

**OPTN Patient Affairs Committee
Meeting Summary
July 21, 2022
Conference Call**

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

Introduction

The OPTN Patient Affairs Committee (the Committee) met via Citrix GoTo Meeting teleconference on 06/21/2022 to discuss the following agenda items:

1. Orientation
2. Volunteer Opportunity
3. Volunteer Recruitment Update
4. Debrief: Scientific Registry for Transplant Recipients (SRTR) Task 5 Consensus Conference

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

1. Orientation

The Committee welcomed new Committee members. The Committee reviewed the current membership of the Committee, the structure of the OPTN, the Committee's role in the OPTN, and the policy development process.

Summary of discussion:

A member asked for more information on the post-implementation review phase of the policy development process. Staff responded that all implemented projects have individual monitoring plans, which are part of the public comment proposal. Data reports are developed based on the individual monitoring plan for the post-implementation review of a project, and presented to the sponsoring Committee. Sometimes these reports are posted on the OPTN website, but not always. If there are negative, unintended consequences revealed during the post-implementation review, a Committee will develop an additional project to address such issues.

The Vice Chair emphasized that regional meetings should allot time for the patient representatives to introduce themselves.

2. Volunteer Opportunity

The Committee reviewed how to get involved in regional nominating committees.

Summary of discussion:

Regional nominating committees recommend candidates for regional representation on certain OPTN Committees. Each regional nominating committees plans to include one patient or donor family representative. A member shared that they enjoyed their experience engaging on a regional nominating committee.

3. Volunteer Recruitment Update

The Committee was provided an update on volunteer recruitment. The Committee reviewed data to analyze the progress on increasing patient and donor family representation on OPTN committees. The Committee was encouraged to engage with their networks by sharing the call for nominations information, encouraging individuals to submit a volunteer interest form, and sending referrals to staff.

4. Debrief: Scientific Registry for Transplant Recipients (SRTR) Task 5 Consensus Conference

Several Committee members attended SRTR's Task 5 consensus conference.

Summary of discussion:

The Vice Chair noted concern regarding the lack of data transplant professionals have in determining how long a patient will have to wait if an organ offer is turned down. The Vice Chair stated that the patients attending the consensus conference were vocal in their request for knowing their life expectancy.

A member was surprised at physicians' stated inability to interpret data. The member added that inability to interpret risk adjustment data appeared to be a major concern.

The Vice Chair stated that some attendees at the consensus conference disregarded equity in access as an important issue that needs to be addressed. Another member agreed that this disregard was concerning. The member elaborated that some attendees at the consensus conference stated concern with new metrics that may highlight specific transplant programs possibly having an equity problem.

Next steps:

The Committee will continue to debrief on the SRTR's Task 5 Consensus Conference.

Upcoming Meetings

- September 15, 2022 (Richmond, Virginia)
- September 20, 2022 (teleconference)
- October 18, 2022 (teleconference)

Attendance

- **Committee Members**
 - Calvin Henry
 - Dana Hong
 - Diana Dixon
 - Eric Tanis
 - Garrett Erdle
 - Julie Spear
 - Justin Wilkerson
 - Justine Van Der Pool
 - Lorrinda Gray-Davis
 - Molly McCarthy
 - Sejal Patel
 - Steven Weitzen
 - Wendy Leavitt
- **HRSA Representatives**
 - Jim Bowman
 - Megan Hayden
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Anna Wall
 - Alex Carmack
 - Kaitlin Swanner
 - Kristina Hogan
 - Lauren Motley
 - Matt Belton
 - Sara Rose Wells
 - Susan Tlusty