

**OPTN/UNOS Patient Affairs Committee  
Meeting Minutes  
November 21, 2017  
Conference Call**

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

**Introduction**

The Patient Affairs Committee met via Citrix GoToTraining teleconference on November 21, 2017 to discuss the following agenda items:

1. AHIRC Annual Report and Policy 17: International Organ Transplantation

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

**1. AHIRC Annual Report and Policy 17: International Organ Transplantation**

Summary of discussion:

Committee leadership requested more education on OPTN policies and related OPTN topics for Patient Affairs Committee (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 17: International Organ Transplantation. Ad Hoc International Relations Committee (AHIRC) Chair Susan Gunderson, MHA, and Vice Chair Kishore Iyer, MBBS presented to Committee members.

During the presentation, PAC members asked questions of the presenters. One question included how data was collected on whether the person was in the country for transplant or for other reasons. This is a data entry that takes place at the transplant center and is reported by staff within the center. This is self-reported data and, as such, it may sometimes be difficult to understand why a determination of the status was applied. An additional question involved the reporting of follow-up data on patient outcomes for foreign nationals. AHIRC stated that it is on their radar, but there is currently no data on that. Another question involved how foreign nationals – after receiving an organ – would handle a decline in health following the transplant in which an emergency transplant would be necessary. AHIRC does not collect this data, but it may be possible to do so. This is particularly true because the individual would be allowed to be listed normally given the circumstances. Finally, a Committee member asked whether demographics used as a data overlay within the regions when analyses were performed. The Committee member pointed out that Region 10 has one of the largest Arabic-speaking populations in the United States, which could skew data on the amount of foreign nationals receiving transplants given family affiliations to certain regions.

Lastly, Susan Gunderson gave a brief overview of the AHIRC's annual report. Each meeting of the Board of Directors features information and data from the AHIRC. However, AHIRC members want to know how the report could be better organized and presented to patients, especially those who are Board members. PAC leadership stated that the Committee will discuss the AHIRC report at their next meeting. Upon reviewing, the Committee will present information to the AHIRC in order to better inform patients of international organ allocations within the United States.

Next steps:

- Review AHIRC Annual Report

**Upcoming Meeting**

- December 19<sup>th</sup>, 2017

## Attendance

- **Committee Members**
  - Kristie Lemmon
  - Ann Grosscup
  - Debi Hammel
  - Mary Baliker
  - Mary Beth Callahan
  - Jeffrey Graham
  - Leslie Wyers
  - Luis Mayen
  - Garrett Erdle
  - Julia Coleman
  - Stephanie Little
  - Sandi Amaral
  - Beth Rubinstein
  - Denise Neal
  - Anil Kotru
- **HRSA Representatives**
  - Jim Bowman
  - Melanie Deal
- **SRTR Staff**
  - Katherine Audette
- **OPTN/UNOS Staff**
  - Kim Uccellini
  - Heather Neil
  - Heather Stocker
  - Jill Finnie
  - Elizabeth Miller
- **Other Attendees**
  - Susan Gunderson