

**OPTN Patient Affairs Committee  
Meeting Summary  
October 20, 2020  
Conference Call**

**Darnell Waun, R.N., M.S.N., Chair  
Garret Erdle, M.B.A., Vice Chair**

## **Introduction**

The Patient Affairs Committee (PAC) met via Citrix GoToMeeting teleconference on 10/20/2020 to discuss the following agenda items:

1. Regional Meeting Debrief
2. Policy Oversight Committee (POC) Update/Cross Committee Workgroup Report Out
3. Minority Affairs Committee (MAC) Presentation
4. Liver Committee Presentation

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

### **1. Regional Meeting Debrief**

The PAC discussed their experiences with the Summer 2020 Regional Meetings.

#### Summary of discussion:

Members agreed that the highly medical conversations made it difficult for the general population to understand the patient issues. The Chair suggested to pursue a path that would allow patient representatives to update the region's patient population during regional meetings. Members agreed with this suggestion.

A member suggested having more ongoing and dynamic conversations on policy issues throughout the year, rather than only having the opportunity twice a year.

### **2. Policy Oversight Committee (POC) Update/Cross Committee Workgroup Report Out**

The Vice Chair updated the Committee on the Policy Oversight Committee's (POC) strategic policy priorities, project alignment, and project sequencing.

#### Summary of discussion:

##### *Multi-organ Workgroup*

A member explained the purpose of the Workgroup is to develop policy to prioritize multi-visceral organ transplants. The member explained they are working on the fairness and consistency of multi-organ practices.

##### *Provisional Yes Workgroup*

A member of the Workgroup explained that while the intent of the provisional yes process is good, it has made the system less efficient. The Workgroup has been discussing potential project recommendations to present to the POC. The Chair asked if this includes all organ groups. The member confirmed.

##### *Facilitating Patient Navigation Workgroup*

A member of the Workgroup shared that they are waiting for internal discussions to be completed before proceeding with a white paper, or what is deemed most appropriate to the group's purpose.

### **3. Minority Affairs Committee (MAC) Presentation**

A MAC representative presented their project, *Data Collection to Assess Socioeconomic Status (SES) and Access to Transplant*, and requested feedback from the PAC.

#### Summary of discussion:

A member agreed with the overall goal of the project, but expressed concern over the MAC's method for collecting the requested information. The member also expressed concern that income, by itself, is a poor proxy for determining total resources.

A member asked at what time point will SES information be collected. The member explained that candidates may be on the waitlist for a period of time in which their financial situation could change. The MAC representative responded that ideally this data would be captured every time a patient came in for evaluation. However, with the data fields being in the transplant candidate registration (TCR) form, the data would only be captured at the time of listing.

The Chair expressed their concern over the potential development of a quota in regards to certain populations not receiving transplants. The Chair explained that they do not see the benefit of SES data collection for the patient and requested to hear the specific actions and solutions to reduce inequities based off of this data collection. The Chair asked if the MAC has considered collecting this SES information at time of transplant. The MAC representative responded that literature shows the biggest hurdles for patients occur before they are listed, because of this, MAC decided to collect this data at the point of listing to gather more information at that time period.

A member stated that providing an option of "do not want to provide" for SES data collection, would be well received by the patient community. The member added they would be supportive of this effort if the physical address of the patient was also collected as a data field.

### **4. Liver Committee Presentation**

The Chair of the Liver and Intestinal Organs Transplantation Committee (the Liver Committee) informed the PAC of a patient-led effort to update the Primary Sclerosing Cholangitis (PSC) guidance within National Liver Review Board (NLRB) Guidance.

#### Summary of discussion:

During the Summer 2020 Public Comment cycle, the Liver Committee sponsored a proposal to incorporate a number of improvements to the NLRB. The public comment proposal received a significant amount of comments on the PSC guidance, even though there were no changes to PSC guidance in the proposal. As a result, the Liver Committee is considering updates to PSC guidance as part of an upcoming public comment proposal.

The Chair asked what the Liver Committee is requesting from the PAC. The Chair of the Liver Committee responded that it would be helpful to have patient representatives work with the PSC population to relate this information and receive feedback.

### **Upcoming Meetings**

- November 17, 2020 (teleconference)
- December 15, 2020 (teleconference)

## Attendance

- **Committee Members**
  - Anita Patel
  - Christopher Yanakos
  - Darnell Waun
  - David Skinner
  - Diego Acero
  - Earl Lovell
  - Eric Tanis
  - Garrett Erdle
  - James Sharrock
  - Julie Siegel
  - Kenny Laferriere
  - Marvin Lim
  - Molly McCarthy
  - Sarah Koochmaraie
  - Stephanie Little
- **HRSA Representatives**
  - Jim Bowman
  - Melanie Deal
- **SRTR Staff**
  - Allyson Hart
- **UNOS Staff**
  - Anne Zehner
  - Kelley Poff
  - Lindsay Larkin
  - Matt Cafarella
  - Matt Prentice
  - Meghan McDermott
  - Sara Rose Wells
  - Shannon Edwards
- **Other Attendees**
  - James Trotter
  - Oscar Serrano
  - Beth Rubinstein