

**OPTN/UNOS Minority Affairs Committee  
Meeting Minutes  
March 21, 2017  
Chicago, IL**

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

**Introduction**

The Minority Affairs Committee met in person in Chicago, IL on 03/21/2017 to discuss the following agenda items:

1. Update: Policy Oversight Committee Update
2. Overview: OPTN/UNOS Board of Directors, Committee on Committees / Board Nominations
3. Active Project Update: A2A2B Workgroup
4. OPTN/UNOS Equity Access Project
5. Project Ideas: Part I
6. Update: Kidney Paired Donation (KPD)
7. Project Update: Cultural Competency Workgroup
8. Public Comment (Special Session) Presentation: Guidance on Increased Risk Organs
9. Project Ideas: Part II

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

**1. Update: Policy Oversight Committee**

The Vice Chair provided a brief overview of the role and process of the POC and a list of recently approved projects for all OPTN committees.

Summary of Discussion:

No comments.

**2. Overview: OPTN/UNOS Board of Directors, Committee on Committees / Board Nominations**

The OPTN Board President provided an overview of the Board initiative to enhance the Board and Committee recruitment process to create greater transparency and diversity. The group will also create a better structure for succession planning.

The second part of the presentation included an overview of the Board nomination process, timeline, and upcoming open positions.

Summary of Discussion:

A committee member noted that there is support for the effort, but not much has changed in the last two years. The Board reviews its needs and open positions and then attempts to match those needs with candidates of diverse backgrounds. It may be a three to five year process.

A workgroup member asked if the overall committee composition would differ if the Minority Affairs Committee were not included. This breakdown will be produced and sent to members.

Staff discussed all positions (filled and unfilled) in greater depth. There is no plan to increase the size of the Board, but the Board is creating ways for members to engage outside of only the Board and Committee structures. The Chair noted that committee members can continue to lead and serve on workgroups.

A committee member suggested that Board members or contacts create a tour to locations to better engage new members to serve. The process and deadlines seem mysterious. Current members of committees and regional representatives can help to disseminate this information. The Board is continuing to work on ways to develop broader outreach. Regional representatives are expected to share this process with centers, but the process is not working well. The regional meetings are fairly clinical and difficult for nonclinical folks to participate.

Next Steps:

Please consider and submit any potential candidates to staff

**3. Active Project Update: A2A2B Workgroup**

This workgroup explored reasons why centers are not using the voluntary A2A2B to B matching provision to benefit disadvantaged blood group B. The Policy Oversight Committee approved a project in December 2016 for the workgroup to create a guidance document to encourage centers to participate. An educational webinar will also be created to complement the webinar.

Summary of Discussion:

A committee member volunteered to use his program to help with webinar and voiced support and encouragement for the project. Several committee members work at institutions that have seen success with this program. Two members voiced support for making this provision mandatory in the future.

Next Steps:

Ensure that the guidance be reviewed by blood bank professionals and the Histocompatibility Committee. The workgroup continues to work on this and is meeting next on 4/4/2017. Committee members should send program examples or volunteer to help with webinar by contacting Staff.

**4. OPTN/UNOS Equity Access Project**

Research Staff presented on the UNOS led project to address the gap in ability of the OPTN to measure and track equity in access to transplantation. A full report is being created, with plans to continue to automatically track and report results periodically.

Summary of Discussion:

A member asked if the A2A2B policy were mandatory, would this change reduce disparity among minorities? Can models be created to predict the impact? Staff agreed that this would likely contribute to improved equity. It was considered as part of KAS, but was left to programs. This provision is not mandatory because it gives centers the ability to make best decisions. Mandatory policy would also affect labs. The Chair noted that this may be an unfunded mandate and may alienate programs.

A member asked about the status of a multi organ payback system. Staff said this is a study limitation and does not include multi-organ. Paybacks were removed when KAS was implemented. The member clarified that this is a safety net for multi-organ, not payback. There is data indicating kidney and other transplants together do not fare as well as kidney transplants alone. Multi-organ recipients may negatively impact other candidates only needing kidney transplants. An OPTN multiorgan policy project will be created soon, starting with liver, but this has not yet been started.

A committee member commented that DSA drives a large proportion of variation of time to transplantation. What factors drive the DSA variation at the center level? Supply and demand, willingness to accept less than ideal organs, and OPO performance are factors.

A committee member asked about the differences in data pre and post KAS. All of this data is blended together for one year (during transition) and what accounts for a major difference.

A committee member asked if bias in access to the list is part of this study. Staff said this will be part of study eventually, but data for it is more difficult to acquire. Institutions outside of UNOS have reliable data and this will be included in the future.

## **5. Project Ideas: Part I**

The Vice Chair led the Committee in prioritizing new project ideas focusing on vulnerable populations. The group began by prioritizing vulnerable populations in transplantation and then breaking into groups to list project ideas.

### Summary of Discussion: Committee Name Change

The Committee voted to change its name previously, but it was put on hold as part of an OPTN-wide effort to align projects to new strategic goals (2015). This would need to be approved by the POC or go straight the Executive Committee. The name in consideration was Minority and Vulnerable Populations Committee or MVP. The Committee can still pursue projects that focus on vulnerable populations without changing its name.

A member suggested the Committee include the word “disadvantaged,” but some members did not agree. Most literature use the term “vulnerable.” The Chair emphasized the importance of keeping the word “minority” in the name and expressed concern over the minority voice if all vulnerable populations are included in one committee.

