

**OPTN/UNOS Minority Affairs Committee  
Meeting Minutes  
May 22, 2017  
Teleconference**

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

**Introduction**

The Minority Affairs Committee met via Teleconference on 05/22/2017 to discuss the following agenda items:

1. Opening Remark and Welcome
2. Overview: Pediatric Kidney Transplant Transition Project
3. Overview: ASTS Diversity Committee
4. Active MAC Project Update / Past Project Update
5. Discussion: Ethics White Paper – Guidance Regarding Organ Donation by Competent Terminally Ill Donors
6. Staff Presentation: The Opioid Epidemic and its Impact on Deceased Donor Transplants
7. Other Discussion

The following is a summary of the Committee's discussions.

**1. Opening Remarks and Welcome**

- There are nine new committee members, including one visiting Board member starting on 7/1/2017.
- The two upcoming in person Chicago meetings for MAC are 9/8/2017 and 3/5/2018.
- All email invitations for calendars sent by email.

**2. Overview: Pediatric Kidney Transplant Transition Project**

Staff presented an overview of beginning project work, initiated by the Pediatrics Committee. Long term follow-up data is vital to understanding post-transplant survival for all pediatric recipients. This is particularly important as the data reported to the OPTN by transplant programs drives policy decisions and communication with the public. Pediatric heart, lung, and liver transplant recipients are often transferred to adult transplant programs for post-transplant care when the recipients become adults. This practice ensures the continuity of recipient follow-up data reporting to the OPTN. However, this transition practice (transfer to an adult transplant program) is not consistent for pediatric kidney transplant recipients. Payers, and to some degree a recipient's geographic location, influence where a pediatric kidney recipient receives post-transplant follow-up care after becoming an adult. The Pediatric Committee formed a working group to examine the problem of pediatric transition and to develop guidance on the same. The project was approved to begin work in April 2017. The Committee would like to have the document ready for Board consideration in June 2018.

Summary of Discussion

Committee members supported the project. Staff indicated that the geographic data by zip code will be examined. Liver and Kidney data will be reviewed.

A member asked if there has been comment from other committees yet, but there has not been because the project is in the early stages.

### **3. Overview: ASTS Diversity Committee**

A MAC member serves on the American Society of Transplant Surgeons ASTS Diversity Committee and presented an overview of the group's work and overlap with the MAC.

The group ensures balanced representation among under-represented and underserved minorities specific to organ donation and transplantation. Current work includes presenting at the American Transplant Congress (2017) and the 2017 Fellows Symposium, a website survey, and highlighting the MAC non-A1/non-A1B (A2A2B) to blood type B project. The group is also creating new project ideas. It is collaborating with a company for funding and help to transplant centers translate websites nationwide.

#### Summary of Discussion:

A Committee member suggested that translation services start with Hispanic areas in greatest need. A request to post the upcoming MAC sponsored non-A1 /non-A1B (A2A2B) to Blood type B guidance document on the ASTS website and work to collaborate on an ATC 2018 submission on the same topic was suggested. There should be more opportunities to do collaborative projects.

### **4. Active MAC Project Update / Past Project Update**

#### a. Active Project: A2A2B

Survey results were presented at two conferences recently (Transplant Management Forum 2017 and ATC 2017) and well received. The Guidance Document name has changed to non-A1/non-A1B to blood type B guidance to be consistent with OPTN Policy labels and recent literature. Major document sections include Protocol development, titer testing protocol, obtaining informed consent, and financial considerations. It will be reviewed by the Histocompatibility and Kidney Committee leadership before being reviewed by the MAC to vote to send to Public Comment. The plan is for the Board to review it for approval in December 2017.

A workgroup member individually submitted the A2A2B topic to be presented at the ATC 2018 conference. The submission is pending.

#### Next Steps

Further editing was requested by workgroup members and Committee leadership before a MAC full Committee vote (TBD, early June) to send to Public Comment. All Committee members are asked to review the document before the vote.

#### b. Past Project: Cultural Competency

Staff presented webinar view statistics that indicate the offering was successful and prompted centers to implement cultural competency programs.

#### Summary of Discussion:

The webinar will remain on the site indefinitely.

### **5. Discussion: Ethics White Paper – Guidance Regarding Organ Donation by Competent Terminally Ill Donors**

The Ethics Committee requested that the Minority Affairs Committee review the draft white paper in advance and bring any questions or comments to this meeting. The paper will likely go to July Public Comment, pending a vote by the Ethics Committee.

### Summary of Discussion:

The paper does not address Imminent Death Donation. This paper addresses guidance surrounding those who are not able to provide informed consent. It provides a surrogate for informed consent. Prior to Living Donor informed consent policy created in 2014, there was no national policy requirement. After this went into effect, hospitals became concerned about “living donor” deaths. This paper refers to donation by those with fatal illness and want to be living donors. How to handle physician assisted suicide and organ donation has also been a topic of discussion and concern among hospitals.

A committee member commented that Living Donor death is a real concern. It is important to balance autonomy and regulation. MAC members feel it is important to include other OPTN Committees in reviewing this information. The paper addresses this and states living donor death is a problem and discusses that the policy can potentially be modified.

Has there been interface with any patient groups or associations on this issue? The paper has been shared with other OPTN Committees, such as Operations and Safety and Kidney.

The Ethics Committee uses this paper to focus on a small subset of Living Donors. Terminally ill donors may be hesitant to become living donors if they are subject to similar follow up requirements.

Why are only 75,000 individuals listed as “active” on the waiting list in the paper? The committee will review this and consider updating this to reflect the OPTN website.

Why do centers have two years to report living donor deaths? Data may lag. This is included in existing policy. If a center becomes aware of a Living Donor death, it must be reported with two years. If the guidance in the white paper becomes policy, the committee would consider recommending exemption from this requirement for these types of living donors in the white paper.

The Committee has discussed donors who have become disabled or ill due to a traumatic event and want to donate, but there is concern that the donors may change their mind if their condition improves over time.

Committee members should feel free to email staff with any additional feedback. The paper will go out for Public Comment in July.

### **6. Staff Presentation: The Opioid Epidemic and its Impact on Deceased Donor Transplants**

Research staff presented statistics on the growing number of overdose deaths since 2005 and its impact on transplants. Staff shared regional annual data and data by race and ethnicity.

### Summary of Discussion:

A Committee member asked if there was mention of prevention from UNOS. Staff responded that it may be out of the scope of the OPTN/UNOS mission and staff is not aware of any prevention outreach. This presentation can be found on the MAC meeting materials SharePoint site.

Half of the growth in transplants is due to the Opioid Epidemic.

### **7. Other Discussion**

- This is the Committee Chair’s last meeting as Chair.
- Certificates not received at March meeting will be sent by mail.
- Nine new Committee members are starting.

- Committee members rolling off are invited to serve on workgroups and stay involved. by submitting ideas. All Committee meetings are public meetings.
- Please fill out Doodle poll (availability) for vote to send NonA1 Guidance Document for Public Comment.

### **Upcoming Meeting**

- July 24th 2017, Teleconference, New Committee Member Orientation and Full Committee Meeting