

**OPTN/UNOS Pediatric Transplantation Committee**  
**Meeting Minutes**  
**November 15, 2017**  
**Conference Call**

**William Mahle, M.D., Chair**  
**George Mazariegos, M.D., Vice Chair**

**Introduction**

The OPTN/UNOS Pediatric Transplantation Committee met via teleconference on November 15, 2017 to discuss the following agenda items:

1. Project Update – Reduce Pediatric Liver Waiting List Mortality
2. Continued discussion on Pediatric Kidney

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

**1. Project Update – Reduce Pediatric Liver Waiting List Mortality**

The Vice Chair shared an update with the Committee regarding the next steps for the project to Reduce Pediatric Liver Waiting List Mortality.

Summary of discussion:

In August 2016, the Committee approached the OPTN/UNOS Policy Oversight Committee (POC) with a proposal to address three areas of concern in pediatric liver transplantation. The proposal intended to reduce pediatric liver waiting list mortality for the very young liver candidates (< 1 year old) and status 1B candidates, and address prolonged waiting time for candidates 12 to 17 years old. The POC and Executive Committee supported this proposal, but placed it on hold due to a lack of resources to develop proposal. The Board is considering an enterprise-level proposal at their December 2017 meeting and this may allow needed resources to become available.

For the benefit of new members, UNOS profiled a development timeline for the proposal leading up to present day. This update was well received by the members on the call. The Committee then discussed rationale for why it was appropriate to move forward with this proposal now. The Committee felt that the past proposals from the OPTN/UNOS Liver and Intestine Committee (National Liver Review Board Guidance and the development of a Pediatric National Liver Review Board) would be beneficial to pediatric liver transplantation. However, one peer-reviewed journal paper showed a racial disparity in rates of PELD/MELD Exception applications. Thus, the Liver Committee's work will only provide consistency *if* a liver transplant program applies for an exception on behalf of a candidate. The Committee feels the liver proposal under discussion would eliminate this racial disparity in PELD/MELD exceptions. The Committee also discussed the Liver Committee's proposal to Enhance Liver Distribution. The goal of this proposal was only intended to improve adult liver transplantation with no detrimental impact on pediatric liver transplantation. The Committee reviewed the LSAM modeling used for the Liver Committee's proposal and noted 1) showed a small positive impact on overall pediatric transplant count (this was not broken down further by age, e.g.: <1, 1-5, 6-12, 12-17 y/o), and 2) no predicted change in pediatric liver waitlist mortality. Based on these LASM results and the opportunities in the NLRB proposal, the Committee felt it was appropriate to re-approach the POC and Executive Committee's for resource approval.

The Committee then discussed the matter of alignment with the OPTN Strategic Plan:

- Committee feels this proposal is most closely aligned with Goal III.
  - The proposal is intended to improve pediatric waitlist outcomes by reducing or eliminating mortality in very young liver transplant candidates. Long-term pediatric recipient outcomes (graft and patient survival, growth, psychological development, quality of life, and decreased impact from comorbid conditions) are also expected to be improved by benefits of earlier transplantation. This is due to time-limited opportunity for growth and development (Prudential Lifespan Account), as well as the need to maximize life benefit post transplantation (Fair Innings Concept).
  - These liver transplant candidates, especially very young candidates, are detrimentally impacted from lack of appropriate size matched donors and rapid progression of liver disease.
- Committee acknowledges there will be some impact on Goal II
  - Consensus is that pediatric liver transplant candidates as a population have access to transplantation
  - Project would improve access to liver transplants for all pediatric candidates by prioritizing these candidates higher on match run lists.

Committee members then discussed the importance of messaging this proposal. Recommendations included 1) pediatric liver waiting list mortality is unchanged in the last several years...but this is not acceptable and we can do better, 2) there are expected gains in transplant numbers by expected increases segmental liver transplants, 3) the Committee feels the solution can address this pediatric issue without negatively impacting adult liver transplantation, 4) new data analysis of adult liver transplant outcomes showed equivalent outcomes in segmental vs whole liver transplants in non-status1A adults, and 5) robust support from the Liver Committee to pursue this project with the Committee leading the effort.