Several members expressed support for allowing the name to remain, but to pursue projects including a wider scope of vulnerable populations.

### Action Item:

The committee voted unanimously to keep the name, Minority Affairs Committee.

### Summary of Discussion: Prioritize Vulnerable Populations for Projects:

Populations mentioned include: race, cognitively impaired, low income / financially disadvantaged, low socioeconomic status/ access, uninsured, non-English speaking, cultural barriers to waitlist, older populations (staff suggestion), geographically isolated (staff suggestion). Pediatrics will not be included because a committee exists.

HRSA Staff commented that organdonor.gov is now in Spanish.

Some of the data, including cognitive impairment, is not captured in UNOS data. It is also important to consider access to transplant and support system when problems are identified.

Surveys to collect data can be conducted to identify problems.

The committee informally voted on priority populations and assigned a leader for each “break out group”:

- Non English Speaking
- Uninsured / Impoverished
- Geographically isolated / Rural
- Minorities / Race

### Next Steps:

The Committee will break into groups after lunch.

## **6. Update: Kidney Paired Donation (KPD)**

Research Staff presented a data update on the OPTN KPD program, implemented in 2010. Major data updates includes waitlisted and transplanted candidates by ethnicity and age from 2010-2016.

Minority participation in the OPTN KPDPP is less than expected from the demographics of the KPDPP center waitlists. Increased sample size is needed to determine if participation in the KPD Pilot Program results in the number of minority transplants being proportionate to their participation level.

### Summary of Discussion:

A workgroup member asked if analysis was done on donors and recipients that are not participating in KPD. There is data collected, the presenter referred back to a slide in the presentation, but no analysis is done on difference in distributions. Most living donor transplants go to white recipients. This update is similar to the last two updates. No action items.

## **7. Project Update: Cultural Competency Workgroup**

The workgroup lead provided an overview of the recently released Cultural Competency Webinar, encouraging centers to implement programs to non English speakers. It is based on a successful Hispanic Kidney Living Donor Program at Northwestern. The recorded webinar was released on 3/3/2017.

### Summary of Discussion:

The workgroup lead requested that the committee discusses future steps to increase cultural competency.

This was released using every outlet of communication OPTN can use (websites, emails). Some committee members did not see this and staff will send the link again. Nephrologists can disseminate this as well. Is there a way to make this happen? Since UNOS is focused on the transplant community, the communication beyond this is limited.

The webinar had over thirty views to date.

The webinar was generic, so can apply to other groups. Patients and families can also be targeted for the future.

A committee member referenced a Spanish language site developed by the workgroup lead and suggested it be posted on the HRSA website.

A committee member asked if there is any data on centers that have a low cultural competency score and if these centers can be targeted. The lead provided a few examples of data his center collects. There is no data currently collected by the OPTN.

A committee member encouraged everyone to engage social workers in championing this cause.

### Action Items:

HRSA will follow up on potentially posting Juan Carlos Caicedo's Spanish language program site (not the webinar) as a link on the HRSA site.

Staff will resend the link to the 26 minute webinar.

Some follow up ideas can be incorporated into the next meeting session today to create new project problems and ideas.

## **8. Public Comment (Special Session) Presentation: Guidance on Increased Risk Organs**

The Disease Transmission Advisory Committee (DTAC) member presented on a proposal that will go to the Board for consideration in June, but will go out for Public Comment for thirty days. This is outside of the normal Public Comment cycle. The transplant community has requested assistance how to best explain relative risk of disease transmission involving increased risk organ donors to potential organ recipients. A guidance document was produced.

### Summary of Discussion:

No discussion. This proposal will go out for Public Comment shortly and will be posted on the OPTN website.

## **9. Project Ideas – Part II**

The committee members arranged into groups of four to come up with problems associated with the prioritized populations in the morning sessions. The groups discussed ideas for twenty minutes in the small groups and reassembled as a committee to share ideas.

### Summary of Discussion:

#### Group 1: Geographically isolated / Rural

- Idea to review distance to transplant center and examine time to transplant, transplant outcome, income/insured or uninsured. This can be examined for all organs and be separated by organ type. Not much research has been done on this topic.

#### Group 2: Uninsured / Impoverished

- Focus on Kidney because there is data available on ERSD through dialysis centers. Research which zip codes have low incomes and education status, based on minority. How many go on to receive transplants? After this, examine barriers to care. Examples may be lack of transportation, lack of support network, lack of education. What is the cost benefit to giving more transplants versus keeping them on dialysis? How can OPTN get these patients funding or better access? This may be a research project and not a policy project.

#### Group 3: Non-English Speaking

- Use cultural competency group to work on this. One idea is to create a hotline for different languages. Do patients have access to nephrologists who speak different languages?
- The scope of the problem should be determined. There are different languages in different parts of the country. If this project turns into increasing awareness about transplant, this could increase the size of the waiting list.
- More PSAs in non-English for organ donation are needed, in general

#### Group 4: Minorities / Race

- Focus should be on living donation and to increase living donation in diverse populations.
- There is a need to increase knowledge for potential recipients (transplant is an option); also there is a need to educate patients post-transplant so they can care for themselves.
- One member commented that dialysis centers are supposed to educate patients, but it is not clear if this is monitored.
- There is also a need to increase education about VCA donation as it becomes more in demand (skin color matching).

Next Steps:

Staff will record the project ideas and the committee can prioritize new projects at the next full committee meeting in May.

**Upcoming Meeting**

- May 22, 2017, Teleconference