

OPTN/UNOS Pediatric Transplantation Committee
Meeting Summary
March 30, 2016
Chicago, IL

Eileen Brewer, M.D., Chair
William Mahle, M.D., Vice Chair

Discussions of the full committee on March 30, 2016 are summarized below. All committee meeting summaries are available at <http://optn.transplant.hrsa.gov/>.

Implemented Committee Projects

1. Pediatric Heart Allocation

UNOS staff provided an update on the recent implementation of Phase I of the Pediatric Heart Allocation changes. Phase one of the Pediatric Heart Allocation changes was implemented on March 22, 2016. This included new pediatric status 1A and status 1B listing requirements. Ryan Davies and William Mahle participated on a webinar hosted by UNOS on March 14, 2016 to educate the community about the new changes. A total of 152 individuals participated on the webinar; this webinar will be available in the education archives on the TransplantPro website.

Phase II of the changes will be implemented in the fourth quarter of 2016. Phase II include changes to the isohemagglutinin titers for ABOi listing, allocation to urgent candidates less than one year-old, and elimination of the in-utero registration option.

2. Update on Pediatric KAS data one year post-implementation

The Committee reviewed data from the OPTN regarding impact on pediatric kidney candidates from the recently approved Kidney Allocation System (KAS). The Committee was concerned about the potential to disadvantage adolescent candidates with high PRAs. The discussion identified additional data requests that were submitted to UNOS staff for analysis at future calls/meetings. The Committee will continue to examine post-implementation data and reconsider a project of regional kidney sharing for highly sensitized adolescents if the data identifies a need.

Other Significant Items

3. 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, and provided an overview of the discussions regarding projects that are nearing Board consideration, projects that are early to mid stages of development, and newly identified projects. The Committee was optimistic the projects to address the ethics of multi-organ allocation will consider the common sentiment that kidneys being “taken away” from solitary kidney candidates by candidates in need of multiorgan transplants (including a kidney). The Vice Chair will continue to serve as a conduit between the Pediatric Committee and POC.

4. Transplant Outcomes and SRTR Data

The Chair of the Committee was approached by a small number of transplant colleagues at different centers who expressed their concerns over media reports of transplant

outcomes. Specifically, U.S. News and World Report has requested data from the Scientific Registry of Transplant Recipients (SRTR) for use in a feature ranking pediatric transplant programs. As a result of pediatric transplantation having low volume, the SRTR is unable to have risk-adjusted models for pediatric metrics. The central question is, is it appropriate to use this data to rank pediatric hospitals?

The Committee discussed this issue at length and considered generating correspondence to U.S. News and World Report to clarify what the data from SRTR does and does not mean. The Committee decided against generating this correspondence by vote (yes-5, no-8, abstain-1).

5. Future project Discussion

The Committee discussed three potential projects that arose from brainstorming discussions in October 2015. These included:

- Pediatric Liver Priority (Goal I) – The Committee discussed data reports from the OPTN on the topic of pediatric liver transplantation. The Committee was concerned about the “routine” practice amongst the community to request PELD and MELD exception points for pediatric candidates. As a result, many liver transplant professionals feel that pediatric liver transplant candidates are disadvantaged by the current scoring system. The Committee formed a Working Group to further examine these concerns. Additional data reports from the OPTN are pending and will be presented to the Committee at future conference calls.
- Tracking Outcomes in Pediatric Recipients Following Transition to Adult Transplant Programs (Goal III) – the Committee discussed data reports from the OPTN on the frequency of “lost to follow-up” on Transplant Recipient Follow-up (TRF) forms in pediatric recipients. Pediatric heart, lung, and liver transplant recipients are often “handed off” to adult transplant programs for post-transplant care after recipients turn 18 years old. This process varies for pediatric kidney transplant recipients, who may be transitioned to an adult renal transplant program or just to an adult nephrologist or nephrology group. This “lost to follow-up” classification for pediatric recipients negatively impacts true understanding of long term pediatric recipient graft and patient survival. Additional data reports from the OPTN are pending and will be presented to the Committee at future conference calls.
- Living Donation to Pediatric Candidates (Goal I) - The Committee discussed data reports from the OPTN on the topic of living donation to pediatric candidates. The number of living donors to pediatric candidates has decreased over time. There is some belief in the pediatric transplant community that individuals who are willing to donate have comorbidities that disqualify them. Additional data reports from the OPTN are pending and will be presented to the Committee at future conference calls.

6. Feedback on proposal from MPSC – Definition of a Transplant Hospital

The MPSC Vice Chair presented a project to the Committee to update the definition of a transplant hospital in the OPTN Policies and Bylaws. The intent of the presentation was to obtain feedback from key OPTN committees before the proposal is considered for public comment. As currently written, the definition in the OPTN Policies is different from the definition in the OPTN Bylaws, it is too simplistic, and vulnerable to differing interpretations. The goal of the project is to better define the basic accountable unit in which organ transplantation occurs. The Committee discussed the proposal and supported the efforts by the MPSC.

7. Discussion on education/outreach efforts to support Pediatric Bylaws

In December 2015, the Board approved new training and experience requirements for transplant hospitals with a pediatric component. The Committee was made aware of concerns from the MPSC regarding bylaw language re: the emergency membership exception for heart and liver transplant programs. The Committee discussed the concerns and will examine any potential gaps in the language at future conference calls/meetings.

8. Communication from UNOS

UNOS staff facilitated a survey of the Committee to assess the content, quality, and frequency of communications from UNOS. The purpose of the survey was enhance how UNOS liaisons communicate with committees. Measures in the survey included volume, frequency, effectiveness, and value. Committee members are asked to complete the survey and return to the Committee liaison.

9. Committee Recognition

The Chair recognized outgoing Committee members, and thanked them for their contributions and support in the last two years. Certificates of appreciation from the OPTN were presented to the following members:

- Nadia Ovchinsky, M.D.
- Susan May
- Linda Book, M.D.
- Jayme Locke, M.D.
- Julia Steinke, M.D.
- Steven Kindel, M.D.

The Vice Chair recognized the Chair for her resolve, leadership, and contributions in the last two years. A certification of appreciation from the OPTN, a gift card, and an award was presented to Eileen Brewer, M.D.

Upcoming Meetings

- May 18, 2016 (conference call)
- June 15, 2016 (conference call)
- July 2016 (conference call – pending)
- August 2016 (conference call – pending)
- September 2016 (conference call – pending)
- October 2016 (Chicago, IL – pending)