidates waiting by year and age at listing;
- Updated death rate by age/diagnosis/status 1b/region (Chronic liver disease, metabolic, tumor, other)
- Time to death for pediatric candidates on the liver waiting list;
- Offer and acceptance trends for pediatric candidates who died;
- Offers of pediatric deceased donor livers eventually transplanted to adults to pediatric candidates.

The Chair thanked members for the update and opened the floor for discussion. Members shared that they were pleased to see this project move forward after earlier delays. UNOS staff then profiled a work plan for the project in the approaching months.

Next steps:

Members will remain engaged with the working group in the approaching months, and report back to the Committee during conference calls and meetings.

3. Update from OPTN/UNOS Board of Directors Meeting

The Board of Directors meeting was held in Richmond, Virginia on June 11-12, 2018. Fifteen proposals were considered by the Board; five of the proposals were discussed in detail and approved. The remaining ten proposals were approved by the Board by a vote of 37 yes, 0 no, 0 abstentions.

In other discussions, there was an inquiry letter from Secretary of Health and Human Services requesting OPTN review compliance with the Final Rule relating to the liver allocation policy. This is ongoing and comes at the heels of earlier legal action taken by a law firm regarding lung allocation policies in 2017. This is directed at one specific organ allocation algorithm and less so at the entire organ allocation system.

The 2018-2021 strategic plan was adopted. This was presented by the VCA Committee earlier this year. The Board did approve the resource allocation changes so that increasing number of transplants was receiving 40% of resources for projects to increase organ transplants, and that 30% of resources would be dedicated to improving access and equity in transplantation. Each of the remaining goals received 10% allocation. The need to reevaluate the OPTN Strategic Plan comes up every three years, and ensures OPTN work is in alignment with these strategic goals.

Also discussed was proof of concept for constituent committees. The Committee heard a prior proposal on improving the function of OPTN committees during the spring of 2018. This proof of concept will be conducted with the Patient Affairs and Transplant Coordinators Committees to establish ways to get broader engagement from these two populations. They will report back to the Board after six months to discuss if this is a model OPTN can use to get wide engagement for a high functioning transplant system and good input on governing policies.

There were also breakout sessions regarding member quality optimization and overview of organ allocation analytics.

4. Chair's Remarks

The Chair thanked the Committee members for their diligent and thoughtful engagement over the last two years. He looks forward to continuing to serve the Committee in an at-large capacity for the next year.

With no further business to discuss, the call was adjourned.

Upcoming Meetings

- July 28, 2018 4-5 PM (Eastern)
- August 15, 2018 4-5 PM (Eastern)
- September 19, 2018 4-5 PM (Eastern)
- October 17, 2018 4-5 PM (Eastern)
- November 6, 2018 9 AM-3 PM (Chicago, IL)
- December 19, 2018 4-5 PM (Eastern)
- January 16, 2019 4-5 PM (Eastern)
- February 20, 2019 4-5 PM (Eastern)
- March 19, 2019 8:30 AM-3:30 PM (Richmond, VA)
- April 17, 2019 4-5 PM (Eastern)
- May 15, 2019 4-5 PM (Eastern)
- June 19, 2019 4-5 PM (Eastern)