

**OPTN Patient Affairs Committee
Meeting Summary
August 15, 2023
Conference Call**

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

Introduction

The Patient Affairs Committee (Committee) met via WebEx teleconference on 08/15/2023 to discuss the following agenda items:

1. Welcome, announcements, and in-person meeting reminders
2. New member introductions
3. Regional Meeting Update
4. OPTN Updates

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

1. Welcome, announcements, and in-person meeting reminders

The Chair welcomed members to the call and staff gave a few reminders. The Chair reminded members that the in-person meeting will be held on September 12, in Detroit, MI. Staff reminded members of the groups for reviewing and providing feedback on the public comment items that the Committee will hear in the in-person call.

2. New member introductions

A new member of the Committee was introduced and invited to share details about themselves and what they hope to gain from this experience.

3. Regional Meeting Update

The Committee was reminded of the regional meeting schedule and then discussed how regional meetings have been going so far.

Presentation Summary:

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

Summary of Discussion:

Members that have already presented at a regional meeting were invited to share their thoughts about presentation and discussion timing, suggestions for future topics, advice for future presenters, and any other feedback about the experience.

A member stated that the discussion and presentation time was sufficient and advised future presenters to take their time and add their personal experience into the presentation. Another member added that it is helpful to start out with a personal experience to set the stage. A member agreed, and added that re-introducing yourself as a presenter is a good idea. Another member said that the experience

attending the regional meeting was very worthwhile. Members also added that the networking opportunities at the regional meetings are important and valuable.

4. OPTN Updates

The OPTN Special Counsel and Project Director joined the meeting to provide some updates on requested OPTN topics.

Presentation Summary:

The presenter noted that there are a lot of changes and action happening in the transplant world, and that this presentation aims to clarify some of the questions surrounding these topics. The relationship between the Contractor and the OPTN was introduced. The National Organ Transplant Act (NOTA) was introduced in 1984 and the OPTN Final Rule was introduced in 2000. The OPTN Contract has always gone out for competitive bid, and the Health and Human Services Administration (HRSA) has awarded the contract to the current Contractor each time it has been up for bid. The presenter also introduced some themes and tasks of the current OPTN Contract and the work it encompasses.

The Contract is currently funded through HRSA appropriated funds (10 percent) and through OPTN registration fees (90 percent). The annual budget is approved by the OPTN Board. The current OPTN Contract was extended by HRSA for six months to March 29, 2024. Current congressional bills would open up future contracts to multiple vendors, for-profit organizations, and no cap on appropriated funds from HRSA to the OPTN.

The presenter also shared details about the OPTN Board of Directors Independence Plan. The OPTN and the Contractor have used a unitary board approach since the inception of the OPTN. While compliant with NOTA and the OPTN Final Rule, and required by current contract, separate boards could strengthen public trust in oversight and accountability. A recent contract modification by HRSA requested a plan with required activities, timelines, and milestones. This plan will accomplish critical goals of continuity of service, eliminating any potential or perceived conflicts of interest, and ensuring OPTN independence from current or future OPTN contractors. The presenter explained the OPTN governance structure. The presenter noted that OPTN projects can include changes to policy, bylaws, and data collection, as well as member requirements, guidance documents, and white papers.

The presenter also explained that HRSA is undergoing an OPTN Modernization Initiative which they announced on March 22, 2023. This initiative includes technology, data transparency and analytics, governance, operations, and quality improvement and innovation. HRSA is currently engaging stakeholders.

Summary of discussion:

A member asked for clarification on the contract timeline, and the presenter clarified the steps for requesting bids, negotiations, and final award. This member also asked for more information about the cost structure, and the presenter noted that these discussions are ongoing within HRSA, and that no final decisions have been made. A HRSA representative explained that multiple organizations may receive separate parts of the current contract, and current contract activities may also be supported by non-contract means such as through grants.

The Chair thanked the presenter for the information.

Upcoming Meeting

- September 12, 2023

Attendance

- **Committee Members**
 - Garrett Erdle
 - Molly McCarthy
 - Sejal Patel
 - Wendy Leavitt
 - Denise Abbey
 - Kristen Ramsay
 - Steve Weitzen
 - Calvin Henry
 - Julie Spear
 - Lorrinda Gray-Davis
 - Tonya Gomez
 - Wendy Leavitt
 - John Sperzel
 - Andreas Price
- **HRSA Representatives**
 - Mesmin Germain
 - Kala Rochelle
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Alex Carmack
 - Desiree Tenenbaum
 - Rebecca Murdock
 - Roger Brown
 - Liz Robbins Callahan
 - Tina Rhoades
 - Krissy Laurie
 - Kim Uccellini
 - Kaitlin Swanner
 - Susan Tlusty
- **Other Attendees**