

**OPTN Executive Committee
Patient Engagement Workgroup
Meeting Summary
February 7, 2022
Conference Call**

Brad Kornfeld, Chair

Introduction

The OPTN Patient Engagement Workgroup met via Citrix GoToMeeting teleconference on 02/07/22 to discuss the following agenda items:

1. Overview of patient representation
2. Role of patient representatives
3. Discussion: Improving patient engagement

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

1. Overview of patient representation

The Workgroup reviewed OPTN requirements for patient representation and how many patients currently reside on each committee.

Summary of discussion:

There was no discussion.

2. Role of patient representatives

The Workgroup discussed qualities of a strong patient representative and the type of input the OPTN seeks from them.

Summary of discussion:

A member commented that patient perspective from all backgrounds, whether they be informed by professional experience in healthcare, informed by professional (finance, business, etc.) expertise, or informed by neither, should be represented. A member added that patients with challenges to being transplanted (economic, transportation, etc.) should have a voice in the OPTN policy development process. Another member noted that most current OPTN patient representatives have college or advanced degrees and that this is not necessarily reflective of the entire population of people being transplanted. Members agreed that the OPTN should seek to involve patients with strong sense of self and self-advocacy skills. The Workgroup favored the idea of additional patient- focused policy development trainings. Members discussed the importance of engaging with patients from all parts of the country, as patients living in urban, suburban, and rural areas will have varying experiences. A member commented that the current at-large appointment process inadvertently encourages these positions to be filled by physicians and surgeons, not patients and families.

3. Discussion: Improving patient engagement

The Workgroup discussed ways to invite patients to engage with the OPTN.

Summary of discussion:

In order to develop the patient representative pipeline, the Workgroup recommended outreach to the following groups:

- Organ Procurement Organizations (OPOs) - Donor families
- Transplant coordinators (pre- transplant, post- transplant, living donor)
- Transplant administrators via listserv
- The Alliance (education programs)
- Ad hoc groups: Support groups, social media
- Society of Transplant Social Workers (STSW)

A member suggested the OPTN provide feedback during and after the volunteer application and nomination process, as some of their peers have applied repeatedly but not been selected to serve. A member recommended making the call for nominations more specific and including a list of committee needs at that time. Members agreed that the OPTN should maintain connections with volunteer applicants who are not selected to serve, as the committees' future needs may match previous applicants' skillsets.

A member suggested pairing new OPTN patient representatives with experienced patient representatives to guide them in their role on the committee. Staff added that the Patient Affairs Committee (PAC) has implemented a similar idea and this has provided additional support for these new members. Another member suggested a separate, patient- focused call for OPTN volunteers.

Currently, the Final Rule requires the Board of Directors to consist of at least 25% patient representatives and at least one patient representative to sit on each OPTN committee. Members agreed that the volume of patient representatives should be increased, while also better engaging with patients within the OPTN. They also suggested that specific space be made for patient representatives to comment during meetings. Members recommended the OPTN Minority Affairs Committee, Living Donor Committee, and the UNOS Ambassadors program as "training grounds" for OPTN patient representatives.

Next steps:

The Workgroup will continue discussions on the role and engagement of patient representatives.

Upcoming Meeting

- March 7, 2022, 3:00- 4:00 pm ET

Attendance

- **Workgroup Members**
 - Brad Kornfeld
 - Mindy Dison
 - Valinda Jones
- **HRSA Representatives**
 - Chris McLaughlin
 - Shannon Taitt
- **UNOS Staff**
 - Kaitlin Swanner
 - Sara Rose Wells
 - Kelley Poff
 - Anna Wall
 - Susie Sprinson