OPTN/UNOS Minority Affairs Committee
Meeting Summary
March 23, 2015
Chicago, IL

Meelie DebRoy, MD, Chair
Jerry McCauley, MD, MPH, FACP, Vice Chair

Discussions of the full committee on March 23, 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 and High Risk Populations

UNOS staff briefed the Minority Affairs Committee (hereafter, referred to as the Committee) on the status of the guidance document. The workgroup, comprised of members from the Minority Affairs, Kidney, Living Donor and Ethics Committees, reconvened in January and expedited work on the resource to ensure its completion coincided with the June Board meeting. Once the workgroup finalized a draft, the guidance document was circulated to those full committees for review and endorsement. The Committee voted to send the guidance document to the Board in June (12-Support, 3-No, 0-Abstain).

2. Open Discussion/New Project Brainstorm

The Committee concluded the meeting with a brainstorm session of potential new project ideas that would align with the Organ Procurement and Transplant Network's (OPTN) new strategic goals. Ideas generated included gap time analysis for waitlisted patients (based off of the Patient Affairs Committee's proposal); discard rate of kidneys as it pertains to older donors; waitlist mortality of older patients; geographic disparities and the specifity of data UNOS/ OPTN was able to collect; vulnerable populatin patient education; development of a risk index for living donors; a "Centers of Excellence" program designation for transplant centers as endorsed by the Minority Affairs Committee; living donor assistance based on a pilot program already being conducted; research project on illegal immigrant populations as donors and/or recipients. Committee leadership was tasked with analyzing ideas and selecting the ones that seemed most urgent, feasible and promising.

Committee Projects Pending Implementation

3. A Patient's Guide to Referral to Kidney Transplantation

During the process of developing a referral guide for providers, the Committee determined that a significant portion of the information was more appropriately disseminated to patients directly. With that consideration, the Committee collaborated with the Patient Affairs Committee (PAC) to develop a companion patient-centric referral guide. This resource was completed and UNOS staff are shepherding it through the internal approval process, including design and dissemination. This project does not require programming. The planned implementation date is June 2015.

Review of Public Comment Proposals

4. **Improve reporting of aborted procedures and non-transplanted organs – Living Donor Committee**

   The Committee heard the proposal and had no comments.

5. **Clarify Individual Wait Time Transfer Policy and Process – Patient Affairs Committee**

   The Committee was supportive of this clarification of current policy. However, although this proposal does not address "gap time" (the interval between registrations when a patient is ineligible for transfer), the Committee expressed concern over patients delisted from one transplant program who have yet to be relisted at another transplant center. This "gap time" could potentially have a negative impact on access to transplant for patients, especially patients from vulnerable populations. While there are many circumstances why a patient may be delisted from a transplant center's waiting list and the population affected is fewer than 3,000 patients each year, the Committee would like to collaborate moving forward with the PAC and the Transplant Administrators Committee (TAC) in determining whether this is a problem. In particular, the Committee would like to be included when data is available to examine this issue.

6. **Address Requirements Outlined in the HIV Organ Policy Equity Act – Organ Procurement Organization (OPO) Committee**

   The Committee was supportive of this proposal as it supports the OPTN's Strategic Plan by increasing the number of transplants and increasing access to transplants, particularly in regards to a vulnerable population. The Committee was supportive of including living donors in the research study although they acknowledged that it is currently unknown how many HIV+ people would be eligible to be living donors and felt that special attention be paid to informed consent, whether as part of the IRB protocol, the transplant evaluation process or both. The Committee is interested in the data to be collected as well as additional metrics set by NIH.

7. **Membership Requirements for VCA Transplant Programs – Vascularized Composite Allograft (VCA) Committee**

   The Committee heard the proposal and had no comments.

8. **Establish Pediatric Training and Experience Bylaws Requirements – Pediatric Transplantation Committee**

   The Committee expressed concern in regards to two specific aspects of the proposal: 1) access and 2) definition of a pediatric patient. In regards to the former concern, the Committee discussed disparities in access-not just the physical geography of where pediatric centers are located, but socioeconomic factors that affect families. In regards to the proposal's definition of a pediatric patient, while legally the age of < 18 is true, in terms of transplantation, other criteria might be more critical, e.g. weight, size. Members agreed that that smallest and youngest patients would indeed benefit from being cared for by experienced pediatric specialists, however there were concerns raised about the mandate to transfer older children to pediatric centers, when admitted to adult centers (for e.g. 17- yr. old patient in acute liver failure). Given that 98% of programs already appear to be within the parameters of the proposed requirements, it would behoove the MPSC to communicate with the 2% of programs that do not meet these requirements, if indeed outcomes of pediatric patients transplanted at those centers are worse than

expected. Members of the Committee also questioned that of the 2% of centers that do not meet standards, are their outcomes significantly different than the other 98%?

Upcoming Meetings

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