

OPTN/UNOS Pediatric Transplantation Committee
Meeting Summary
October 19, 2016
Chicago, Illinois

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

Discussions of the full committee on October 19, 2016 are summarized below. All committee meeting summaries are available at <https://optn.transplant.hrsa.gov>.

Committee Projects

1. Revisions to Pediatric Emergency Membership Exception Pathway (Goal III)

The Chair provided an update to the Committee from the Working Group involving colleagues from the OPTN/UNOS Membership and Professional Standards Committee (MPSC). The Working Group appears to have a good understanding of the gaps in the bylaw language and has agreement on many concepts that need to include in the language revisions. The Committee held a lengthy discussion on the project, including the concept of requiring consultation with a high performing pediatric transplant program and the question of medico-legal risk of a transplant specialists providing consultation. Members of the Pediatric Committee supported the project's progress to-date. Conference calls to develop the modifications to the emergency membership exception will continue through the fall of 2016. The target date for public comment solicitation on the amendments is August 2017.

Implemented Committee Projects

2. Post implementation monitoring of Heart Status 1A/1B

In June 2014, the OPTN/UNOS Board of Directors (Board) approved a proposal to change the clinical criteria for pediatric heart status 1A and 1B candidates. This proposal was implemented in March 2016 and the Pediatric Transplantation Committee requested UNOS staff share post-implementation data in October 2016. Based on the data provided, the Pediatric Committee noted the percentage of listings with exceptions doubled for status 1A and status 1B, and also noted the percentage of transplants with exceptions almost quadrupled for status 1A transplants (5% to 19%) and increased for status 1B from (30% to 46%). The Pediatric Committee will send a memo to the Thoracic Committee to suggest collaborating on this data analysis and future discussions.

The Committee also briefly discussed the concept of guidance for pediatric heart exceptions. UNOS staff will catalog this new project idea for future discussion.

3. Post-implementation Monitoring of Kidney Allocation System (KAS)

The Committee examined several data reports regarding KAS during the March 30, 2016 in-person meeting and requested additional data from UNOS staff for the October 2016 in-person meeting. UNOS staff updated the Committee on several items, including:

- Solitary deceased donor kidney transplants under KAS
- CPRA 99-100% recipient "bolus effect"
- High dialysis time recipient "bolus effect"
- Transplant rates per active year by candidate age

- Pediatric transplant rates per active year by region
- Kidney Utilization by KDPI
- Trends in pediatric transplants
- Geographic distribution of pediatric kidney transplants from deceased donors

The Committee was concerned about variation in pediatric kidney transplants by region, noting declines in pediatric kidney transplant rates post-KAS in five of the 11 regions in the U.S. The Committee requested several additional data reports from the OPTN in order to gain a better understanding of the problem. UNOS staff will provide reports on the data requests at future calls/meetings.

Other Significant Items

4. Policy Oversight Committee Update

The Vice Chair provided an update of the recent OPTN/UNOS Policy Oversight Committee (POC) discussions. The Vice Chair also discussed the role of POC, the current resource allocation for OPTN committee projects, project counts by committee, and an overview of the POC discussions regarding several projects. The Vice Chair will continue to serve as a conduit between the Pediatric Committee and POC.

5. Roles of UNOS Research and SRTR in Committee Support

Wida Cherikh (UNOS Research) and Jodi Smith (Scientific Registry of Transplant Recipients – SRTR) provided an overview of the respective organization's support role to the Pediatrics Transplantation Committee. Dr. Smith also presented content on the Liver Simulated Allocation Model (LSAM) requests and answered several questions from the Committee regarding LSAM.

6. Update & Discussion on Pediatric National Liver Review Board Guidance

Several members of the Pediatric Committee have collaborated with colleagues on the OPTN/UNOS Liver and Intestine Transplantation Committee to develop guidance on pediatric liver exceptions. The goals for this guidance are to establish consistency in information submitted on status 1B, MELD, and PELD exceptions. The Pediatric Committee held a lengthy discussion on the project, including the need to add content on combined liver/kidney transplant candidates. However, the Pediatric Committee felt this addition was outside the scope of the current project and could jeopardize the project time frames. Thus, the Pediatric Committee did not recommend that guidance on an exception for combined liver/kidney candidate be added to the document. Members of the Pediatric Committee supported the project's progress to-date. Conference calls to develop the document will continue through the fall of 2016. Despite the benefits of this project, the Pediatric Committee felt the project did not address disparities in the use of exceptions scores.¹

UNOS staff will catalog the new project idea for guidance on pediatric combined liver/kidney transplant candidates for future discussion.

¹ Hsu, EK, Shaffer, M, Bradford, M, Mayer-Hamblett, N, and Horslen, S. "Heterogeneity and disparities in the use of exception scores in pediatric liver allocation", *American Journal of Transplantation* 15, no. 2, (2015), 436-444

7. Tracking Outcomes in Pediatric Recipients Following Transition to Adult Transplant Programs (Goal III)

UNOS staff reported on data requests previously submitted by the Committee. Following a review of the data reports, the Committee discussed:

- potential barriers to reporting transplant recipient follow-up (TRF) forms after transition,
- whether there was a need to follow-up with transplant programs who entered “lost to follow-up” excessively on TRF forms, and
- the potential need for the OPTN to define “transition.”

Committee members Sharon Bartosh and Eileen Brewer shared an update from a Consensus Conference on transition involving the American Society of Transplantation (AST) and Genentech. These groups are considering, development of AST-endorsed Transition Guidelines, an AST-hosted Transition Web Portal, an AST Transition Training Course, and to publish conference proceedings to share with the transplant community.

Committee member Melissa McQueen shared an update regarding a project with the OPTN/UNOS Patient Affairs Committee, *What Every Parent Needs to Know*. Members of the Committee felt this was an excellent opportunity for collaboration.

A Working Group was formed to diligently examine the problem(s) based on the data available and develop a high level solution. This Working Group will meet by conference call in November 2016 and will report back to the Committee in December 2016. A time frame to approach the POC with a well-vetted new project idea has not been identified.

8. Pediatric VCA Transplant Update

L. Scott Levin, M.D., VCA Committee Chair, presented an update on the area of VCA transplantation in pediatrics. The Committee wishes to stay informed of developments in this area.

Upcoming Meetings

- December 21, 2016 4:00-5:00 PM Eastern (conference call)
- January 18, 2017 4:00-5:00 PM Eastern (conference call)
- February 15, 2017 4:00-5:00 PM Eastern (conference call)
- March 15, 2017 4:00-5:00 PM Eastern (conference call)
- April 21, 2017 10:00 AM-4:00 PM Eastern (Chicago, IL)
- May 17, 2017, 4:00-5:00 PM Eastern (conference call)
- June 21, 2017 4:00-5:00 PM Eastern (conference call)