

**OPTN Patient Affairs Committee
Meeting Summary
February 18, 2025
Teleconference**

**Molly McCarthy, Chair
Lorrinda Gray Davis, Vice Chair**

Introduction

The OPTN Patient Affairs Committee (the Committee) met via WebEx teleconference on 2/18/25 to discuss the following agenda item:

1. Welcome
2. Updates
3. Region 5 and Region 7 meeting debrief
4. March 12th Agenda Preview
5. Public Forum

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

1. Welcome

The Chair welcomed the Committee. The Committee reviewed the agenda and received an update on OPTN contractor staff support for the Committee.

Summary of discussion:

No decisions were made by the Committee.

There were no questions or discussion.

2. Updates

The Committee reviewed updates regarding the OPTN regional meeting schedule and agenda, committee in-person meetings, the public comment items that the Committee will review during the Winter 2025 public comment period, policy development related to transplants for candidates living with Human immunodeficiency Virus (HIV), and committee recruitment status.

Summary of discussion:

No decisions were made by the Committee.

The Chair noted that the virtual format for the regional meetings still accommodates free-flowing conversation and the regional representatives of the Committee will still be able to present their updates. Since the Committee's March meeting will now be held virtually, the meeting will be shorter to facilitate engagement, and the Committee will review two public comment items. The Committee reviewed the member assignments for reviewing the public comment items.

Regarding committee recruitment, the Chair asked members to stay engaged and to encourage people within their networks to volunteer to serve on the Committee.

The Visiting Board Member asked for feedback from the Committee regarding committee structure. The Chair recommended more opportunities for people to show up and for the patient voice to not just be heard but to be included in policies. The Chair recommended more patient voices showing up purposely amongst all of the committees, and more frequent participation at the Board level. The Chair also recommended direct connection with some of the incoming OPTN contractors. Other members agreed with the sentiments shared by the Chair.

The Visiting Board Member agreed that the OPTN needs to be more effective at getting things done. The Chair mentioned meeting with a new OPTN contractor to share feedback on the policy making process. The Chair mentioned that the Committee has found it challenging that policymaking does not seem to be a way to innovate or drive improvement. The Chair said the Committee lacks clarity on how OPTN projects save lives, and the return on investment for projects in terms of number of lives saved. A member said the issue is not the committee structure but rather that the policy development process is cumbersome and takes too long. Another member agreed with the sentiments raised by the Chair.

A member said that the focus should not be limited to changing the committee structure but should also consider how to reconstruct the system. The member is concerned that patients will be handed a new system that doesn't work very well. The Visiting Board Member said the OPTN Board of Directors has also emphasized the importance of being engaged throughout ongoing changes.

A member said the current policy structure stifles innovation. The member said there is a lack of transparency around policy projects and how sponsoring committees incorporate feedback from other committees into their policies. OPTN contractor staff explained that the briefing paper posted on the OPTN website for each proposal contains a summary of the public comment feedback, the Committee's response to the public comment feedback, and any changes made to the policy based on public comment feedback. Staff cited the *Modify Waiting Time for Candidates Affected by Race-Inclusive Estimated Glomerular Filtration Rate Calculations*¹ proposal as an example of a project where the Committee's feedback helped to support policy changes prior to approval and implementation of the policy. The member suggested that the policy process could be more clear to link that information together.

The Visiting Board Member shared a couple of additional updates:

- A bill has been introduced in Congress to allow HRSA to collect the OPTN registration fees.
- A HRSA staff member is no longer with HRSA.

3. Region 5 and Region 7 meeting debrief

A member shared updates from the Region 7 meeting. The member recommended that Committee members focus on providing the patient perspective regarding collecting data on patients, and for any members in the medical field to read and provide feedback on the request for feedback sponsored by the Multi-Organ Transplantation Committee.² The Chair said that the Committee updates were well received by attendees.

¹ <https://optn.transplant.hrsa.gov/policies-bylaws/public-comment/modify-waiting-time-for-candidates-affected-by-race-inclusive-estimated-glomerular-filtration-rate-egfr-calculations/>.

² "Establish Comprehensive Multi-Organ Allocation Policy," OPTN, Request for Feedback, <https://optn.transplant.hrsa.gov/policies-bylaws/public-comment/establish-comprehensive-multi-organ-allocation-policy/>.

Summary of discussion:

No decisions were made by the Committee.

There were no questions or discussion.

4. March 12th Agenda Preview

The Chair presented the proposed agenda for the extended virtual meeting in March.

Summary of discussion:

No decisions were made by the Committee.

There were no questions or discussion.

5. Public Forum

There were no public forum requests for this meeting.

Upcoming Meetings

- March 12, 2025
- April 15, 2025

Attendance

- **Committee Members**
 - Molly McCarthy
 - Patrice Ball
 - Michael Brown
 - Liz DeVivo
 - Tonya Gomez
 - Calvin Henry
 - Robert Johnson
 - Karlett Parra
 - Cathy Ramage
 - Cody Reynolds
 - Michael Slipowitz
 - John Sperzel
 - George Surratt, Visiting Board Member
 - Steve Weitzen
 - Justin Wilkerson
- **SRTR Staff**
 - Avery Cook
- **UNOS Staff**
 - Cole Fox
 - Lindsay Larkin
 - Kaitlin Swanner