

**OPTN Executive Committee
Patient Engagement Workgroup
Meeting Summary
March 31, 2022
Conference Call**

Brad Kornfeld, Chair

Introduction

The OPTN Patient Engagement Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 03/31/2022 to discuss the following agenda items:

1. Discuss draft recommendations

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

1. Discuss draft recommendations

The Workgroup reviewed and gave input on draft recommendations.

Summary of discussion:

A member confirmed that any alterations made to the OPTN regional structure would not impact the efforts of the Workgroup.

The Workgroup discussed outreach to organizations for the purpose of engaging patients. An attendee suggested the addition of NATCO to the list of organizations. They also recommended the OPTN Transplant Coordinators Committee (TCC) and the OPTN Transplant Administrators Committee (TAC) be included on the list of targeted committees for patients to grow their experience. Another member suggested that committee chairs should provide specific space during meetings for patients to participate in the discussion. This member noted that transplant centers and Organ Procurement Organizations (OPOs) could sponsor patient and donor representative attendance at regional meetings to expose them to the OPTN policy development process.

A member suggested that patients could become involved with the breakout sessions held before some regional meetings. Another member noted that patient-specific breakout sessions may benefit them more, as oftentimes discussion between transplant professionals can be clinical. Members suggested gathering feedback on how to best involve patients in breakout sessions at regional meetings. A member suggested that the occurrence of breakout sessions be standardized across all regions. UNOS staff informed the Workgroup that the structure of future in-person regional meetings will aim to be more uniform with most activity taking place in the main meeting room.

The Workgroup discussed the number of patient representatives that should sit on each committee. A member noted that patients are a diverse group and ideally, three patients should sit on each committee including one living donor, one deceased donor recipient, and one donor family representative. Ultimately, the Workgroup supported requiring at least two patients with different perspectives on each OPTN committee, and said that committees should include additional patient representatives as needed to support project work. A member suggested highlighting the patient-focused questions and potential impact on patients in the At-A-Glance included with each public comment document.

The Workgroup discussed the OPTN committee application process. A member noted that most committee volunteers have attained a higher level of education and that the OPTN should consider inclusion of more diverse levels of education and socioeconomic status. A member suggested developing an OPTN region- based ambassador role for patients who are not selected for committee participation, but interested in becoming involved with the OPTN. Another member suggested that the differences between an OPTN ambassador and a UNOS ambassador would need to be clearly defined.

Next steps:

UNOS staff will compile these recommendations for Workgroup review.

Upcoming Meeting

- As needed

Attendance

- **Workgroup Members**
 - Brad Kornfeld
 - David Mulligan
 - Earnest Davis
 - Mindy Dison
 - Melissa McQueen
 - Valinda Jones
- **HRSA Representatives**
 - Chris McLaughlin
- **UNOS Staff**
 - Anna Wall
 - Kailin Swanner
 - Meghan McDermott
 - Susie Sprinson
 - Tina Rhoades
 - Carrie Caumont