Next steps:

The Vice Chair will present the proposal to the POC on November 17, 2017. If approved, the Executive Committee will consider the proposal in January 2018. UNOS staff will update the Committee in January 2018.

**2. Continued discussion on Pediatric Kidney**

During the October 2017 in-person meeting, the Committee heard a guest presentation regarding the impact of the Kidney Allocation System (KAS) on pediatric kidney transplantation. The Committee had follow-up discussions on this area of concern.

Summary of discussion:

The Committee has had several discussions on recent conference calls and meetings regarding concerns of decreased transplant rates for pediatric kidney transplant candidates as a result of KAS implementation. As a result of these conversations, there is a strong desire with members to sponsor policy changes to KAS to address gaps for pediatric kidney candidates.

Contemporaneously, the OPTN/UNOS Kidney Transplantation Committee has shared similar concerns during their conference calls and identified the need to amend KAS to address:

- Decreased transplant rates for pediatric kidney transplant candidates, and
- Highly sensitized kidney transplant candidates.

The Kidney Committee has reviewed post-implementation data on KAS to gain a better understanding of the potential issues. As a result of this analysis, the Kidney Committee Chair has committed to further discussion and review of additional data in December 2017. The

tentative plan is to develop a proposal for POC consideration in the early part of 2018. If approved, the Kidney Committee will need kidney transplantation partners from the Committee.

At the conclusion of the presentation, the Chair opened the floor for discussion. Members felt the earlier conversations have been informative, however they were not convinced that delayed graft function (DGF) cited in these presentations was influential in pediatric kidney transplant outcomes. One member commented that the issue is not that there is detriment to pediatric kidney candidates on the waiting list due to KAS, rather there's an indirect disadvantage; the pediatric community is not seeing the improvement that adult kidney transplantation has seen from KAS. Others on the Committee shared their agreement with this position and affirmed the need to analyze additional data to understand the issues at play.

Members verbalized concern that a Kidney Committee-driven project may not diligently consider the pediatric perspective. These concerns included the potential for other priorities for the Kidney Committee and that the pediatric perspective would not be carefully considered, and the low number of pediatric specialists on the Kidney Committee. UNOS staff reminded the Committee that their historical role has been to serve in an advisory/consulting capacity to other organ-specific committees. There has been some divergence from this role when the Committee sponsored changes to the training and experience requirements for key personnel at pediatric transplant programs.

To mitigate members' concerns, UNOS staff recommended members be receptive to participating on an inter-committee working groups to develop policy changes. Such working groups are a frequent occurrence to address policy development needs with diverse perspectives. This approach is used to carefully engage stakeholders early in the development phases of proposal. This collaboration is often needed for the life-cycle of the proposal's development. Pediatric Committee members tasked to the working group would be responsible for participating on conference calls, maintaining two-way communication between the Committee and working group, and providing frequent updates. Members on the call were receptive to this approach and seven individuals volunteered to participate on the working group.

The Chair thanked the members for their thoughtful discussion and asked the Committee to continue to be strong advocates for pediatric transplant candidates and recipients.

#### Next steps:

- The Chair will communicate with the Chair of the Kidney Committee in the next week to support the formation of a working group to develop a future proposal to update KAS.
- UNOS staff will keep the Committee informed of updates from the Kidney Committee.
- UNOS staff will share a list of volunteers from the Committee who are interested in collaborating on working group. Additional members who were interested in volunteering on a future working group were asked to share their desire with UNOS staff.

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

#### **Upcoming Meetings**

- January 17, 2018 4-5 PM Eastern (full committee conference call)
- February 21, 2018 4-5 PM Eastern (full committee conference call)
- March 21, 2018 4-5 PM Eastern (full committee conference call)
- April 19, 2018 9-3 Central (Chicago, IL)
- May 16, 2018 4-5 PM Eastern (full committee conference call)
- June 20, 2018 4-5 PM Eastern (full committee conference call)