

**OPTN/UNOS Minority Affairs Committee
Report to the Board of Directors
December 1-2, 2015
Richmond, VA**

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

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This report reflects the work of the OPTN/UNOS Minority Affairs Committee during the May 2015 – November 2015 period.

Action Items

1. None

Committee Projects

2. Guidance on Informed Consent for Living Donors Representing Vulnerable High Risk Populations

At the June Board of Directors meeting, the Board voted (34-yes, 4-no, 0-abstentions) to table the Minority Affairs Committee's (hereafter, referred to as the Committee) guidance document. The Board advised the Committee to develop the document further and resubmit at a future meeting. Closer collaboration with the Living Donor Committee was encouraged, as was involving other stakeholders such as the professional societies.

A new workgroup formed post-Board meeting consisting of leadership from the Minority Affairs, Living Donor, and Ethics Committees to continue working on the guidance document. However, several factors stymied progress. There was a lack of consensus among workgroup members regarding the amount of rework the document needed to be ready for the December Board meeting. Under the new OPTN strategic plan, this project became a lower priority to the Committee, which was keen on pursuing other projects. Further, time was a major constraint. This project's status and the circumstances affecting progress were presented at the Committee's September 15, 2015 in-person meeting. The Committee voted unanimously to put this project on hold to free up resources to pursue other projects.

Committee Projects Pending Implementation

3. None

Implemented Committee Projects

4. The Patient's Guide to Referral to 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, and UNOS-maintained 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

Committee leadership reviewed the slate of proposals released for public comment August 14, 2015 and selected five for the full Committee to review at their fall meeting September 15, 2015. The Committee received presentations on the following proposals. Committee comments and sentiment are summarized below.

5. Establish Pediatric Training and Experience Bylaws Requirements

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?"

6. Simultaneous liver kidney allocation

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-orthotopic liver transplantation 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.

7. Revise KPD priority points

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.

8. Increase Committee terms to three years

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.

9. Modify pediatric lung proposal

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 Committee Work

10. Future Projects

The Committee brainstormed potential project ideas at their September 15th in-person meeting.

- Use of marginal organs/high discard rate
- Access to transplant among elderly population
- A2/A2B kidneys and Blood type B candidates (KAS)
- Minority Affairs Committee name change
- Increasing cultural competency
- Access to transplant among veterans
- VCAs and minority donors
- Educating patients on the HOPE Act

11. Minority Affairs Committee Name Change

For several years, the Committee has informally discussed broadening the scope of the Committee and changing its name to ensure that issues and special needs of other vulnerable populations-not just racial and ethnic minorities-are considered and addressed. This idea aligns with Goal 2 (Increase equity in access to transplants) and Goal 3 (Improve waitlisted patient, living donor, and transplant recipient outcomes. The Committee will submit this idea for the Policy Oversight Committee's consideration in 2016.

12. A2/A2B kidneys and Blood type B candidates

As of the 6-month post-implementation report, 47 A2/A2B transplants have occurred during the six months after KAS implementation compared to just six over the six months prior to KAS. Though small in absolute numbers, this increase is highly statistically significant ($p < 0.0001$) and suggests that this aspect of the policy has already started to make a difference in access to transplants for blood type B patients. This policy element was borne of a Minority Affairs Committee-sponsored variance in the early 2000's that sought to-and achieved-increasing access to renal transplantation for blood type B candidates.

Unfortunately, UNOS has not seen many programs utilizing this new change. There has been a very small increase in transplants for this population despite the much larger potential.

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The Committee has prioritized this idea and has already formed a workgroup with members from the Kidney and Transplant Administrator Committees. The workgroup seeks to explore the reason why this element of KAS is underutilized and provide a solution to encourage more centers to participate.

13. KAS Desensitization Workgroup

The Histocompatibility Committee invited MAC to participate in the Kidney Allocation System (KAS) Desensitization Workgroup. For more information see the **Histocompatibility Committee's Report to the Board** and the minutes from the October 29, 2015 Histocompatibility Committee meeting.

14. SLK Subcommittee

The Kidney Transplantation Committee invited MAC to participate in the Simultaneous Liver Kidney Subcommittee. For more information see the **Kidney Transplantation Committee's Report to the Board** and the Minutes from the October 26, 2015 Kidney Transplantation Committee meeting.

Meeting Summaries

The committee held meetings on the following dates:

- July 14, 2015
- September 15, 2015
- November 17, 2015

Meetings summaries for this Committee are available on the OPTN website at:
<http://optn.transplant.hrsa.gov/converge/members/committeesDetail.asp?ID=19>