# OPTN/UNOS Pediatric Transplantation Committee Meeting Summary May 18, 2016 Conference Call

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

Discussions of the full committee on May 18, 2016 are summarized below. All committee meeting summaries are available at https://optn.transplant.hrsa.gov.

#### **Other Significant Items**

#### 1. Reduce Pediatric Liver Waiting List Mortality

The Pediatric Liver Working Group provided an update from their May 6, 2016 conference call. Past Committee members joined the call to share their perspective regarding past pediatric liver projects, advice on what strategies may/may not work well in the future, as well as insight about current liver transplant initiatives. The consensus of the Working Group is the data shows unacceptable Waiting List mortality for very young candidates and an opportunity exists to address this problem.

The Committee reviewed requested data reports from UNOS staff on pediatric Liver Waiting Times and Death Rates by Diagnosis and had a lengthy discussion about these data and the Working Group's update. The Working Group will continue to meet and discuss potential solutions to address pediatric liver Waiting List mortality. The Committee will receive updates from the Working Group at future calls and meetings.

## 2. New Pediatric Heart Status 1A/1B Requirements & Incidence of 1A/1B Exceptions

An analysis of Status 1A exceptions was presented by transplant colleagus from Vanderbilt University Medical Center at the ISHLT meeting in Washington, D.C. in April 2016. This analysis of data prior to the implementation of the new pediatric heart status 1A and 1B criteria noted significant regional variations in approval of pediatric heart status 1A exceptions. The Vice Chair shared that he has received feedback from the pediatric heart transplant community regarding the new pediatric heart status 1A and 1B criteria, and the early impact especially on one segment of candidates, specifically pediatric cardiomyopathy transplant candidates who are not VAD candidates, yet are not well enough to be discharged home on inotropes. This population of candidates may be subject to extended waiting times at Status 1B, unless a Status 1A exception is submitted and approved by the Regional Review Board. The Committee discussed these concerns, the historical regional variations in heart status 1A exceptions, and the role of Regional Review Boards, most with limited pediatric membership, in the pediatric exception process. The Committee and UNOS staff will closely monitor postimplementation data regarding pediatric effects of the new Status 1A and 1B eligibility criteria. Reports back to the Committee will be made at future in-person meetings in October 2016 and April 2017.

## **Upcoming Meetings**

- June 22, 2016 4:00-5:00 PM Eastern (conference call)
- July 20, 2016 4:00-5:00 PM Eastern (conference call)
- August 17, 2016 4:00-5:00 PM Eastern (conference call)
- September 21, 2016 4:00-5:00 PM Eastern (conference call)
- October 19, 2016 10:00 AM-4:00 PM Eastern (Chicago, IL)
- November 16, 2016 4:00-5:00 PM Eastern (conference call)
- December 21, 2016 4:00-5:00 PM Eastern (conference call)