

**OPTN/UNOS Pediatric Transplantation Committee  
Meeting Minutes  
July 18, 2018  
Conference Call**

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

**Introduction**

The Pediatric Transplantation Committee met via conference call on July 18, 2018, to discuss the following agenda items:

1. Welcome and Introduction of New Member
2. Impact of Geography Discussion & Critical Comment to Department of Health and Human Services (HHS)

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

**1. Welcome and Introduction of New Member**

The Chair welcomed the committee and the new member. The leadership of the Committee has transitioned as of July 1<sup>st</sup>.

**2. Impact of Geography Discussion & Critical Comment to Department of Health and Human Services (HHS)**

UNOS staff provided an update re: the impact of discussion on use of Donation Service Areas (DSAs) or regions in organ allocation policies.

Summary of the Discussion

The Committee was previously briefed on June 20, 2018 to ensure the Committee was aware of the discussions. On June 25, 2018, the OPTN response to HHS was that the use of DSAs and regions really was not rationally determined or consistently applied. The OPTN/UNOS Liver and Intestine Committee is moving forward with a plan to eliminate the use of DSAs and regions in liver distribution, and it will be done in a very quick manner hoping to have Board consideration in December of 2018. It will be done so in a short timeframe but also a diligent manner with the goal of reducing the likelihood of unintended consequences.

Where these things touch pediatric organ allocation policies are that the pediatric heart allocation policy uses DSA as the first level and then jumps to Zone "A". The pediatric lung allocation policy uses zones. The kidney allocation policy uses DSAs and regions heavily, as does pancreas. Action is needed to amend the allocation policies removing the use of DSAs or regions as units of organ distribution. This is a defensive maneuver to reduce organizational risk and protect the OPTN's autonomy to develop healthcare policy for transplantation.

UNOS staff then profiled the impact to the Pediatric Committee. The guidance is very near to completion and will not be affected by the need to work on organ allocation policies. The transition guidance will go out for public comment starting on August 3, 2018. The Vice Chair will be presenting a national webinar on August 6, 2018, and the Chair will present the same slides to the Patient Affairs Committee on August 27, 2018. UNOS Regional Administration actively work with major transplant societies and getting feedback on OPTN proposals. UNOS staff liaisons will identify other organizations that may be smaller in scope to be sure that they are aware the proposal is out for public comment.

There will be, however, a need to shift the focus of the Pediatric Committee from two active projects, which are the Kidney-Pediatric Working Group's work on *Improving Pediatric Kidney Transplant Candidate Access* and the Pediatric-Liver Working Group's work on *Reduce Pediatric Liver Waiting List Mortality*. The Committee is requesting that members team up on task forces and attend other organ specific committees' calls. The goal is that members will return to working group projects in late Q4 of 2018.

The Chair emphasized the need to continue to work energetically on all of the themes, even though it may look slightly different in terms of how that is done. One question that needs clarification is whether the shift of focus is going to be reinstated for the kidney working project and the liver project at the same time or if it would be released in steps. UNOS staff responded this likely be a uniform release of resources in late Q4 2018. One member commented that there may be a unique opportunity for the Pediatric Committee in the new allocation scheme. The Committee needs to be crystal clear on its goals, and it may be able to reintroduce splits or mandate splits beyond the regional "noise". The Chair verbalized his support for this sentiment and thought the Committee is well-positioned to identify problems and solutions. The Vice Chair also agreed that it was an opportunity for the pediatric community to give input and to become focused on what is needed.

- The Kidney Committee will need to remove DSA & regions from allocation policies, but there is time to address it. Conference calls are being planned, and the proposal that would come from the Committee would go to public comment in January of 2019, which will be a standard 60-day public comment. The track would be consideration by the Board in June of 2019. The first conference call for kidney with the new focus will be the first week of August. The Chair asked kidney representatives be present for the conferences calls, or have another volunteer present to advocate for the pediatric issues.
- The Thoracic Committee will be having two conference calls per month with the first call being 7/19 5-6 p.m. It will follow the same track as kidney with public comment in January 2019. There is a need for pediatric task force representation for future calls and to communicate back to the Committee. Thoracic representatives verbalized their commitment to work out a rotating schedule to ensure representation on the Thoracic Committee calls.
- The Liver Committee has, and will continue to, conduct weekly conference calls to identify a modeling request for the Scientific Registry of Transplant Recipients (SRTR). The Chair and Vice Chair have been engaged on these calls and shared their support for the progress to-date. Other liver representatives are encouraged to join the task force to decrease the burden on the Chair and Vice Chair.

The Chair then asked if UNOS staff could initiate a Basecamp site for the Committee. Such a site would be critical to maintain member engagement for the quick pace of committee work in the weeks ahead. Other members supported this idea and UNOS staff will get this started in the coming days.

### Next Steps

A take-home suggestion was for the next call to summarize from each respective organ system what the strategies are for the key problems or key priorities.

Committee members will collaborate with UNOS staff to identify who would be able to participate on conference calls with organ-specific committees.

**Upcoming Calls/Meeting:**

- Calls -- 3rd Wednesday of each month 4-5 PM (Eastern)
- November 6, 2018 (Chicago)
- March 19, 2019 (Richmond)