

**OPTN Patient Affairs Committee  
Meeting Summary  
July 18, 2023  
Conference Call**

**Garrett Erdle, MBA, Chair  
Molly McCarthy, Vice Chair**

## **Introduction**

The Patient Affairs Committee (Committee) met via WebEx teleconference on 07/18/2023 to discuss the following agenda items:

1. Welcome and announcements
2. New member introductions
3. Public Comment preview
4. Regional Meeting Update
5. Board of Directors Meeting review
6. Adjourn

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

### **1. Welcome and announcements**

The Chair welcomed members to the call and gave an overview of what participation on the Committee has meant for himself and what he hopes it will mean for others. Staff gave a reminder that the in-person meeting will be held on September 12, in Detroit, MI.

### **2. New member introductions**

Each new member of the Committee was introduced and invited to share details about themselves and what they hope to gain from this experience. New members were also assigned to their mentors.

### **3. Public Comment preview**

The Committee received a preview of the items out for public comment.

#### Presentation summary:

The OPTN public comment period opens on July 27 and closes on September 19. The Committee will be reviewing two items in-depth as teams for the in-person meeting. Those two items are *Ethical Considerations of Normothermic Regional Perfusion (NRP)* put forth by the OPTN Ethics Committee and *Concepts for a Collaborative Approach to Living Donor Data Collection* put forth by the OPTN Living Donor Committee. Members may comment on any public comment item as individuals. The teams that will review each item were introduced and the Chair gave a brief overview of what each that the Committee will review item covers. Staff also briefly introduced the other Committee items out for public comment and encouraged members to review these items as well.

### **4. Regional Meeting Update**

The Chair reviewed the regional meeting schedule and the current assigned speaker; for those unable to attend in person there will be a virtual option. Staff reviewed the regional meeting presentation

Committee members will be presenting at the regional meetings and will be reaching out to schedule prep sessions.

## **5. Board of Directors Meeting Review**

A member who attended the Board of Directors (BOD) meeting as the Committee representative provided a review of the discussion topics at the meeting.

### Presentation Summary:

The member shared that the discussion at the Board of Directors meeting focused on the following areas:

- Organ Allocation and Utilization
  - System designed for “perfect” organs
  - High number of patients and marginal organs
  - Offer filters
  - Risk aversion
- Organ Procurement Organization (OPO) Performance
  - OPO duties and responsibilities
  - OPO Staffing
  - What happens to poor performers?
  - Patients in transition
- Information Technology (IT) System Upgrades and Security
  - Health and Human Services (HHS) required security upgrade requirements and deadlines
  - IT staffing at centers
  - IT Budgeting
- Budget
  - Congressional budget and waitlisting fees
  - IT Staffing concerns
- Whistle Blower Protection
  - What constitutes retaliation against volunteers?
  - Commitment to whistleblower protections
  - Commitment to volunteer and staff training
  - Official statement of protection to whistle blowers
- The updated Patient Information Letter was presented and accepted by the BOD
- A request was made for continued work on communication with the patient community

### Summary of discussion:

A member asked if the BOD clarified what was meant by the request for continued work on communication with the patient community, and the presenter answered that the BOD did not provide additional details but encouraged the Committee to focus on high-impact issues.

## **6. Adjourn**

The Chair ended the meeting informing the Committee of a Senate hearing in Washington, D.C. The Chair pointed out that all viewpoints are welcome within the Patient Affairs Committee, and adjourned the call.

### **Upcoming Meeting**

- August 15, 2023

## Attendance

- **Committee Members**
  - Garrett Erdle
  - Andreas
  - Calvin Henry
  - John Sperzel
  - Justin Wilkerson
  - Justine van der Pool
  - Lorrinda Gray-Davis
  - Sejal Patel
  - Steve Weitzen
  - Tonya Gomez
  - Wendy Leavitt
- **HRSA Representatives**
  - Mesmin Germain
- **SRTR Staff**
  - Katie Audette
- **UNOS Staff**
  - Alex Carmack
  - Desiree Tenenbaum
  - Kieran McMahon
  - Laura Schmitt
  - Kim Uccellini
- **Other Attendees**