

**OPTN/UNOS Patient Affairs Committee  
Meeting Minutes  
December 19, 2017  
Chicago, IL**

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

**Introduction**

The Patient Affairs Committee met via Citrix GoToTraining teleconference on 12/19/2017 to discuss the following agenda items:

1. Follow Up on Ad Hoc International Relations Committee Presentation
2. Education: Living Donor Committee

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

**1. Follow Up on Ad Hoc International Relations Committee Presentation**

Summary of discussion:

Kristie Lemmon, PAC Chair, presented a response discussion coming as a result of presentations given by the OPTN/UNOS Ad Hoc International Relations Committee (IRC) during the previous month's PAC meeting. This presentation revolved around non-citizen and non-resident (NCNR) transplant activity in the United States. Key points included the following:

- Review of 2013-2016 transplant activity
- Discussion of OPTN policy, Final Rule, and international efforts to counter transplant tourism
- IRC requesting OPTN/UNOS discussion on significance of NCNR activity and impact on the United States population
- Education on the Declaration of Istanbul created to clarify issues of transplant tourism, trafficking, and commercialism while also providing ethical guidelines for practice in organ donation and transplantation

PAC was asked to consider the goal of Policy 17.1, in which transparency is ensured with regard to transplantation of international patients who travel to the United States for the purpose of transplant (with the reminder that it is not expressly the purpose of the policy to prohibit such transplants). The following questions arose:

- Should additional goals be considered?
- Should the number of international patients who get transplanted be considered regardless of why these patients traveled to the United States?
- What does the data tell us about whether there is a concern or problem?
- Are ethical issues associated with utilizing United States based organs for non-residents when there are not enough organs to meet the needs of the current United States listed candidates? In the absence of policy guidance, how should thresholds for review of program specific results be developed?
- Should there be OPTN limitations on international sharing?

Some concern was voiced by PAC members, including the fact that many of the international transplants are for patients from wealthy countries in the Middle East. However, the reverse was also posited, namely that United States patients may also receive transplants abroad. As such, simply prohibiting international transplants may put American patients at risk while abroad.

Further discussion yielded that different programs across the country will handle international patients uniquely, with some accepting, some accepting with caveats, and some not accepting such patients at all. As such, there is considerable variability across the country.

Another major topic of discussion involved the disproportionate rate of registrations and transplants for residents from the Gulf States, namely Saudi Arabia and Kuwait. While this may suggest a pattern of systemic referral to the United States, members also pointed out that it may not be any more significant than general healthcare issues. In particular, people with means are going to seek the best care possible, and the United States system can provide that to such patients. There may also be positive consequences associated with such interactions, such as large research donations received by United States centers that will go on to benefit United States citizens.

Questions also arose as to how centers with large volumes of NCNR patients are affected by such access of international patients. Upon evaluation of available research, however, it appears that even centers with higher volumes of NCNR patients are not adversely affected. Members did voice that this ultimately raises question of public trust and may give the appearance that money can buy transplants.

## **2. Education: Living Donor Committee**

### Summary of discussion:

Lee Bolton, OPTN/UNOS Living Donor Committee Policy Analyst, gave a presentation on the Living Donor Committee and living donation. This included a history of living donation, the formation of the Living Donor Committee, and current issues in living donation of importance to the transplant community.

An important area of discussion involved living donor follow-up. Current data shows that only approximately 50 percent of programs are meeting the requirements for living donor follow up. This posits a unique discussion for PAC, especially when considering the interplay of transplant patients and living donors.

### **Upcoming Meeting**

- January 16, 2018 from 3-4pm EST

## **Attendance**

- **Committee Members**
  - Kristie Lemmon, MBA
  - Darnell Waun, MSN, RN
  - Mary Beth Callahan, LCSW
  - Luis Mayen
  - Debi Hammel
  - Stephanie Little, MSW, LCSW
  - Ann Grosscup, MS
  - Elizabeth Rubinstein
  - Anil Kotru, MD
  - Sandi Amaral, MD
- **HRSA Representatives**
  - Melanie Deal
  - Raelene Skerda
- **SRTR Staff**
  - Katie Audette, MS
- **OPTN/UNOS Staff**
  - Emily Ward
  - Heather Neil
  - Elizabeth Miller
  - Lee Bolton