

OPTN/UNOS Ad Hoc International Relations Committee
Meeting Minutes
October 31, 2017
Teleconference

Susan Gunderson, MHA, Chair
Kishore Iyer, MD, Vice Chair

Introduction

The Ad Hoc International Relations Committee (AHIRC) met by teleconference on 10/31/2017 to discuss the following agenda items:

1. Report from Executive Committee Presentation
2. 2014-2016 High Volume Center Report
3. Proposed Voluntary Program Inquiry
4. Other Significant Items

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

1. Report from Executive Committee Presentation

Summary of Discussion:

The Committee Chair provided an overview of the June 5, 2017 presentation to the Executive Committee. She noted that this was the first opportunity in several years to provide information on the Committee's work on the annual report. The 2016 report was the fourth iteration of the annual report using the new definitions that clearly categorize individuals as non-US citizens/non-US residents (NCNR). The definitions also identifies those individuals who are in the United States specifically for the purpose of transplantation and those in the US for reasons other than transplantation.

The number of NCNR waitlist additions and transplants remains low. In 2016, 1.3% (760) of the total waitlist additions were non-US residents. Of those, 0.5% (287) were in the US for transplant and 0.8% (473) were in the US for reasons other than transplant. In 2016, 1.2% (340) of the total deceased donor transplants performed were non-US residents. Of those, 0.5% (141) were in the US for transplants and 0.7% (199) were in the US for reasons other than transplant. Candidates coming to the US specifically for transplantation were primarily from the Gulf States, with Saudi Arabia and Kuwait comprising the largest number of travel-for-transplant patients.

The Committee Chair noted that the purpose of the report to the Executive Committee was to provide an update and to solicit support and guidance on the path forward identified by the Committee. The Executive Committee agreed it is important for the AHIRC to continue to review the data and develop a process to request additional information from transplant programs. The Executive Committee acknowledged that the requests should be informational and descriptive and should continue to be voluntary as outlined in OPTN policy. There was a recommendation to inquire about activities that might bring these patients to the US, such as specific marketing or financial arrangements with foreign nations. Additionally, it might be beneficial to confirm that transplant hospitals understand and apply the definitions for citizenship when completing the candidate registration forms. A Committee member noted that the transplant administrators should be the point of contact for these future inquiries.

One Committee member noted that the allocation of organs based on country of residency is not something that most people want to change. Once a candidate is on the waiting list in the US, they are allocated organs based on their medical necessity and not on their citizenship status. The Committee also discussed the issue of non-US residents becoming donors while in

the country. However, the Committee acknowledged that the donor data is difficult to collect and might actually be underreported.

2. 2014-2016 High Volume Center Report

Summary of discussion:

The Committee had previously discussed identifying certain transplant centers for the initial requests for additional information. The Committee agreed that defining and identifying “high volume” transplant centers would be an appropriate first step. For example, the Committee discussed using inclusion criteria such as a three-year period with greater than 5% NCNR transplants in any one of those years and with absolute numbers of at least 5. This threshold would capture 20 kidney, 14 liver, 5 heart, 2 lung, 5 intestine, and 4 pancreas programs.

Next steps:

The Committee will continue to refine the trigger for an inquiry.

3. Proposed Voluntary Program Inquiry

Summary of discussion:

The Committee reviewed and discussed a draft questionnaire. The Committee members provided feedback and acknowledged that the goal of the conversation is to gain a better understanding of the activities related to the transplantation of non-US residents. The Committee also recognized that these transplants could impact access to organs for US citizens. As part of the questionnaire, the Committee plans to provide data that compares a transplant center to other high volume centers as well as other centers in the region. This data will include:

- Median time to transplant
- MELD/PELD at transplant
- Waitlist mortality

The Committee members made several edits to the draft questionnaire. There was also a discussion about the impact of transplanting international candidates on a transplant program’s ability to provide follow-up care and the potential impact on the graft and patient survival metrics used in the program-specific reports.

One Committee member asked what the Committee plans to do with the information provided by the transplant centers. The Committee Chair noted that once we start collecting the information, it will help the Committee better understand the impact of these transplants. These initial inquiries could help transplant centers better understand the impact on their candidates. As previously discussed, while the overall national impact is small, there could be a significant impact locally or regionally.

Next steps:

Several Committee members will continue to revise the draft questionnaire.

4. Other Significant Items

- Proposed Region 9 Sharing Agreement with Quebec – The Committee was provided with an update on this agreement being developed in Region 9. UNOS staff is working with the program director for the New York State Consortiums to refine the agreement prior to review by the AHIRC.

Upcoming Meeting

- December 14, 2017 (Teleconference)