

**OPTN Patient Affairs Committee  
Meeting Summary  
December 17, 2024  
Teleconference**

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

## **Introduction**

The OPTN Patient Affairs Committee (the Committee) met via WebEx teleconference on 12/17/2024 to discuss the following agenda item:

1. Public Comment Preview
2. Organ Procurement Organization (OPO) CEO Presentation and Discussion

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

### **1. Public Comment Preview**

Contractor staff presented the list of items set for OPTN Public Comment, which begins on January 21, 2025.

#### Presentation summary:

Contractor staff listed each item that is currently slated for the January 2025 OPTN public comment period, along with a brief description of each item.

#### Summary of discussion:

No formal decisions were made by the Committee.

The Chair of the Committee noted that the upcoming public comment items concerning estimated glomerular filtration rate (eGFR) and an ethical analysis of organ allocation out of sequence caught their attention and may be good for the Committee to review. They recommended the Committee select no more than four items to review. The Vice Chair of the Committee agreed, and suggested emailing the list to the Committee to allow for all members to provide input on which items the Committee should review.

#### Next steps:

Contractor staff will email the list of public comment items, with a description of each item, to the members of the Committee. The Committee members will then vote on up to four items to be considered for discussion by the Committee to provide public comment. Committee leadership will then select the items for review by the Committee.

### **2. OPO CEO Presentation and Discussion**

An invited speaker presented a list of his top concerns as the CEO of an organ procurement organization (OPO). He then focused and elaborated on three of those concerns.

#### Presentation summary:

The speaker was invited to present to the Committee to provide the perspective of an OPO CEO within the organ donation and transplantation system. He shared how he personally became involved with organ donation and transplantation. He highlighted that chronic diseases that could potentially be treated with organ transplantation (lower respiratory diseases, liver disease, and kidney disease) were responsible for about 7.3% of deaths in the United States in 2021. He listed ten items he considers to be his top concerns as an OPO CEO. He focused on three specific topics as his primary concerns. These include CMS recertification criteria, the effects of OPTN restructuring, and innovations in transplantation.

Summary of discussion:

No decisions were made by the Committee.

A member of the Committee asked the presenter to elaborate on his concerns regarding performance metrics used to evaluate OPOs. The speaker described organ donation as an eight-step process:

1. Referral from the donor hospital
2. Donor evaluation
3. Approach the donor family
4. Obtain authorization for organ donation
5. Procure the organs
6. Allocate and transport the organs
7. Transplant the organs [performed by transplant programs]
8. Follow up with the donor family and support them

The speaker said that if an OPO is not managing any one of those steps that are under their purview, then the OPO has opportunity for improvement. The speaker expressed his belief that the current evaluation of whether an OPO is performing well doesn't look at all of those areas.

Another member asked about OPO decertification and the process an OPO would follow when taking over a new area. The speaker noted that there are regional and cultural differences, health disparity differences, and differences in health care delivery across the country that influence how OPOs operate so if one OPO takes over another area, the processes in place for that OPO must be able to supplement and improve the processes for the decertified OPO to be successful.

A member asked about OPTN restructuring involvement and how that could impact how OPOs approach their work. The speaker noted that there is always opportunity to improve and expressed hope that bringing in expertise from other industries will help to advance the donation and transplant industry, but noted that caution should be taken when adding in new entities to a complex system. The speaker highlighted the importance of engagement between members of the community and policymakers to collaborate and share information.

A member asked the speaker if reports of OPOs misusing resources are overblown in the media. The speaker shared an example of an OPO inadvertently using federal funds for funeral expenses due to misunderstanding regulations about donor family support but said that he does not think there is widespread waste and abuse.

The speaker highlighted the importance of patient participation in opportunities like public comment since the patient voice is extremely powerful.

A member asked about the challenges OPOs face and where improvement is most needed. The speaker shared his experience conducting workshops at approximately 30 different OPOs. He explained that

each OPO faces unique regional challenges and cultural considerations but maintained that most are well-run organizations that effectively adapt to their specific circumstances. He emphasized that every OPO visit provides opportunities for mutual learning and improvement.

#### **Upcoming Meetings**

- January 21, 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**
  - Earnest Davis
- **UNOS Staff**
  - Alex Carmack
  - Kaitlin Swanner
  - Desiree Tenenbaum
  - Lindsay Larkin
- **Other Attendees**
  - Harry Wilkins