

**OPTN Data Advisory Committee  
Meeting Summary  
February 10, 2020  
Conference Call**

**Sandy Feng, MD, PhD, Chair  
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## **Introduction**

The OPTN Data Advisory Committee (DAC) met via Citrix GoToTraining teleconference on 02/10/2020 to discuss the following agenda items:

1. New UNOS Support Staff Introductions
2. VCA Living Donor Form Project Introduction
3. Kidney Medical Urgency Project Check In
4. Next Steps

The following is a summary of DAC's discussions.

### **1. New UNOS Support Staff Introductions**

A new UNOS policy analyst and policy associate were introduced to DAC.

### **2. VCA Living Donor Form Project Introduction**

UNOS support staff presented this proposal to DAC in order to receive DAC endorsement before Policy Oversight Committee (POC) consideration.

#### Data Summary:

The number of VCA and uterus transplants has been increasing since 2017; however, no data collection surrounding these transplants is currently required. This causes a gap in knowledge, which may lead to unknown outcomes that are difficult to track and therefore difficult to remedy if necessary. .

The proposed data solution is a tandem project with the OPTN Living Donor Committee to update OPTN Policy 14 which addresses living donation. This project will require additional data fields to collect information concerning VCA living donors. The guiding OPTN principle for this proposal is to ensure patient safety when no alternative sources of data exist.

#### Summary of discussion:

A member inquired about UNOS living donor data collection policies and mentioned that there were 5 organs that involved living donor: liver, kidney, pancreas, lung, and small intestine. It was mentioned that this data collection should also be tailored to the above organ types and not just VCA.

Staff clarified that only liver and kidney have sections regarding living donors, while VCA has exclusions regarding living donor data collection. The volume of non-liver, non-kidney living donors was too sparse when the requirement for living donor information was implemented that the decision to collect the data was given to the organ-specific Committees. Since the living donor data collection started, there has actually been fewer and fewer non-liver and non-kidney living donations.

A member inquired as to who looks at the outcomes of the living donor data collection and whether it is actually reviewed since it's not included in the quarterly review.

Staff mentioned that the OPTN Living Donor Committee just recently looked at the outcome data for liver and kidney and created a report, which is available on the OPTN website, as part of the post-implementation stage in the policy development process. There is also robust literature based on centers who have done SRTR reviews that answer specific questions about the living donor pool.

DAC endorsed VCA Living Donor Form Project.

### **3. Kidney Medical Urgency Project Check In**

Vince Casingal, Chair of the OPTN Kidney Committee, presented this update to DAC.

#### Summary of discussion:

After the OPTN Kidney Committee transitioned from DSA's to an Acuity Circle model with proximity points in kidney allocation policy, the Committee wanted to address how medical urgency would be defined in order to continue to prioritize these candidates in the new allocation system.

This project seeks to develop a national standard definition for medically urgent candidate and proposes the solution is to collect candidate information about loss of vascular and peritoneal access and document the data in Waitlist. The guiding OPTN principle is to develop transplant, donation and allocation policies.

This project is in public comment stage and has received largely supportive comments. The main theme among comments is whether the medical urgency review should be prospective or retrospective.

A member inquired if the plan was to have a similar form on Waitlist that would document the exhaustive dialysis information for a candidate. Staff replied that there will be aspects of the wait list form in the new form filled out by the transplant surgeon and nephrologist documenting whether the candidate meets the requirements for medical urgency. This form would then be used for retrospective review by the OPTN Kidney Committee. It was also mentioned that the OPTN Kidney Committee have only decided on what areas of data to collect, not specific fields.

A member inquired what the current opinion is related to the prospective review issue. It was mentioned that if the OPTN Kidney Committee was specific enough in their definitions of medical urgency then the review process wouldn't have to be prospective. The Medical Urgency Subcommittee also wanted to make this review retrospective given the timeliness of medical urgency and because the UNOS Organ Center Operations Staff facilitating a prospective review of medically urgent candidates operate under normal business hours.

A member mentioned that reviewing medically urgent candidates retrospectively could result in gaming, where organs are declined until an organ in a better condition becomes available. This member suggested that data be collected on declines of organ offers for medically urgent candidates. Staff agreed that this was good feedback and would bring it up with the OPTN Kidney Committee.

Staff pointed out that the OPTN Kidney Committee should come back to DAC, after Public Comment, to present the actual data fields to be collected rather than just the categories that went out for Public Comment.

### **4. Next Steps**

DAC will hear more Public Comment proposals during the next committee meeting on March 9<sup>th</sup>. Staff to give DAC updates on the OPTN OPO Committee's DDR Review project, OPTN DTAC project, and Refusal Codes project at the in-person meeting on March 27<sup>th</sup>.

**Upcoming Meetings**

- March 9, 2020 (teleconference)
- March 27, 2020 (Chicago, Illinois)

