OPTN/UNOS Minority Affairs Committee Meeting Summary September 20, 2016 Chicago, IL

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Discussions of the full committee on September 20, 2016 are summarized below. All committee meeting summaries are available at <u>https://optn.transplant.hrsa.gov</u>.

Committee Update

1. Policy Oversight Committee

The Vice Chair provided an overview of the purpose and role of the Policy Oversight Committee (POC). All current committee projects, as aligned to the strategic plan goals were reviewed, in addition to the sixteen proposal titles that are currently out for public comment. Four of the proposals were presented to the committee in the second half of the all-day meeting. The Vice Chair explained that POC is currently placing new projects on hold due to a change in UNOS Staff resources.

The Chair provided a brief update on a Board initiative to increase diversity on the Board and on Committees. The Workgroup began to meet and a more comprehensive update will be provided at the next meeting.

Committee Projects

2. Transplant Programs Conducting A2/A2B Deceased Donor Kidney Transplants to Blood Type B Recipients

UNOS staff presented the results of a survey sent to all kidney program administrators. The survey was created by the Workgroup to better understand why programs are not participating in a voluntary provision of the new Kidney Allocation System (KAS). The survey resulted in a 22 percent participation rate of completion. Results indicate that program administrators are unsure of how to implement the provision and may not be aware of data that indicates the number of successful transplants when implemented.

The Workgroup lead led a discussion to determine next steps. A guidance document and a webinar were discussed. A committee member suggested waiving this participation metric from outcomes measures and to conduct cost effective analysis to share with programs. It was also suggested that outcome data be sent to all centers.

The Workgroup lead informed the Committee that the survey results were selected to be presented for the 2017 Transplant Management Forum. The Lead would also like to submit the results to be presented at the 2017 American Transplant Congress.

Committee feedback will be considered at the next Workgroup meeting.

3. Cultural Competency

The Committee is beginning work on a new project to provide guidance on Cultural Competency to specific populations. The idea is modeled after a program that has produced a seventy percent increase in kidney living donors among the Hispanic population.

The Workgroup lead provided the Committee with an overview of literature and successful programs in existence, following an open discussion about next steps. Committee members suggested a webinar or a webinar series targeting four groups: Hispanics, Asian Americans, African Americans, and American Indians. The Committee suggested using a standard structure or template for each subgroup. The Committee discussion will be considered during the next workgroup meeting.

4. Other Project Discussion

Committee members suggested that the UNOS and OPTN websites could be translated into additional languages. This could be a future committee project.

The Federal government representative suggested this has been discussed as a priority and may be considered to be included as a future OPTN contract directive.

Other Significant Items

5. Kidney Allocation System Update and Presentation on Variance Data

The Chair of the Kidney Committee presented data on kidney allocation since the new system was implemented in late 2015. Several follow up questions concerning the effect on vulnerable and minority populations were addressed.

A committee member then presented independently collected data on the change in organs allocated in West Virginia since the KAS implementation. West Virginia previously operated under an exception that allowed more kidneys to remain in the state under the older system. The member indicated that West Virginia donors and recipients may be at a disadvantage under the new system.

The Committee indicated that it would be helpful to see the effect of KAS on all areas previously operating under exception variances to determine if there may be inequity present.

Review of Public Comment Proposals

6. Changes to the OPTN Transplant Program Outcomes Review System

The Committee has several questions clarifying the changes and the proposal's effect on smaller transplant programs. There was no significant opposition.

7. Modifications to Informed Consent Requirements for Living Donor

The Committee questioned the rationale for creating the modifications, but had no opposition or favorable comments to contribute.

8. Liver Distribution Redesigning Modeling

The Committee had several questions about how this proposed new system would operate, but no strong opposing or supportive comments were offered.

9. Modification of the Adult Heart Allocation System

The Committee did not have any comments on this proposal. The Chair prompted the Committee members, and also confirmed a lack of thoracic expertise on the Committee.

Upcoming Meeting

• November 21, 2016, Teleconference