

OPTN/UNOS Pediatric Transplantation Committee
Meeting Summary
January 21, 2015
Conference Call

Eileen Brewer, MD, Chair
William Mahle, MD, Vice Chair

Discussions of the full committee on January 21, 2015 are summarized below and will be reflected in the committee's next report to the OPTN/UNOS Board of Directors. Meeting summaries and reports to the Board are available at <http://optn.transplant.hrsa.gov>.

Committee Projects

1. Pediatric Transplant Training and Experience Considerations in the Bylaws

The Chair presented a slide that has been added to the proposal presentation which shows that the 61% of transplant programs that currently meet the proposed case volume criteria (acquired between January 1, 2005 and July 31, 2014) performed 98% of the pediatric transplants that occurred during the same timeframe. The Ex Officio reminded the Committee that center volume is a necessary proxy for individual primary surgeon volume because of how OPTN data is collected. However, this analysis provides additional evidence that this proposal preserves access to pediatric transplantation. One Committee member requested the percentage of transplants the 61% of programs performed over the past 3 years.

A Committee member questioned whether the current proposal contains a continuity clause. It does not, meaning that a program that performed the majority of its caseload requirements years ago, but has since not performed many pediatric transplants, could still meet the necessary requirements. However, the proposal does require currency of transplant experience, as it is currently defined in the Bylaws, within the past two years.

Mobilizing Participation in Public Comment

The Committee discussed options for mobilizing participation in public comment. Committee members can reach out to colleagues through professional networks and publications and encourage them to comment on the proposal on the OPTN website. Members can also reach out to individual patients or patient advocacy groups and invite them to participate in public comment. Committee members may also encourage patients, patient advocates, and interested members of the public to attend their Regional Meetings.

One Committee member, a surgeon and member of the ASTS, also encouraged continued consensus-building with the professional societies.

Regional Meeting Preparation

To prepare for the Regional Meeting presentations, the Liaison has scheduled meetings with small groups of Regional Representatives approximately one week prior to their meetings. She is providing presenters with a slide presentation and script, as well as an FAQ. Any questions or concerns regarding the proposal that are important to include in the FAQ should be emailed to the Liaison.

One Committee member suggested meeting with adult transplant colleagues ahead of the Regional Meeting. Committee members may share the presentation with a trusted colleague and ask for their feedback to help anticipate the type of feedback they will receive at the Regional Meeting.

After the presentation, Regional Representatives are asked to share feedback in real time. The Liaison asked that Regional Representatives share how the presentation was received, what questions were asked, and any suggestions for future improvement. The goal is to strengthen the proposal presentation by learning from our experience at each Regional Meeting.

Other Significant Items

The Vice Chair of the Vascularized Composite Allograft (VCA) Committee presented the second part of a presentation on the future implications of VCA for pediatrics. While a pediatric VCA has yet to be performed in the United States, several transplant programs have IRB-approved protocols. The organizational, financial, and ethical considerations for pediatric VCA are great for any one program to navigate alone. Therefore the Vice Chair is encouraging those interested in pediatric VCA to partner, through the OPTN, to establish the necessary infrastructure for successful pediatric VCA. In response to this call to action, the Pediatric Transplantation Committee Chair will designate two members to attend future VCA calls where agenda items of interest to the pediatric community will be discussed.

Upcoming Meetings

- February 18, 2015
- March 18, 2015