# OPTN/UNOS Patient Affairs Committee Meeting Minutes June 13, 2017 Conference Call

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

#### Introduction

The Patient Affairs Committee met via Citrix GoToTraining teleconference on 06/13/2017 to discuss the following agenda items:

- 1. What Every Parent Needs to Know
- 2. Organ Allocation Primer
- 3. Other Significant Items

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

#### 1. What Every Parent Needs to Know

The workgroup chair provided an update to the Committee regarding the status of the project.

#### Summary of discussion:

Since the last update provided to the Committee, the draft has undergone multiple revisions, which necessitated an extension of the project timeline. The workgroup is finalizing the most current draft to deploy to external reviewers and stakeholder organizations to obtain additional feedback. Initially, this was going to also include review by health literacy experts, however, this was abandoned due to associated fees.

#### Next steps:

- The workgroup will present a final draft to several other OPTN Committees for review and endorsement.
- UNOS staff will begin drafting layout and design options for the workgroup to consider.
- The estimated completion date for this resource is August 2017.

#### 2. Organ Allocation Primer

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 organ allocation.

#### Summary of discussion:

There was little substantive discussion after the presentation but Committee members commended the speaker on how she explained a complex topic.

#### 3. Other Significant Items

The Vice Chair provided a Policy Oversight Committee update to the Committee. There were no questions or discussion.

# **Upcoming Meeting**

• August, 2017

#### **Attendance**

#### • Committee Members

- o Kristie Lemmon
- o Darnell Waun
- o Jan Finn
- o Joseph Hillenburg
- o Debi Hammel
- o Anna Zitnay
- o Sandi Amaral
- o Luis Mayen
- o Ann Grosscup

### HRSA Representatives

- o Bob Walsh
- SRTR Staff
  - o Katie Audette

#### • OPTN/UNOS Staff

- o Kim Uccellini, MS, MPH
- o Liz Friddell
- o Heather Stocker
- o Jill Finnie
- o Lori Gore

#### • Other Attendees

- o Deanna Santana
- o Garrett Erdle