

# 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

# MAC Project Updates

OPTN

# The Problem:

**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 uninformed 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 it's importance
- How to self refer to transplant evaluation
- Pre-transplant processes and general candidacy requirements
- Transplantation myths
- Patient Information Resources

# The Problem

**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 9<sup>th</sup>**
  - 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

OPTN

# 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 w/in 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](mailto:Meelie.DebRoy@rwjuh.edu)
- **Jerry McCauley, MD**  
**Vice Chair, Minority Affairs Committee**  
[Jerry.McCauley@jefferson.edu](mailto:Jerry.McCauley@jefferson.edu)
- **Deanna L. Parker, MPA**  
**Minority Affairs Committee Liaison**  
[Deanna.parker@unos.org](mailto:Deanna.parker@unos.org)