Minority Affairs Committee Report

OPTN/UNOS Board of Directors
Meelie S. Debroy, MD, Chair
June 23-24, 2014
Highlights

MAC Project Updates

- A Patient’s Guide to Referral to Kidney Transplantation
- Educational Guidance on Informed Consent for Living Donors Representing Vulnerable Populations

Other Activities

- KPDPP Updates
- OPTN Committee Project Collaborations
- Reframing MAC Focus

OPTN
MAC Project Updates
Delayed or non-referral reduces opportunities for successful kidney transplant outcomes.

Eligible patients uninformed about transplant options and often wait too long on dialysis prior to referral to kidney transplant evaluation.

Many uniformed about benefits of early referral and self-referral process
A Patient’s Guide to Referral to Kidney Transplantation

- Patient-focused resource with high level referral messages (downloadable brochure, patient FAQ)

- Targeted to ESRD patients, patients approaching ESRD, and those currently on dialysis

- Intended for patient information/education and provider distribution to patients
A Patient’s Guide to Referral to Kidney Transplantation

- High Level Patient Messages:
  - Definition of early referral and its importance
  - How to self refer to transplant evaluation
  - Pre-transplant processes and general candidacy requirements
  - Transplantation myths
  - Patient Information Resources
Despite the prevalence of data on known underlying risk factors for specific living donors, there is no uniformity in how these patients are counseled about their risks.
Ed. Guidance on Informed Consent for Vulnerable Living Donors:

- AA male LDs have highest absolute risk of ESRD post-donation (lowest relative risk compared to healthy non-donors)

- MAC concern regarding counsel provided to potential living donors representing specific high risk groups

- Joint subcommittee collaboration on an educational resource for living donor informed consent

- Resource to include talking points for transplant professionals when counseling specific high risk donors
Ed. Guidance on Informed Consent for Vulnerable Living Donors:

Ensure safety and accessibility of living donation in vulnerable patient populations by:

- Achieving consensus in defining individual risk factors of patients within specific populations.
- Achieving consensus on the specific counsel to patients based on their individual/group risk profile.
- Providing consistent information and counsel to patients based on their individual long term risk.
Project Status

- Joint Subcommittee convened June 9th
  - Review problem Statement
  - Discuss/gain consensus on definition of “vulnerable population” targeted
  - Develop project plan

- Joint subcommittee to review MAC analyses and key findings in literature
Other MAC Activities
Review of KPD Pilot Program Updates

- MAC interest in expanding minority participation in KPDPP

- Ongoing review of data for early examination/identification of KPD minority impacts:
  - Demographic information on candidates and recipients in pilot program (age and ethnicity)
  - Geographic location of and patient demographics at participating centers

- Review of highlights of KPD program participation survey

- KPD Abstract submission
OPTN Committee Project Collaborations

- **Geographic Disparities**
  - Early review/input into development of equity measures for all organs; related redistricting work

- **Access to Transplantation**
  - Review of projects proposed to improve access to transplant; for minority impacts

- **Multi-Organ Allocation**
  - Early input into SLK allocation review for minority impact

- **Revisions to Organ Allocation Policies**
  - Early input into major changes to organ allocation/distribution
Reframing MAC Focus

- Early discussions surrounding reframing MAC focus:
  - Alignment with disadvantaged populations outlined in the Final Rule
  - Expanded emphasis on characteristics within demographic groups
  - Potential change in committee name
  - Redefine committee charge to address expanded demographic profile

- Initiative longer term committee goal
- Initiative will include committee discussion and member input
Special Thanks

Deanna L. Parker, MPA, Liaison to the Minority Affairs Committee

Wida Cherikh, Ph.D, Senior Biostatistician
Questions?

- Meelie S. Debroy, MD
  Chair, Minority Affairs Committee
  Meelie.DebRoy@rwjuh.edu

- Jerry McCauley, MD
  Vice Chair, Minority Affairs Committee
  Jerry.Mccauley@jefferson.edu

- Deanna L. Parker, MPA
  Minority Affairs Committee Liaison
  Deanna.parker@unos.org