OPTN Minority Affairs Committee
Meeting Summary
April 1, 2020
Virtual Meeting

Irene Kim, MD, Chair
Paulo Martins, MD, PhD, Vice Chair

Introduction

The OPTN Minority Affairs Committee (the Committee) met via Citrix GoToTraining teleconference on 04/01/2020 to discuss the following agenda items:

1. COVID 19 Update
2. Continuous Distribution Presentation
3. Socioeconomic Status (SES) Post- Public Comment Discussion
4. UNOS Equity Project

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

1. COVID 19 Update

The Committee heard an update on the UNOS and OPTN responses to the developing COVID-19 situation.

Summary of discussion:

A member asked if UNOS had reached out to any private registries that are monitoring COVID. This member reported hearing from several registries who are all attempting to document COVID 19 cases, which could cause overlap in efforts. Another member asked how many patients had reported being COVID positive so far? UNOS staff reported that as of now, policy only mandates that suspected donor derived cases need to be reported to the Patient Safety Portal. There has been no known donor derived transmission to- date. A member asked if OPOs have the resources available to test donors for COVID. UNOS staff responded that this varies across the country, but action is being taken to add fields to DonorNet to indicate if a donor has been tested and report results.

Next steps:

UNOS staff will follow up with the MAC about private registries once more information on the issue becomes available.

2. Continuous Distribution

The Committee heard a presentation on Continuous Distribution.

Summary of discussion:

A member commented that it could take the Thoracic Committee a few tries to get the composite allocation score and prioritization process correct, but they believe that this project is going in the right direction. Another member asked how the OPTN plans to consider situations where there may be differing values such as prejudices against patients with intellectual disabilities or other minority populations. UNOS Staff reported that as much as possible, this method should be driven be clinical

data. Staff added that the information gathered is advisory. Any policy developed will still have to fall under the umbrella of the Final Rule and the precedent set by the OPTN.

Next steps:

MAC members will receive an email inviting them to participate in a prioritization exercise. This will help the OPTN to begin developing the continuous distribution system.

3. Socioeconomic Status (SES) Post- Public Comment Discussion

The MAC discussed overall public comment sentiment on their proposal "Data Collection to Assess Socioeconomic Status and Access to Transplant".

Summary of discussion:

A member reminded the Committee that some of the listed concerns were out of the hands of the MAC. An example of this is the concept that the proposal would not capture those patients who were never placed on the OPTN waiting list. While this concern has been discussed at length in public comment, the ability to gather data on patients that are not listed is out of the preview of the OPTN. Another critique of the proposal is that patients will not be honest about their income. This member reported that this can be true of any self-reported data, but that some data is better than not having any data at all.

The Committee reflected on their work and discussed the reasoning behind the community's approval of the proposal at the last three regional meetings:

- The rework of the SES presentation slides helped to tell the proposal's whole story
- Highlighting literature and legislature as real- life examples

The Committee also discussed areas for improvement and ideas moving forward:

- Clarity about what the data will be used for and details of its intention to help the community
- Investigate if institutions do/do not collect financial information during the psychosocial assessment and what (if any) data points are captured
- Present to stakeholder organizations to better educate them and give them the opportunity to ask questions before the submit their public comments.
- Engage with the patient population and work with them to find a resolution they find more appropriate
- Investigate how the MAC can build trust and reassure patients that their information will not be misused/used for listing

Next steps:

The Committee has determined that the proposal has not garnered enough support to be presented to the Board of Directors in June 2020. Instead, the MAC plans to revise the proposal and resubmit to a future public comment cycle. Overall, feedback acknowledged that SES is an important topic in transplantation that should be addressed, but that the proposed method for acquiring the data and addressing inequality should be reconsidered. The MAC will continue work on this proposal by developing a plan for the use of this data that is more defined and accessible to the community. The Committee's revisions will aim to thoroughly address the community's addressed concerns and revisit key stakeholders in order to find a more palatable solution.

4. UNOS Equity Project

The Committee heard a presentation on the UNOS Equity project.

Summary of discussion:

A member asked if it is possible to link a UNOS database with another database with the use of a patient's social security number. UNOS staff responded that this can be done sometimes, but there are often kinks when trying to connect the two. This member also asked if similar research would be done for livers. Staff responded that there is a model for livers in the dashboard.

Upcoming Meeting

- May 18, 2020 (Teleconference)