

**OPTN Patient Affairs Committee
Meeting Summary
September 21, 2021
Conference Call**

**Garrett Erdle, M.B.A., Chair
Molly McCarthy, Vice Chair**

Introduction

The Patient Affairs Committee met via Citrix GoToMeeting teleconference on 09/21/2021 to discuss the following agenda items:

1. Opening remarks and welcome
2. Kidney Transplantation and Minority Affairs Committees Public Comment Presentation – *Reassess Inclusion of Race in Estimate Glomerular Filtration Rate (eGFR) Equation*
3. Regional Meetings – Final debrief and discussion

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

1. Opening remarks and welcome

UNOS staff provided an overview of the agenda and Committee staffing update.

2. Kidney Transplantation and Minority Affairs Committees Public Comment Presentation – *Reassess Inclusion of Race in Estimate Glomerular Filtration Rate (eGFR) Equation*

Dr. Martha Pavlakis, Chair of the OPTN Kidney Transplantation Committee, and Precious McCowan, Patient Representation on the OPTN Kidney Transplantation Committee, presented the cosponsored public comment presentation *Reassess Inclusion of Race in Estimate Glomerular Filtration Rate (eGFR) Equation*.

Summary of discussion:

The PAC would like to see this change as soon as possible, and would like to help in any way they can to support this work. Many of the members expressed that they were never aware of the use of a race coefficient. A member also pointed out that having this as a binary option, either “Black” or “Not Black” does not make sense. This member also recommended that the committees make sure to focus on the scientific reasons for making these changes. A few members stated that they would be bringing this up to their own centers to ensure that they use a race-neutral formula.

A member added that this is one example of a way that transplant centers handle things differently, and in this case, it can result in disadvantaging some patients. One member expressed concern about the level of knowledge that patients are expected to have, especially regarding protocols that are handled differently depending on the center. The member added that a patient’s health outcome can depend on whether they know the right questions to ask or are confident in advocating for themselves. Overall, the committee is highly supportive of a policy that requires the use of a race-neutral eGFR equation and removes the use of any race-based calculations.

Next steps:

UNOS staff will compile the feedback from today's conversation to develop the official public comment for the committee. If members have any additional questions or comments on the proposal, please reach out to UNOS staff.

3. Regional Meetings – Final debrief and discussion

The Committee Chair initiated a conversation regarding the member's experience at the regional meetings and requested their feedback.

Summary of discussion:

A member suggested strengthening the mentor program, specifically reaching out to the Assistant Regional Councillors to see if they would be interested in taking on a mentor. This would allow the PAC member to have someone to directly connect and engage with at the regional meeting. A member shared that since the onboarding process is so close to the regional meetings, it can be very overwhelming for PAC members and patient representatives to be inundated with so much information.

The Vice Chair suggested that PAC members might be more apt to recruit nonmedical individuals by providing a better understanding of what Committee involvement actually looks like. The Chair further stated that increasing patient involvement would be more successful if driven by patients.

Next steps:

The Region 11 meeting is the final regional meeting occurring Friday, September 24. If members have not been able to attend a regional meeting, they are encouraged to attend the Region 11 meeting.

Upcoming Meeting

- October 19, 2021
- November 16, 2021
- December 21, 2021

Attendance

- **Committee Members**
 - Anita Patel
 - Chris Yanakos
 - Christopher Woody
 - Darnell Waun
 - David Skinner
 - Diego Acero
 - Earl Lovell
 - Eric Tanis
 - Garrett Erdle
 - James Sharrock
 - Julie Spear
 - Justine van der Pool
 - Kenny Laferriere
 - Kristen Ramsay
 - Molly McCarthy
 - Sarah Koochmaraie
 - Sejal Patel
- **SRTR Staff**
 - Allyson Hart
 - Katie Audette
- **UNOS Staff**
 - Abby Fox
 - Eric Messick
 - Kelley Poff
 - Laura Schmitt
 - Lindsay Larkin
 - Sara Rose Wells
 - Susan Tlusty
 - Tina Rhoades
- **Other Attendees**
 - Martha Pavlakis
 - Precious McCowan