# OPTN/UNOS Ad Hoc International Relations Committee Meeting Summary February 28, 2017 Teleconference

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Discussions of the full committee on February 28, 2017 are summarized below. All committee meeting summaries are available at <u>http://optn.transplant.hrsa.gov/</u>.

### **Committee Projects**

#### 1. Non-US Citizen/Resident Transplant Activity

The Committee continues to evaluate data on non-US citizen/non-US resident (NCNR) transplant activity to better understand the impact on US residents awaiting transplant. Committee leadership has provided updates to the Ethics Committee, Pediatric Committee, and Kidney Transplantation Committee. All three committees agreed that more detailed analysis is needed to better understand the issues. There was general interest from the committees about the impact that NCNR candidates have on the waiting times and transplant rates of US citizens.

UNOS Research staff noted that there have been two recent changes to the citizenship information that is collected on the transplant candidate registration (TCR) form. In 2012, the OPTN Contractor began collecting NCNR information for "traveled not for transplant" and "traveled for transplant." In March 2015, the OPTN Contractor began collecting the "country of residence" information.

#### The Committee requested the following data during its Nov. 2016 conference call:

- 1. Describe waiting list candidates added in the U.S. with a reported citizenship of Non-US Citizen/Non-US Resident.
- 2. Describe deceased donor transplants performed in the U.S. for recipients with a reported citizenship of Non-US Citizen/Non-US Resident.
- 3. For centers with the highest volumes, compare their waiting times and waiting list mortality information to the distribution of the same metrics at other centers in their region.
- 4. For living donor liver and kidney transplants performed in the U.S. 2013-2015, provide the recipient citizenship by region, organ, donor relation to recipient, year of transplant, and encrypted transplant center.
- 5. For living donor liver transplants performed in the U.S. 2013-2015 for recipients with reported citizenship of Non-US Citizen / Non-US Resident, number and percentage relisted for deceased donor transplant by citizenship category and region.

## Waitlist Registrations Added - Kidney

Of the registrations added for NCNR candidates April 2015 – May 2016: For Mexico as country of residence, traveled for other reason made up 254 of 469 total NCNR registrations. Excluding Mexico, travel for other reason yielded a higher number of registrations (140) than traveled for transplant (61). 40 out of 50 Middle Eastern NCNR registrations had a citizenship status of traveled for transplant. For pediatric registrations, traveled for other reason is slightly higher (13) than traveled for transplant (10), with Middle East being 1 traveled for other reason and 7 traveled for transplant.

Of the registrations added at centers who listed NCNR candidates 2013 – 2015: Kidney: NCNR make up 1.6% of registrations at these centers. Traveled for other reason (908) yielded a much higher number of registrations than traveled for transplant (194). For pediatric registrations, the trend was opposite: 6 travel for other reason, 26 traveled for transplant. 89 of the 120 centers register more traveled for other reason than they registered traveled for transplant.

#### Deceased Donor Transplants Performed - Kidney

Of the transplants performed for NCNR recipients April 2015 – May 2016: Mexico, traveled for other reason made up 39 of 163 total NCNR transplants. Excluding Mexico, traveled for other reason (99) yielded a higher number of transplants than traveled for transplant (24). 7 out of 8 Middle Eastern NCNR transplants had a citizenship status of traveled for transplant. In pediatric transplants, traveled for other reason (6) is equal to traveled for transplant (6), with Middle East being no traveled for other reasons and 2 traveled for transplant.

Of the transplants performed at centers who transplanted NCNR recipients 2013 – 2015: NCNR make up 1.5% of transplants at these centers. Traveled for other reason yielded a much higher number of transplants (191) than traveled for transplant (53). For pediatric transplants, the trend is opposite with 14 traveled for other reason and 17 traveled for transplant. 75 out of 83 centers registered more traveled for other reason than they register traveled for transplant.

