

**OPTN Patient Affairs Committee  
Meeting Summary  
January 21, 2025  
Teleconference**

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

## **Introduction**

The OPTN Patient Affairs Committee (the Committee) met via WebEx teleconference on 1/21/2025 to discuss the following agenda item:

1. Welcome and Announcements
2. HOPE Act Update
3. Regional Meeting Preview
4. Public Comment Overview

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

### **1. Welcome and Announcements**

The Chair welcomed attendees to the call. The in-person meeting is tentatively scheduled for March 12, and additional information on location and booking travel will be distributed in the coming days. Members will receive a poll to determine availability for travel to the in-person meeting.

### **2. HOPE Act Update**

Contractor staff presented an update on the HOPE Act.

#### Presentation summary:

The Hope Act has been updated to remove the requirement for research protocols for HIV to HIV transplants. The OPTN Board of Directors (the Board) will consider policy changes to align with the updated regulations, and public comment will be retrospective.

#### Summary of discussion:

No formal decisions were made by the Committee.

The Chair questioned how the policy could be implemented prior to public comment. Contractor staff responded the OPTN bylaws includes provisions for the Board to implement emergency policies prior to a public comment period. The Chair asked what would happen if public comment feedback is unsupportive of the change and staff responded the Board could then decide to update the policy.

A committee member commented that they accepted an organ with Hep B which has resulted in difficulties getting their health insurance to cover necessary medication. The Vice Chair encouraged OPTN committees to consider these potential consequences when writing new policies

A member asked if any committees are working on efforts to expand HIV transplantation across transplant programs now that there will be fewer barriers to doing these transplants. Staff commented

they are not aware of any efforts planned to encourage accepting HIV positive organs outside of this policy update.

Next steps:

The Board will consider these policy changes and next steps in the coming weeks.

**3. Regional Meeting Preview**

The list of upcoming regional meetings was shared with the Committee. Contractor staff then reviewed the proposed format of the PAC update to be given at regional meetings.

Presentation summary:

The PAC update presentation at the regional meetings will cover personal connections to organ transplant, PAC membership, committee activity, and encouraging patient involvement.

Summary of discussion:

No decisions were made by the Committee.

The Chair encouraged regional representatives to share their personal story to their preference level. Members requested to reserve space on the in-person meeting agenda for OPTN modernization updates.

Next Steps:

Regional representatives will attend regional meeting prep sessions. Regional representatives will report back to the committee about any regional meeting feedback.

**4. Public Comment Overview**

Committee members received an overview of the process planned to prepare for public comment review.

Presentation summary:

Contractor staff shared that four proposals were selected by Committee leadership for full Committee review and response:

1. The Ethics Committee's *Ethical Analysis of Allocating Organs Out of Sequence* white paper
2. The MPSC's *Update Membership Requirements* proposal
3. The Disease Transmission Advisory Committee's *Clarify Requirements for Reporting a Potential Disease Transmission* proposal
4. The Minority Affairs Committee's *Monitoring Ongoing eGFR Modification Policy Requirements* proposal

Committee leadership shared that the PAC has historically divided into teams to review selected proposals, with team leaders identified from the Committee membership and informed by survey responses from Committee members. Members are asked to review the proposals independently and complete a survey that includes general requests for sentiment and comment alongside any specific questions included in the proposal itself. The team leader will review the results of the survey at the March 12 meeting. A final Committee response for each proposal will be drafted at the conclusion of these discussions and approved before submission on the OPTN website.

Committee members were asked to review the assigned proposals and complete the corresponding survey once it is circulated. All Committee members were encouraged to review any additional proposals that they wish to share their own personal thoughts on.

Summary of discussion:

No formal decisions were made by the Committee.

A member commented they find it valuable to review all items out for public comment and encouraged other members to join regional meetings virtually as schedules allow.

Next steps:

Contractor staff will prepare surveys and alert committee members to their assigned proposal for review. A review of the survey results and follow-up discussion will take place at the March 12 meeting.

**Upcoming Meetings**

- February 18, 2025

## Attendance

- **Committee Members**
  - Molly McCarthy
  - Lorrinda Gray-Davis
  - Patrice Ball
  - Liz DeVivo
  - Michael Slipowitz
  - Michael Brown
  - Steve Weitzen
  - Cathy Ramage
  - Cody Reynolds
  - Andreas Price
  - John Sperzel
  - Calvin Henry
  - Tonya Gomez
  - Justin Wilkerson
  - Karlett Parra
- **SRTR Staff**
  - Avery Cook
  - Earnest Davis
- **UNOS Staff**
  - Alex Carmack
  - Kaitlin Swanner
  - Desiree Tenenbaum
  - Lindsay Larkin
  - Houlder Hudgins