

**OPTN/UNOS Minority Affairs Committee
Meeting Minutes
July 16, 2018
Conference Call**

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Introduction

The Minority Affairs Committee (the Committee) met via Citrix GoToTraining teleconference on 07/16/2018 to discuss the following agenda items:

1. MAC News
2. Geography Update
3. Patient Perspective
4. Volunteer Survey

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

1. MAC News

The Committee discussed recent publications that are relevant to the focus of the Committee. The Committee was informed about an article on the rates and practices of transplantation for non-citizens and non-residents. This is a topic the Committee previously discussed and expressed interest in. A Committee member encouraged other members to read the article. The article proposes increasing transparency by asking centers to capture data. The Committee also heard about a publication on the APOL1 gene and its potential impact on transplantation, and discussed feedback from the American Transplant Congress (ATC).

2. Geography Update

The Committee heard an update on changes to geographic distribution in the allocation systems and what the timeline would look like.

Summary of discussion:

The use of Donation Service Area (DSA) and region as geographic units is systematically being eliminated from OPTN policies. After alternative distribution proposals are developed, there will be opportunity for community feedback during public comment. A Committee member asked whether there would be a discussion of the distribution changes during regional meetings. This will be discussed at the regional meetings. In terms of a timeline, the changes to liver distribution will go out for public comment in October and to the Board in December, and the changes to VCA, kidney, pancreas and thoracic organs will go out for public comment in January and to the Board in June of 2019.

A Committee member noted the importance of avoiding unintended consequences on minority communities and communities of lower socioeconomic status. The Committee also identified that the vulnerable populations checklist needs to be utilized by the different committees as they consider changes to geographic distribution.

Next Steps:

The Committee will review the geographic frameworks out for public comment August 3 through October 3, 2018 during their in-person meeting on September 17, 2018.

3. Patient Perspective

The Committee heard from the patient representative on the Committee who is a living kidney donor. The patient representative gave an overview of his experience as a patient, the process for being evaluated for living donation, and becoming a living donor. The patient representative is working on the Patient Affairs Constituent Council (PACC) to connect with other patients and provide a line of communication between patients and the committees they serve.

The Committee liaison clarified that the PACC stemmed from the expert councils concept paper that went out for public comment in Spring 2018. The constituent council is a proof of concept to broaden participation within the current committee structure and empower patients. The Committee thanked the patient representative for sharing his story and for bringing the patient perspective to both the Committee and to the PACC, aiding the effort to improve and support the transplant community.

4. Volunteer Survey

The Committee discussed results from the volunteer survey that is sent annually to assess volunteer engagement and areas of improvement.

Summary of discussion:

This year's volunteer survey showed the Committee respondents showed a lower score in rating access to the tools and training for success, encouragement of new ideas, and having a sense of meaning in volunteering. Because the full results are not available, it is unclear whether the concern stemmed from one or two people or was more indicative of how the whole Committee felt. On the call, the Committee agreed that they had access to the tools and training for success, encouragement of new ideas, and felt a sense of meaning in volunteering. Committee members noted that the expert councils public comment cycle could have influenced the responses in the survey, since members had a lot of concerns about that proposal and whether it reflected all the perspectives in the transplant community. A Committee member suggested comparing the previous year to this one to see if there was an improvement or decrease in engagement and satisfaction.

The Committee liaison thanked members for their positive feedback and encouraged them to respond to the poll next year, so a larger sample size can give a better reflection of the views of most of the Committee members. The Committee members will explore using Basecamp to, as another tool to help Committee members participate in Committee discussions.

Next Steps:

The Committee liaison will set up a Basecamp site for the Committee to use.

Upcoming Meetings

- September 17, 2018
- November 19, 2018