#### Time to Transplant - Kidney

No centers had noticeably higher percent of added registrations receiving deceased donor transplants within one year relative to their respective regions. 3 out of 7 centers had noticeably lower percent of added registrations receiving deceased donor transplants within one year relative to their respective regions.

Overall, these centers had a noticeably lower percent of added registrations receiving deceased donor transplants within one year relative to their respective regions. 1 out of 7 centers had a noticeably higher percent of added registrations transplanted within three years relative to its respective region. 3 out of 7 centers had noticeably lower percent of added registrations transplanted within one year relative to their respective regions. Overall, these centers had a noticeably lower percent of added registrations transplanted within one year relative to their respective regions.

### Waitlist Mortality – Kidney

No center had a noticeably different percent of added registrations removed for death within one year of listing relative to their respective regions.

Overall, the percent of added registrations removed for death within one year is not noticeably different between these centers and their respective regions. 1 out of 7 centers had a noticeably lower percent of added registrations removed for death within three years of listing relative to its respective region. 1 out of 7 centers had a noticeably higher percent of added registrations removed for death within three years of listing relative to its respective region. Overall, the percent of added registrations removed for death within three years of listing relative to its respective region. Overall, the percent of added registrations removed for death within three years of listing is not noticeably different between these centers and their respective regions.

#### Living Donor Transplants Performed – Kidney

NCNR make up 2.3% of living donor transplants at centers performing at least one transplant for NCNR recipients. Traveled for other reason yielded a similar number of transplants (105) to traveled for transplant (111). Most living donor transplants for NCNR at these centers are from biologically-related donors.

### Waitlist Registrations Added – Liver

Of the registrations added for NCNR candidates April 2015 – May 2016: Middle Eastern, traveled for transplant make up 107 of 178 total NCNR registrations. 107 out of 109 Middle Eastern NCNR registrations had a citizenship status of traveled for transplant. Excluding Middle Eastern countries, traveled for other reason yielded a higher number of registrations (43) than traveled for transplant (26). With the exception of Region 5, each region had more traveled for transplant registrations than traveled for other reason registrations.

For pediatric registrations, traveled for other reason is much lower (2) than traveled for transplant (32), with Middle East being 1 traveled for other reason and 27 traveled for transplant.

Of traveled for transplant registrations, 50% register with an allocation MELD/PELD < 15, 87% register with Allocation MELD/PELD < 30. Of traveled for other reason registrations, 29% register with an allocation MELD/PELD < 15, 56% register with Allocation MELD/PELD < 30.

Of US Citizens, 40% register with an allocation MELD/PELD < 15, 81% register with an allocation MELD/PELD < 30.

Of the registrations added at centers who listed NCNR candidates 2013 – 2015: NCNR make up 1.8% of registrations at these centers. Traveled for other reason yielded a much lower number of registrations (111) than traveled for transplant (312).

For pediatric registrations, the difference was more pronounced with 13 traveled for other reasons and 63 traveled for transplant. Pediatric diagnoses follow no distinct

pattern. The largest group is "Other, Specify" diagnosis, which covers 17 of the 63 traveled for transplant registrations.

### Deceased Donor Transplants – Liver

Of the transplants performed for NCNR recipients April 2015 – May 2016: Middle Eastern, traveled for transplant make up 51 of 124 total NCNR transplants. 51 out of 57 Middle Eastern NCNR transplants had a citizenship status of traveled for transplant.

Excluding Middle Eastern countries, traveled for other reason yielded a similar number of transplants (33) to traveled for transplant (34). Region 3 performs the most transplants for traveled for transplant, Region 5 performs the most transplants for traveled for other reason.

In pediatric transplants, traveled for other reason is much lower (3) than traveled for transplant (22), with Middle East being 2 traveled for other reason and 15 traveled for transplant.

Of the transplants performed at centers who transplanted NCNR recipients 2013 – 2015: NCNR make up 2.4% of transplants at these centers. Traveled for other reason yielded a much lower number of transplants (73) than traveled for transplant (190).

For pediatric transplants, the difference is similar: 11 traveled for other reason and 51 traveled for transplant.

