

**OPTN/UNOS Pediatric Transplantation Committee  
Interim Report: November 27, 2012 Meeting**

**Heung Bae Kim, M.D., Chair  
Eileen Brewer, M.D., Vice Chair**

*The OPTN/UNOS Pediatric Transplantation Committee (the Committee) met by teleconference on November 27, 2012, to discuss those policy proposals that UNOS distributed for public comment consideration on September 21, 2012. The following summarizes the Committee's discussion for each proposal it reviewed.*

1. Proposal to Substantially Revise The National Kidney Allocation System (Kidney Transplantation Committee) - The Committee's Vice Chair and recent member of the Kidney Transplantation Committee, Dr. Eileen Brewer, presented the proposal. She noted that elements of the proposal that specifically address pediatric kidney candidates were guided by the Committee's recommendations. The Committee was particularly interested in the new classifications and sharing parameters for highly sensitized kidney candidates. The Committee is interested in this because of past analyses that show highly-sensitized pediatric kidney candidates have not realized the same benefit from the "Share 35" policy changes as lowly- or non-sensitized pediatric kidney candidates. The Committee understood that elements of the proposal addressing highly-sensitized candidates did not have any age restrictions. As such, highly-sensitized pediatric kidney candidates who meet the requirements outlined in the proposal would receive additional priority and be categorized among highly-sensitized adult candidates. The Committee was content with this classification of highly-sensitized pediatric kidney candidates, but asked that additional clarification be added to the policy language so that its understanding as it pertains to the inclusion of these candidates is explicit. The Committee believes that this is an important group of candidates that should not be forgotten and more explicit policy language that references highly-sensitized pediatric kidney candidates will help prevent this from happening.

The Committee unanimously approved a motion (17 support, 0 oppose, 0 abstentions) to support the proposal as written, along with a recommendation that additional policy language be drafted that explicitly states pediatric kidney candidates are included among those highly-sensitized kidney candidates who will receive additional priority, as described in this proposal.

2. Proposal to Remove the OPTN Bylaw for the Combined Heart-Lung Transplant Program Designation (Thoracic Organ Transplantation and Membership and Professional Standards Committees) - UNOS staff reviewed the proposal for the Committee. After minimal discussion, the Committee voted unanimously to support the proposal as written (17 support, 0 oppose, 0 abstentions).
3. Proposal to Change the Composition of the OPTN Finance Committee (Executive Committee) - UNOS staff reviewed the proposal for the Committee. Committee members raised questions pertaining to the implementation of these changes, noting they are slated to go in effect immediately if adopted by the OPTN/UNOS Board of Directors. Specific questions raised by the Committee include:
  - How will the composition of this Finance Committee be determined?
  - What will be the term length for these Finance Committee members?

- Will there be requisite qualifications that dictate who may serve on this Finance Committee?
  - The Committee was curious if any Board member would be allowed to serve on this Committee, or if some financial or business background would be mandatory.
- Who will provide oversight of the decisions made?
  - The Committee had some concerns that oversight would come from the same individuals whom are making recommendations on how resources will be used. The concern is that certain projects that are of personal interest to a small group on the Finance Committee may obtain more support than what the membership and transplant community would deem appropriate.

Ultimately, the Committee voted to support (15 support, 0 oppose, 2 abstentions) the proposal, but believes that implementation details must be more thoroughly outlined. The Committee believes understanding these details is especially important considering that the timing of implementation is anticipated to coincide with the OPTN Board of Director's consideration of this item.

4. Proposal to Change the OPTN/UNOS Bylaws to Better Define Notification Requirements for Periods of Functional Inactivity (Membership and Professional Standards Committees) - UNOS staff also presented this proposal for the Committee. The Committee raised concerns that the term "affected groups" was subjective and not well defined. Similarly, there were also concerns raised with the term "potential candidate," arguing that someone is either a candidate (registered on the waiting list) or not.

The Committee also raised concerns about members' ability to comply with this new bylaw. Due to the consideration of inactivity periods over the past 365 days, the Committee indicated it is difficult for members to keep track of their inactivity and when notices should be sent. Instead, the Committee recommends that the yearly inactivity thresholds consider periods of inactivity over the past calendar year, as compared to the previous, 365 consecutive days.

Noting the concerns with the term "affected groups," UNOS staff asked the committee to consider if pediatric transplant recipients or adult living donors who have donated to a pediatric recipient should be included among those who would be notified. The Committee agreed that it would not be necessary to notify these groups, assuming that a transplant hospital is still able to provide follow-up care and is only temporarily ceasing a surgical component of its transplant program.

