

OPTN/UNOS Pediatric Transplantation Committee
Meeting Minutes
December 19, 2018
Conference Call

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

Introduction

The Pediatric Transplantation Committee (the Committee) met via teleconference on 12/19/2018 to discuss the following agenda items:

1. Update from OPTN/UNOS Board of Directors (Board) Meeting
2. Kidney-Pancreas Task Force Update
3. Follow-Up from 11/6/18 In-Person Meeting
4. Follow-Up on UNOS Staffing Changes

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

1. Update from OPTN/UNOS Board of Directors (Board) Meeting

The Board met on December 3-4, 2018 in Dallas, Texas. The chair of the Committee provided an update on the Board's actions.

Summary of discussion:

The Board approved the Consent Agenda, which included the Committee's guidance document titled, "Guidance on Pediatric Transplant Recipient Transition and Transfer." The Board approved the "Islet Cell Program Requirements" proposal, which required islet programs to be affiliated with a kidney, liver, or pancreas transplant program. The Board also approved the continuous distribution geographic framework. This framework will be used by UNOS, the committees, and the transplant community to shape future organ allocation systems.

UNOS staff noted that the Committee's guidance document is now available on the Resources page of the OPTN website.

The majority of the discussion at the Board meeting was on the Liver Committee's proposal to eliminate the use of donation service areas (DSAs) and regions in liver and intestine distribution. There were numerous amendments to the proposal brought forth by Board members. The major decision point was choosing between the Broader-2-Circles (B2C) model, which was proposed by the Liver Committee, and Acuity Circles (AC) model, which was put forth as an amendment. There were favorable components to each model. The chair noted that it was valuable to hear the perspective of family and patient representatives on the Board who emphasized considering the broadest sharing regardless of the cost. These representatives also emphasized putting forth an allocation system that is easy to explain to the broader transplant community. After much discussion, the AC model was chosen by a vote of 30-7-2. After this decision, there were several additional amendments, including adjusting the cap on model for end-stage liver disease (MELD) scores and extending the Region 8 split liver variance to all regions. The Board decided not to extend the variance until more detailed analysis by the Liver Committee is done. The Pediatric Committee could have some input on this discussion.

The National Liver Review Board (NLRB) is slated to go into effect in first quarter of 2019, with the new liver allocation being implemented approximately 90 days after the NLRB.

A committee member asked if there is any pending litigation or appeal to try to stop the new liver allocation policy. The chair noted that this concern was voiced as an expectation during the Board meeting. UNOS staff stated that they have not heard of any pending lawsuits at this time.

A committee member mentioned his or her belief that liver allocation has not been settled yet, so the committee should remain vigilant in looking out for pediatric interests in the changing landscape. The committee member also stated his or her concern that multivisceral or liver-intestine candidates will be vulnerable in the new allocation policy. The committee member stated that the NLRB will not provide a proper mechanism for appeal because these candidate's condition is not reflected by a MELD or pediatric end-stage liver disease (PELD) score.

UNOS staff stated that liver-intestine candidates will continue to receive priority and there are mechanisms for appeal through the NLRB system. UNOS staff then asked the committee member to expand upon his or her final point regarding the candidate's condition not being reflected by a MELD or PELD score.

The committee member stated that adult multi-organ candidates with certain conditions do not receive a blanket increase in MELD or PELD points. Instead they get an increase in MELD or PELD points corresponding to a 10% increase in 90-day mortality but do not fit into any of the standard exception categories.

The chair stated that the concern is relevant but there is a mechanism for these vulnerable candidates to receive an appropriate MELD or PELD score. The chair asked UNOS staff to distribute the intestine allocation policy within the Acuity Circle model to the committee. The chair also stated that it may be appropriate to consider assigning multivisceral and liver-intestine candidates a MELD or PELD score greater than median MELD at transplant (MMaT) to account for their additional comorbidities. This can be discussed in the future with the Liver Committee.

The chair noted that the AC model was modelled to be a bit more favorable for pediatric candidates than the B2C model, although B2C would have been an improvement as well. The chair also noted that pediatric donor allocation did move pediatric recipients to a higher sequence than the previously-approved allocation model.

The chair also informed the committee that the Board elected one at-large representative to fill a current vacancy, approved nominees for other Board vacancies, and the budget was approved.

A committee member asked if the committee can monitor at-large vacancies on the Board and potentially recommend pediatric nominees for these positions. A committee member who currently serves on the Board stated that there are already five or six pediatric representatives on the Board. A previous president of the Board made a concerted effort to make sure that all viewpoints are represented on the Board and this effort is being continued.

Next steps:

No next steps were identified.