48% of traveled for other reason transplants were transplanted with an allocation MELD/PELD of 35 or higher. 55% of traveled for transplant were transplanted with an allocation MELD/PELD < 30.

#### Liver Transplants – High Volume Centers

At high volume centers, there is no noticeable difference in allocation MELD/PELD at transplant from that of their respective regions. 34% of traveled for other reason transplanted at a lab MELD/PELD of 35 or higher. For all others citizenship, this is 20% and for traveled for transplant, this is 15%.

At high volume centers, no noticeable difference from region. Highest volume pediatric NCNR center performed 15 transplants for traveled for transplant. At high volume centers, there is no noticeable difference in allocation MELD/PELD at transplant from that of their respective regions. 34% of traveled for other reason transplanted at a lab MELD/PELD of 35or higher. For all others citizenship, this is 20% and for traveled for transplant, this is 15%.

At high volume centers, no noticeable difference from region. Highest volume pediatric NCNR center performed 15 transplants for traveled for transplant.

#### Waitlist Mortality – Liver

2 out of 6 centers had a noticeably lower percent of added registrations removed for death within one year of listing relative to their respective regions. Overall, the percent of

added registrations removed for death within one year is not noticeably different between these centers and their respective regions.

### Living Donor Transplants Performed – Liver

NCNR make up 6.8% of living donor transplants at these centers. Traveled for other reason yielded a noticeably lower number of transplants (3) to traveled for transplant (31). Most living donor transplants for NCNR at these centers are from biologically-related donors.

### Living Donor Recipient Relisting – Liver

3 out of 34 (8.8%) of NCNR living donor liver recipients were later relisted for deceased donor transplant. All three were former traveled for transplant recipients

### Waitlist Registrations Added - Heart

Of the registrations added for NCNR candidates April 2015 – May 2016: Middle Eastern, traveled for transplant make up 25 of 57 total NCNR registrations. 25 out of 28 Middle Eastern NCNR registrations had a citizenship status of traveled for transplant. Excluding Middle Eastern countries, traveled for other reason yielded a slightly higher number (16) of registrations than traveled for transplant (13).

For pediatric registrations, traveled for other reason is much lower (1) than traveled for transplant (13), with Middle East being 1 traveled for other reason and 7 traveled for transplant.

#### Deceased Donor Transplants Performed – Heart

Of the transplants performed for NCNR recipients April 2015 – May 2016: Middle Eastern, traveled for transplant make up 12 of 34 total NCNR. 12 out of 13 Middle Eastern NCNR transplants had a citizenship status of traveled for transplant. Excluding Middle Eastern countries, traveled for other reason yielded a similar number of transplants (10) to traveled for transplant (11).

In pediatric transplants, traveled for other reason is much lower (1) than traveled for transplant (14), with Middle East being 0 traveled for other reason and 6 traveled for transplant.

Of the transplants performed at centers who transplanted NCNR recipients 2013 – 2015: NCNR make up 2.6% of transplants at these centers. For pediatric transplants, NCNR are 7.7% of transplants at these centers. Traveled for other reason yielded a much lower number of transplants (17) than traveled for transplant (52).

#### Time to Transplant – Heart

For centers that had the top 5 registrations or transplants for NCNR in the US for the purpose of transplant from January 2013 – December 2015, 2 out of 5 centers had noticeably lower median times to deceased donor transplant for added registrations than

their respective regions. Overall, these centers had no noticeably different median time to deceased donor transplant for added registrations relative to their respective regions.

### Waitlist Mortality - Heart

For centers that had the top 5 registrations or transplants for NCNR in the US for the purpose of transplant from January 2013 – December 2015, 1 out of 5 centers had a noticeably lower percent of added registrations removed for death within one year of listing relative to their respective regions. Overall, the percent of added registrations removed for death within one year is not noticeably different between these centers and their respective regions. 1 out of 5 centers had a noticeably lower percent of added registrations removed for death within three years of listing relative to its respective region. 1 out of 5 centers had a noticeably higher percent of added registrations removed for death within three years of listing relative to its respective region. Overall, the percent of added registrations removed for death within three years of listing relative to its respective region. Overall, the percent of added registrations removed for death within three years of listing relative to its respective region. Overall, the percent of added registrations removed for death within three years of listing relative to its respective region. Overall, the percent of added registrations removed for death within three years of listing is not noticeably different between these centers and their respective regions.