The Chair of the Committee, alluding to the Committee's current efforts to include pediatric transplant training and experience considerations in the OPTN Bylaws, asked how the "pediatric" component would be defined considering there is no formal UNOS definition for a "pediatric program." Along these lines, if a transplant hospital is still willing and capable of transplanting teenagers but would not be able to transplant infant candidates for a brief period of time- is that hospital expected to notify all pediatric candidates and temporarily stop transplanting all candidates who are younger than 18 years of age? UNOS staff explained to the Committee that if a transplant hospital temporarily inactivated the pediatric component of the program, then it would be expected only to transplant candidates' who are 18 years of age and older. The Committee was concerned with this expectation, indicating that transplant hospitals that care for pediatric candidates may not be inclined to limit the access of candidates who they are fully able to care for; and as such, transplant hospitals

may not inactivate the pediatric component of their transplant programs. The Committee believes this would be a likely, unintended consequence of the proposed bylaws.

The Committee asked that the MPSC consider components of pediatric programs, as compared to the “pediatric component” of the transplant programs. Accordingly, the Committee recommends that the bylaw state that transplant hospitals must notify those candidates whom the hospital is temporarily unable to accept organs on the behalf of. If this is all pediatric candidates, then all pediatric candidates should be notified; if it is all candidates younger than 12 years of age, then only candidates under the age of 12 would need to be contacted.

The Committee indicated that it supports the underlying concepts of this proposal, but it believes there are a number of details that need further consideration before this proposal is considered by the OPTN Board of Directors. Ultimately, the Committee opposed a motion to support the proposal as written (1 support, 16 oppose, 0 abstentions).

5. Proposal to Modify the Imminent and Eligible (I & E) Neurological Death Data Reporting Definitions (Organ Procurement Organization Committee) - UNOS staff provided the Committee with summaries of past discussions related to this proposal, and then presented for the Committee the most recent iteration of this proposal. After minimal discussion, the Committee unanimously supported the proposal as written (17 support, 0 oppose, 0 abstentions).

To conclude the teleconference, participants were reminded that the next full Committee meeting is scheduled for Tuesday, April 9<sup>th</sup>, 2013, and that meeting will be held in Chicago, Illinois.

OPTN/UNOS Pediatric Transplantation Meeting  
November 27, 2012  
Teleconference/LiveMeeting

| <b>NAME</b>                       | <b>COMMITTEE POSITION</b>                | <b>PHONE</b> |
|-----------------------------------|--|--------------|
| Heung Bae Kim, MD                 | Chair                                    | X            |
| Eileen Brewer, MD                 | Vice Chair                               | X            |
| David Campbell, MD                | Ex-Officio                               |              |
| Laura O'Melia, CPNP               | Regional Representative                  | X            |
| Stephen Dunn, MD                  | Regional Representative                  |              |
| Jennifer Garcia, MD               | Regional Representative                  | X            |
| Jose Almeda, MD                   | Regional Representative                  |              |
| David Rosenthal, MD               | Regional Representative                  | X            |
| Andre Dick, MD, FACS              | Regional Representative                  | X            |
| Sharon Bartosh, MD                | Regional Representative                  | X            |
| Richard Hendrickson, MD           | Regional Representative                  | X            |
| Linda Addonizio, MD               | Regional Representative                  | X            |
| Gregory Tiao, MD                  | Regional Representative                  |              |
| Bret Mettler, MD                  | Regional Representative                  |              |
| Sandra Amaral, MD                 | At Large                                 | X            |
| John Bucuvalas, MD                | At Large                                 | X            |
| Blanche Chavers, MD               | At Large                                 | X            |
| Clifford Chin, MD                 | At Large                                 | X            |
| Carmen Cosio, MD                  | At Large                                 |              |
| Alan Farney, MD, PhD              | At Large                                 |              |
| Michael Gautreaux, PhD,<br>D.ABHI | At Large                                 |              |
| Kimberly Hoagwood, PhD            | At Large                                 | X            |
| Simon Horslen, MB, ChB            | At Large                                 | X            |
| William Mahle, MD                 | At Large                                 | X            |
| Debbi McRann, RN                  | At Large                                 | X            |
| Douglas Milbrath                  | At Large                                 |              |
| Gary Visner, DO                   | At Large                                 |              |
| Jim Bowman, MD                    | HRSA                                     | X            |
| Ba Lin, MS, MPH                   | HRSA                                     | X            |
| Monica Lin, PhD                   | HRSA                                     | X            |
| Karen Near, MD, MS                | HRSA                                     | X            |
| Brooke Heubner, MPH               | SRTR-MMRF                                | X            |
| Susan Leppke, MPH                 | SRTR-MMRF                                | X            |
| Jodi Smith, MD                    | SRTR- MMRF                               | X            |
| Sally Aungier                     | UNOS Committee Liaison                   | X            |
| Kerrie Cobb                       | UNOS Business Analyst                    | X            |
| Wida Cherikh, PhD                 | UNOS Research Liaison                    | X            |
| David Kappus, MAS                 | UNOS, Director-<br>Membership Department | X            |
| Jory Parker                       | UNOS Business Analyst                    | X            |
| Ciara Samana, MSPH                | UNOS Committee Liaison                   | X            |
| Chad Waller, MS                   | UNOS Committee Liaison                   | X            |