

OPTN Ad Hoc International Relations Committee

Meeting Summary

May 12, 2020

Conference Call

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Barry Friedman, RN, BSN, MBA, CPTC , Vice Chair

Introduction

The Ad Hoc International Relations Committee (AHIRC) met via Citrix GoToMeeting teleconference on 05/12/2020 to discuss the following agenda items:

1. Review AHIRC Annual Report
2. Policy Oversight Committee Update
3. Other Business

The following is a summary of AHIRC's discussions.

1. Review AHIRC Annual Report

United Network for Organ Sharing (UNOS) staff reviewed the OPTN International Relations 2019 Annual Report.

Summary of discussion:

- Comment was made that the waitlist additions data is not reliable or usable data.
- A member expressed concern about an increase in the number of pediatric waitlist additions; UNOS staff commented the numbers were similar in 2018.
- A point of clarification was made regarding transplant activity, the 436 (1.3%) of transplants were NCNR.

Comments:

- There is a steady increase in NCNR transplants in total; this is not reliable data because of how it is collected. The fact that it has gone up does not mean anything. The same applies for deceased NCNR transplants.
- There was a dramatic increase in NCNR kidney/pancreas transplants; it jumped from less than 1% to over 3.5%. Could this be because the OPTN pushing more kidney transplants nationally?
- Is there missing data in citizenship, and if so, what is missing?
 - UNOS staff commented that some records are incomplete but a very small number
 - Do we know the non-NCNR candidates' average waitlist time by region and is it similar to the NCNR candidates' average waitlist time? For example, if the average wait time is 7 years in region 9 and the average wait time for NCNR candidates is 3 year; that could be a problem.
- Pending survey – is there a wait time question?
 - UNOS staff confirmed that there is a wait time question
- Could we get post-transplant outcomes data on the NCNR patients? If so, how many go on to acquire deceased donor transplants?

- UNOS staff commented, yes we have the data, but only for transplants performed in the United States, the data is not tracked if the transplant takes place in another country.
- How many deceased donor transplants have had previous living donor transplants and are there any consequences to US residents?
 - There could be, but is probably small.
- Country of origin breakdown would help, could the UNOS staff do some more analysis on this data?
 - UNOS staff commented they would pull this data for the committee.
- The percent continues to be about the same, but if you look at the absolute numbers, NCNR registrations are up 23% from 2016 – 2019 and there is a 38% increase in kidney alone.
 - This information is worth looking at.
- Comments were made regarding the new component in the report for each organ type - percent of NCNR and actual number of transplants:
 - This would be useful piece of data to pull out; high percentage centers and high actual number of transplants at centers.
 - AHIRC would like to see how many programs fall into the higher categories.
 - Is there a sense that the increase in region 5 is all related to increased NCNR candidates from Mexico? If so, why are we not seeing this in region 4, specifically Texas?
- There were four kidney/pancreas registrations over the previous three years, and then in 2019 there were 10.
- AHIRC was perplexed about region 5, they would think region 9 and region 10 would see the most increase.
- Some comments were made regarding missing data:
 - 8% for DCD and 10.2% for brain dead is missing citizenship of donors, we have no idea what the status is when the data is not available.
 - A member commented that this is not an area where the centers are going to push hard given the difficult circumstances the families are in.
- Is there one program that only did NCNR transplants?
 - UNOS staff commented that one center did only one intestinal transplant and it was for an NCNR candidate.
- What this data fails to show is there could be a back-story on the impact on local transplant programs.
- Comments on table 10 in the full report:
 - Kidney registrations from Kuwait has disappeared.
 - Can we double check this data as Saudi Arabia is not shown either.
 - AHIRC requested to see a list of the top countries and trends.

2. Policy Oversight Committee Update

AHIRC's Vice Chair provided a Policy Oversight Committee Update

Summary of discussion:

- Timeline refers to going before the board in December; will there be a COVID delay?
 - UNOS staff commented there are currently no delays in projects specifically due to COVID.
- A member commented about liver implementation and how some candidates were disadvantaged, stating that median meld at transplant can vary by state.

3. Other Business

Program Information Request Comments:

- AHIRC agreed to change the qualifications to only meet one rather than both the criteria to receive the survey, especially in dedicated pediatric programs. This would increase the number of programs that would receive the survey.
 - UNOS staff commented they would make the change and run it through the survey approval process.
- A request was made to present survey results to the Executive Committee and possibly the full Board of Directors in December 2020
 - UNOS staff commented they would find out the process for getting on the Executive Committee agenda.

Upcoming Meetings

- TBD