

**OPTN/UNOS Patient Affairs Committee
Meeting Minutes
October 17, 2017
Conference Call**

**Kristie Lemmon, MBA, Chair
Darnell Waun, MSN, RN, Vice Chair**

Introduction

The Patient Affairs Committee met via Citrix GoToTraining teleconference on October 17, 2017 to discuss the following agenda items:

1. Call for Nominations
2. Project Update: Improving Patient Understanding of the Waiting List
3. Liver Update

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

1. Call for Nominations

Summary of discussion:

The Patient Affairs Committee (PAC) will require a Region 8 representative, a Region 11 representative, and two at-large representatives for the upcoming term. PAC is seeking individuals who meet one of the categories (kidney and thoracic organ representative, donor family members, and/or recently transplanted recipients) and have a background in corporate or non-profit governance, patient advocacy, public policy, healthcare administration, patient and peer education, or health literacy. Committee members were informed of nomination deadlines.

2. Project Update: Improving Patient Understanding of the Transplant Waiting List

Summary of discussion:

The proposed solution for aiding patients in understanding the wait list involves an education product for the patient, which will support a resource that the Transplant Coordinator Committee is planning to develop. Research on what is currently available to patients include a "Patient Information Kit," which UNOS provides per OPTN Contract. This kit includes numerous data on the waiting list and a very general overview of the transplant process, including the waiting list, titled "What Every Patient Needs to Know." In addition, only kidney offers a brochure specifically on evaluation and listing, but it is still fairly general in its approach.

In addition to researching UNOS available materials, a general online search was conducted to gather information on what is widely available on the internet. The top search results include the OPTN site, the data landing page on the UNOS website, a governmental site on organ donation statistics, the non-profit site for Donate Life, and a general site on getting on the national wait list. These information contained within these search results, while informative, are still difficult to digest from a patient perspective because the information is primarily statistics. Patients may need a narrative, not statistics. Only one video deals with how the wait list works, and that video is buried within the UNOS website, and does not feature prominently in search results.

Next steps:

- Form workgroup in October 2017
- Gather evidence for areas of need, analyze gaps in understanding, and share evidence with the TCC from fall 2017 to spring 2018

3. Education topic: Policy 5: Organ Offers, Acceptance and Verification

Committee leadership requested more education on OPTN policies and related OPTN topics for PAC members. As a result, the Committee is engaged in a monthly policy learning series to ensure they are comfortable with OPTN policies and are able to contribute informed feedback when reviewing other OPTN Committee proposals. This month's topic was a primer on Policy 5: Organ Offers, Acceptance and Verification. There were no questions.

4. Liver Update

UNOS staff provided a summary of the decision points the OPTN Liver and Intestines Committee voted on during their last meeting. There were no questions.

Upcoming Meeting

- November

Attendance

- **Committee Members**
 - Kristie Lemmon
 - Darnell Waun
 - Julia Coleman
 - Leslie Wyers
 - Luis Mayen
 - Stephanie Little
 - Ann Grosscup
 - Jeff Graham
 - Mary Baliker
 - Sandi Amaral, MD
 - Garrett Erdle
 - Anil Kotru, MD
- **HRSA Representatives**
 - Marilyn Levi
 - Jim Bowman
- **SRTR Staff**
 - Katie Audette
- **OPTN/UNOS Staff**
 - Kim Uccellini, MS, MPH
 - Jill Finnie
 - Ruth Langhorne
 - Heather Stocker
 - Heather Neil
- **Other Attendees**
 - Will Oler