

**OPTN/UNOS Minority Affairs Committee
Report to the Board of Directors
November, 12-13, 2014
St. Louis, Missouri**

**Dr. Meelie Debroy, Chair
Dr. Jerry McCauley, Vice Chair**

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This report reflects the work of the OPTN/UNOS Minority Affairs Committee during the period of June, 2014 - September, 2014.

Action Items

None

Committee Projects

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

Public Comment: N/A

Board Consideration: November 2015 (Estimated)

According to current literature, potential living donors at greatest risk for developing ESRD in the future may be persons from underserved and/or vulnerable populations. The rapid growth of the kidney waiting list has made living kidney donors (LKD's) an important source of organs. The Committee proposes to develop an educational resource for transplant professionals that would standardize talking points for counseling potential living donors about risks for developing ESRD in the future.

The Committee recognizes the sensitivity required to develop a resource that is culturally astute, evidence based, and user friendly across a variety of settings. To ensure that all requirements are met, the Committee will engage representatives from the Living Donor, Ethics, Transplant Administrators, and Kidney Committees in a workgroup to craft a resource.

The Committee received a data presentation on the status of prior living donors who subsequently were referred for dialysis treatment or transplant. The Committee also received a summary of the key findings from the review of the literature on the incidence of ESRD following living kidney donation.

Currently, the Committee is working to compile this data to ascertain what conclusions can be drawn in preparation to begin writing the guidance document. This information will then be shared with the workgroup in preparation to begin writing the educational resource.

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

Public Comment: N/A

Board Consideration: December 2015 (Estimated)

Minorities experience delays in referral, wait listing, and eventual transplantation as compared to Caucasians. Late referral has negative medical consequences for patients and limits future opportunities for successful transplantation. Late referral is also a barrier to pre-emptive transplant and contributes to increased patient mortality.

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The Guidance Document, *[Educational Guidance on Patient Referral to Kidney Transplantation](#)* was approved by the Board in June 2013. The Committee is collaborating with the Patient Affairs Committee (PAC) in developing a companion resource for patients to encourage early referral for transplant.

The Committee has established high-level messages for this resource based upon the work done in the previous referral guidance document for professionals. The joint MAC-PAC Subcommittee has met to review the goals for the project. PAC will take the lead in developing patient-centered FAQ's and other patient self-advocacy resources. The Committee will serve as subject matter experts in developing content around clinical appropriateness for transplant referral and the transplant evaluation process.

Committee Projects Pending Implementation

None

Implemented Committee Projects

None

Other Committee Work

3. KAS Desensitization Workgroup

The Histocompatibility Committee has invited the 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 August 11-12, 2014 Histocompatibility Committee meeting.

Meeting Summaries.

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