2. Kidney-Pancreas Task Force Update

UNOS staff updated the Committee on the status of the Kidney-Pancreas Work Group.

Summary of Discussion:

SRTR modelling was submitted to the OPTN on 12/7/18. Since then, there have been a number of KP work group calls to review the modelling.

UNOS staff informed the Committee that the Kidney Committee decided to move forward with a concept paper, not a policy proposal. This means that they are going to share their ideas and ask for input on these ideas during public comment, but they are not proposing a policy change.

This will allow for more time for additional modeling and for the SRTR to answer questions from the Kidney Committee. There will be ongoing discussion on this topic for the next few months. The policy language is expected to be put out for public comment in the fall of 2019. The need for pediatric kidney expertise on this project will be ongoing.

The chair asked about the timeline of the concept paper and if the committee will be able to provide input on the paper. UNOS staff stated that the concept paper will likely explain the conversation on the topic to date and provide the SRTR modelling. UNOS staff also noted that they were informed of a desire from the Kidney Committee to increase priority for pediatric kidney candidates. Therefore, it would be a good opportunity to ask what the appropriate priority for pediatric candidates is. This can be discussed via the public comment period. A committee member asked if members of the committee would be able to provide input on the concept paper prior to public comment. UNOS staff will find out how the paper is being constructed and reviewed prior to public comment. The chair stated that the committee would be willing to provide input on or contribute a subsection of the paper. Another committee member agreed that it would be ideal for the committee to be involved in the construction of the pediatric component of the paper, but the committee should at least be able to review the paper before it goes out for public comment. The vice chair agreed with this approach. UNOS staff agreed to reach out to the leadership of the Kidney Committee with this proposal.

A committee member stated that this is a good opportunity for the committee to figure out how pediatric kidney and pancreas allocation should change. Another committee member noted that the modelling did not look favorable. It decreased the total volume of kidney transplants, increased travelling, and increased waitlist mortality. The committee member thought that putting out a concept paper was preferable to a policy proposal based on these results. The pediatric population generally did not have poor results. However, kidneys would still be travelling further which could increase rejection rates. The modelling would not have accounted for this so it is difficult to know for sure how the proposed policies would have affected the pediatric population.

The committee member also stated that he or she brought up the issue of pediatric candidate's place in the allocation sequence, specifically the fact that they are allocated after KP candidates, at the December Board meeting. The Board did not take up the issue, but the committee should continue to bring it up. The committee member suggested including this issue in the concept paper. Another committee member stated that having pediatric kidneys allocated to pediatric recipients would be beneficial. This would be an easier concept to put forth than trying to come up with a Kidney Donor Profile Index (KDPI) cutoff for allocating kidneys to pediatric candidates prior of KP candidates. The vice chair stated that this does not mean the committee should not try.

Next Steps:

UNOS staff will reach out to the appropriate stakeholders to see where the committee can provide their input on the concept paper.

3. Follow-Up from 11/6/18 In-Person Meeting

The committee held an in-person meeting on 11/6/18.

Summary of Discussion:

UNOS staff previously circulated a survey that asked the committee members to prioritize new projects. The results of this survey will help chart the course of the committee over the next few years.

UNOS staff presented the communication plan for the pediatric bylaws. UNOS is working on making sure that members have access to all necessary information prior to the application period. UNOS will be creating a toolkit that will be posted on the OPTN website. This toolkit will include the policy language, a reference list, UNOSConnect learning modules, and other resources. UNOS staff will also be providing regular updates to the transplant community.

A committee member stated that the new pediatric program requirements are an issue for some programs because it is difficult to complete the pediatric donor requirements. UNOS staff stated that this feedback will be helpful in making sure that the implementation of the requirements are as smooth as possible. The committee member reiterated that it will be difficult for some qualified surgeons to meet the new requirements. UNOS staff stated that they will do all that they can to make the requirements as least cumbersome as possible. The chair asked if it would be possible to devote 20 minutes on an upcoming call to have UNOS staff discuss recommendations for the pediatric bylaw implementation.

UNOS staff informed the committee of the 2019 regional meeting dates. Because the committee will not have a project out for public comment, regional representatives were asked to provide an update on the committee at their regional meeting. The regional representatives will also be responsible for reporting on how the meeting went.

4. Follow-Up on UNOS Staffing Changes

The chair and vice chair previously informed the committee of staffing changes of the UNOS committee support staff.

Summary of Discussion:

The goals of the restructuring are to ensure that committees receive the best support possible, to preserve institutional knowledge, and to better absorb staff changes. The new support team was introduced. The transition to the new team will occur in the middle of January.

Upcoming Meeting

- January 16, 2019