## Waitlist Registrations Added - Lung

Of the registrations added for NCNR candidates April 2015 – May 2016: Middle Eastern, traveled for transplant made up 25 of 38 total NCNR registrations. 25 out of 26 Middle Eastern NCNR registrations had a citizenship status of traveled for transplant. Excluding Middle Eastern countries, traveled for other reason yielded a lower number of registrations (4) than traveled for transplant (8).

In pediatric registrations, few registrations had either NCNR citizenship status: 1 traveled for other reason and 2 traveled for transplant, with Middle East being 0 traveled for other reason and 2 traveled for transplant.

## Deceased Donor Transplants Performed – Lung

Of the transplants performed for NCNR recipients April 2015 – May 2016: Middle Eastern, traveled for transplant made up 11 of 26 total NCNR transplants. 11 out of 12 Middle Eastern NCNR transplants had a citizenship status of traveled for transplant. Excluding Middle Eastern countries, traveled for other reason yielded a lower number of transplants (5) compared to traveled for transplant (9).

In pediatric transplants, there was 1 traveled for other reason transplant and 2 traveled for transplant, with Middle East being 0 traveled for other reason and 2 traveled for transplant.

## Time to Transplant – Lung

For centers that had the top 5 registrations or transplants for NCNR in the US for the purpose of transplant from January 2013 – December 2015. 4 out of 7 centers had noticeably lower median times to deceased donor transplant for added registrations than their respective regions. 1 out of 7 centers had a noticeably higher median time to deceased donor transplant for added registration than its respective region. Overall, these centers had no noticeably different median time to deceased donor transplant for added registrations than its respective region.

### Waitlist Mortality - Lung

For centers that had the top 5 registrations or transplants for NCNR in the US for the purpose of transplant from January 2013 – December 2015. No center had a noticeably different percent of added registrations removed for death within one year of listing relative to their respective regions. Overall, the percent of added registrations removed for death within one year is not noticeably different between these centers and their respective regions. No center had a noticeably different percent of added registrations removed for death within three years of listing relative to their respective regions. Overall, the percent of added registrations removed for death within three years of listing relative to their respective regions. Overall, the percent of added registrations removed for death within three years is not noticeably different between their respective regions.

### Committee Discussion:

One committee member noted that while the overall numbers are small, there is the potential for disadvantaging US citizens/residents. For example, if a center is transplanting a higher percentage of NCNR candidates than the region, it could create a disadvantage for some candidates? Based on the data presented, the higher volume centers did not have a noticeably different median time to transplant across all organ systems. A committee member noted that one important conclusion that could be made is that once these patients are listed, they are treated the same as all the other patients. They are neither advantaged nor disadvantaged, which is very unique to the United States versus other countries.

The Committee briefly discussed the number of pediatric patients that travel to the country for transplant, particularly from the Middle East. The Pediatric Committee agreed this could impact US citizens/residents, especially if some of the pediatric candidates have metabolic diseases that qualify for Status 1B. Again, the numbers are small and transplant services are not always available in their country of residence.

A committee member noted that one of the liver centers provides an example of one of the major concerns. The numbers are small with five NCNR transplants at a MELD/PELD score of less than 15 and 13 NCNR transplants in three years with MELD/PELD scores below 30. However, when candidates in certain locations are waiting for a liver transplant, the centers need to assess the mortality on their list as well as that of the region.

The Committee will continue to evaluate this data and determine a path forward.

#### **Other Significant Items**

None

## **New Business**

None

## **Upcoming Meeting**

• TBD