

**OPTN Data Advisory Committee  
Meeting Summary  
March 9<sup>th</sup>, 2020  
Conference Call**

**Sandy Feng, MD, PhD, Chair  
Rachel Patzer, MPH, PhD, Vice Chair**

## **Introduction**

The OPTN Data Advisory Committee (DAC) met via Citrix GoToTraining teleconference on 03/09/2020 to discuss the following agenda items:

1. Measuring Transplant Outcomes by Collecting Data on Children Born to Uterus Recipients Project Check-in
2. Update to Vascularized Composite Allograft (VCA) Transplant Outcomes Data Collection Project Check-in
3. Data Collection to Assess Socioeconomic Status (SES) and Access to Transplant Project Check-in
4. National Heart Review Board for Pediatrics Project Check-in
5. Wrap-up & Next Steps

The following is a summary of DAC's discussions.

### **1. Measuring Transplant Outcomes by Collecting Data on Children Born to Uterus Recipients Project Check-in**

United Network for Organ Sharing (UNOS) staff presented a post public comment update on the VCA Transplant Committee's request for feedback concerning whether the OPTN should follow and collect data from children born via transplanted uteruses.

#### Summary of discussion:

Committee members agreed that it's important to gather this information in order to determine whether births via transplanted uteruses are generally safe and if infants born of these transplants have good health outcomes. A member mentioned that the CDC has a milestones tracker for all children up to the age of six. A member suggested that this tracker may be useful as a resource for the parents of children born via transplanted uteruses.

A member inquired if it's fair and ethical to monitor these children even though they weren't the ones that agreed to the transplant and they can't agree to have data collected on them.

A member also explained the increased data burden with following up with children born from uterus transplants. This burden would include increased data collection and tracking these children, who are not patients of the transplant program, in order to collect data. A member mentioned that the living donor community has also struggled with getting donors to follow up with a transplant center and that it might be helpful for the VCA Transplant Committee to look into the living donor policies surrounding follow-up.

## **2. Update to VCA Transplant Outcomes Data Collection Project Check-in**

UNOS staff presented a post public comment update on this project, which proposes adding new data fields to the Transplant Recipient Registrations (TRR) form and Transplant Recipient Follow-up (TRF) form.

### Summary of discussion:

A member mentioned that, in the transplant community, questions regarding patient follow-up are all the same irrespective of how long after transplant. A member inquired whether the data being collected at one year and two year follow-up needs to be collected beyond that time frame. The presenter explained that 5 year follow-up forms typically ask less specific information.

A member also inquired as to whether one of the three proposed psychosocial assessments had been decided upon. Staff explained that this was mentioned in the proposal, and that one hadn't been decided upon yet.

## **3. Data Collection to Assess SES and Access to Transplant Project Check In**

A Minority Affairs Committee (MAC) member presented a post public comment update on this project, which proposes collecting household income and household size to measure SES of transplant candidates.

### Summary of discussion:

Members agreed that questions asking about household income and household size might make patients and programs uncomfortable. The main issues are trust, accuracy, and what this information would be used for since no one's able to change their SES.

The presenter explained that the metrics used to measure SES in transplantation are not up to national standards compared to what other organizations collect. The OPTN currently has ZIP Code data on transplant candidates; however, by adding these two new data fields, the OPTN would be able to collect more granular and accurate data regarding SES.

DAC members inquired whether MAC would be making any post-public comment changes, such as possibly scaling this to a smaller population and making it a pilot project.

The MAC presenter inquired as to whether the proposal would be better received if it asked for an income range or if both questions were made optional. DAC members didn't have any feedback on whether this would make the questions less intrusive.

A member inquired how MAC knows that there are disparities in transplant due to SES. The presenter explained that research surrounding this has been published showing that worse post-transplant outcomes are correlated with lower SES.

A member inquired as to what the goal of this project was: to learn more about what is leading to worse post-transplant outcomes or to improve access to the waiting list for patients with lower SES? If it's the latter, a member mentioned that they are not sure how this data would help. The MAC presenter explained that this data would mainly be used to monitor patient access and outcomes among transplant patients with low SES.

## **4. National Heart Review Board for Pediatrics Project Check In**

UNOS staff presented an update on this project, which proposes moving the exception review into UNet and adding a data field for email address in order to provide an answer to the request in real time.

### Summary of discussion:

No discussion.

## **5. Wrap-up & Next Steps**

DAC will be presented updates on the following projects at their in-person meeting on March 27<sup>th</sup>:

- OPTN Organ Procurement Organization Committee's Deceased Donor Registration Form Review project
- OPTN Disease Transmission Advisory Committee project
- Refusal Codes project

## **Upcoming Meetings**

- March 27, 2020 (teleconference)
- April 13, 2020 (teleconference)