

**OPTN/UNOS Minority Affairs Committee  
Meeting Summary  
September 15, 2015  
Chicago, IL**

**Jerry McCauley, MD, MPH, FACS, Chair  
Sylvia Rosas, MD, MSCE, Vice Chair**

*Discussions of the full committee on September 15, 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. Guidance on Informed Consent for Living Donors Representing Vulnerable/High Risk Populations**

The Minority Affairs Committee (hereafter, referred to as the Committee) voted to send the guidance document to the Board in June (12-Support, 3-No, 0-Abstain) at their last in-person meeting on March 23<sup>rd</sup>. In April, a Board of Directors Ad Hoc policy group voted unanimously to send the guidance document to the Board for approval. At the June Board meeting, the guidance document was pulled from the non-discussion consent agenda by two members of the Board. Those individuals had significant reservations regarding the document and moved that the guidance document be tabled and work continued. Ultimately, the Board voted 34-4 to table the guidance document and encouraged the Committee to continue work on it and resubmit for approval at the December Board meeting.

A new workgroup convened to continue work on this project. However, there were a number of challenges that stymied progress. In addition, there was a lack of consensus among workgroup members around the extent of work required for this guidance document to be ready for the December Board meeting. Finally, the project did not meet the first or second prioritized goals under the new Organ Procurement and Transplantation Network (OPTN) Strategic Plan. The Committee voted unanimously to put this project on hold.

**Implemented Committee Projects**

**2. The Patient's Guide to Referral for Kidney Transplantation**

This project, a collaboration with the Patient Affairs Committee, was implemented in September 2015. This resource is available in English or Spanish. The brochure will be posted on the OPTN website, the UNOS website as well as UNOS' sites TransplantLiving and TransplantPro. In addition to being offered digitally, print brochures will be available. The UNOS Communications department will promote it via social media channels and member societies.

**Review of Public Comment Proposals**

**3. Establish Pediatric Training and Experience Bylaws Requirements**

The Committee reviewed this proposal on 09/15/2015. The Committee was divided on this proposal and consensus was not achieved. Several members opposed it, citing

concerns regarding geographic access, age vs. size, timeframe for achieving case volume requirements, and cost/risk of lengthy medical transports. They felt it may place some children who are in geographically remote areas with no children's hospital at a disadvantage especially if there are competent adult surgeon providers available; this is particularly true for young adults who physiologically more like adults than children. They also felt that pediatrics should be defined as 12 and under, not less than 18. In addition, they requested the timeframe for achieving case volume requirements should be clearly stated. Hawaii was cited as an example; it is geographically isolated and the 7-8 hour medical transport would not only potentially put a child at increased risk, but would be extremely costly. "As a Hawaii mother of four, I would want the option of weighing the risks of transporting my critically ill child versus the risk of a transplant procedure by one of our local transplant surgeons with expertise in transplanting adults." Other members supported the proposal, and did not take issue with the case volume requirements and the stratification of requirements for key personnel by age/weight. Three members were neutral. One question a Committee member posed was, "For the centers that do not meet these criteria, what is the proposed mechanism to transition those who need to move to a center that meets criteria so that these patients will not be forgotten or lost?"

#### **4. Simultaneous liver kidney allocation**

The Committee reviewed this proposal on 09/15/2015. Generally, the Committee felt this would increase fairness and equity in organ allocation in that it addresses a much needed provision for those recipients who have post OLT kidney failure. There was consensus in support for the proposed medical eligibility criteria and most members were on board with the safety net component. One member, a transplant hepatologist, felt the requirement to use the safety net option seems too restrictive and does not allow for any other opportunity for those patients with significant renal dysfunction affecting management of the liver allograft to be considered for priority. For example, someone may have been a recent transplant with a GFR <30 which is low but not low enough for the safety net, yet this GFR affects the hepatologist's ability to use immunosuppression and can place the graft at risk. Another member, a transplant nephrologist, raised the concern that the safety net in effect prioritizes the liver transplant recipient over any other solid organ transplant recipient who has also developed renal failure after their transplant in the first year of transplant. She felt this group, though they may be a minority, will be disadvantaged with this part of the proposal. The Committee is interested in viewing outcomes data.

#### **5. Revise KPD priority points**

The Committee reviewed this proposal on 09/15/2015. The Committee supports this proposal as they felt it would increase efficiency and may increase the number of transplants. This proposal benefits two potentially vulnerable groups: orphan candidates and difficult to match patients.

#### **6. Increase Committee terms to three years**

The Committee reviewed this proposal on 09/15/2015. The Committee supports this proposal. Extending the terms to three years will allow members time to understand the OPTN/UNOS Committee processes, responsibilities and contributions to the transplant community, complete projects, retain historical knowledge, and acclimate to the professional/personal dynamics that make up the committee culture. The Committee discussed two potential negative consequences of extending terms. How should a Committee deal with an unengaged and unproductive member who does not participate

actively in the Committee? Should the Committee have to retain that member for 3 years? Second, will this limit opportunity for others interested in serving, as members will serve longer terms, so new members are added less frequently? One suggestion was to ask members if they would like to serve 2 or 3 year terms at the start of their service.

#### **7. Modify pediatric lung policy**

The Committee reviewed this proposal on 09/15/2015. The Minority Affairs Committee supports this proposal as it will improve equity for pediatric lung candidates. They were particularly supportive of the second part of the proposal. Establishing eligibility criteria for candidates registered prior to their second birthday to receive a deceased donor lung of any blood type should benefit the most vulnerable candidates waiting for lungs: infants.

### **Other Significant Items**

#### **8. New Project Brainstorm**

The Committee concluded the meeting with a brainstorm session of potential new project ideas that would align with the new OPTN strategic goals. The most popular ideas included use of marginal organs and high discard rates, access to transplant among elderly populations, Blood type B candidates and A2/A2B kidneys and changing the name and charge of the Minority Affairs Committee.

### **Upcoming Meetings**

- November 17, 2015