

**OPTN Patient Affairs Committee  
Meeting Summary  
February 20, 2020  
Chicago, IL**

**Darnell Waun, MSN, Chair  
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## **Introduction**

The Patient Affairs Committee (PAC) met in Chicago, IL on 02/20/2020 to discuss the following agenda items:

1. *Addressing Medically Urgent Candidates in New Kidney Allocation Policy* Proposal Review
2. *Data Collection to Assess Socioeconomic Status and Access to Transplant* Proposal Review
3. Kidney Accelerated Placement Project Update
4. Continuous Distribution Update and Analytic Hierarchy Process (AHP)
5. Patient Services Update
6. Policy Oversight Committee Update
7. Communications Focus Group
8. Open Session

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

### **1. *Addressing Medically Urgent Candidates in New Kidney Allocation Policy* Proposal Review**

The Committee discussed the OPTN Kidney Transplantation Committee's *Addressing Medically Urgent Candidates in New Kidney Allocation Policy* proposal out for public comment.

#### Summary of Discussion

OPTN Kidney Transplantation Committee staff presented a summary of the *Addressing Medically Urgent Candidates in New Kidney Allocation Policy* proposal out for public comment.

The Committee discussed the proposal and provided the following comments:

- The new "medically urgent" classification will potentially impact low number of patients but for those patients it will be very important
- Since it is unknown how many patients will fall under the definition of this new classification, there is concern on how this might increase those that are categorized as medically urgent
- A suggestion was made to remove "imminent risk" from the definition
- Allocation for "medically urgent" patients should be kept within 250 NM
- Add more info to the At-a-Glance section of the proposal to help non-transplant professionals understand the complexity of the proposal
- It was suggested to have another independent transplant center sign off on the "medically urgent" status as additional supporting documentation
- It was suggested the terminology should be changed from "medically urgent" to "high urgency" as all patients should be considered "medically urgent"
- A prospective review would be preferred over a retrospective review as proposed

In addition to comments on the individual proposals, the committee expressed they would like to be involved earlier in the policy development process for proposals going forward.

A committee member asked if there other kinds of conditions that are also medically urgent and are not dialysis prescriptive. The Committee was informed the Medical Urgency Subcommittee and the Kidney Transplantation Committee considered this. When they were developing the definition, they reached out to OPOs to see what their definition of “medical urgency” is now and all indicated loss of vascular access determines “medical urgency”.

The Committee was asked where they think “medically urgent” patients should fall in the kidney allocation order. Some committee members said patients with total loss of vascular access should be higher than currently proposed. However, other committee members commented the definition as proposed makes it difficult to determine where they should fall in the allocation order as the way the proposal as written, both the imminent loss and total loss populations would be treated the same.

#### Vote

Kidney Transplantation Committee: Addressing Medically Urgent Candidates in New Kidney Allocation Policy

0 Strongly Support, 6 Support, 0 Neutral/Abstain, 6 Oppose, 1 Strongly Oppose

#### Next Steps

The Committee will draft an amendment for the proposal to be voted on during their next committee meeting. The Committee also requested for the Kidney Transplantation Committee to present six-month follow-up data to the PAC after implementation.

## **2. *Data Collection to Assess Socioeconomic Status and Access to Transplant Proposal Review***

The Committee discussed the Minority Affairs Committee’s *Data Collection to Assess Socioeconomic Status and Access to Transplant* proposal out for public comment.

#### Summary of Discussion

The Vice Chair of the OPTN Minority Affairs Committee presented a summary of the *Data Collection to Assess Socioeconomic Status and Access to Transplant* proposal out for public comment.

The Committee discussed the proposal and provided the following comments:

- It is unclear how this data will be used
- It is unclear how this would protect the patient or enhance the process for the patient
- There is concern this data will create a direct or indirect bias
- The Committee questions the reliability of the data if it is self-reported
- It was recommended to create an ethics guidance document on how this data should be used
- Concern for how this data will be used and what it might lead to (ex. quotas)
- Concern for this data being publicly available as OPTN data
- Concern that this will have a greater impact on the public’s distrust of organ allocation
- Household income does not account for non-income items that may also contribute to financial wellness

A committee member suggested this data could be retrieved from hospital’s electronic systems as they already collect this information.

#### Vote

Minority Affairs Committee: Data Collection to Assess Socioeconomic Status and Access to Transplant  
0 Strongly Support, 1 Support, 2 Neutral/Abstain, 6 Oppose, 4 Strongly Oppose

### 3. Kidney Accelerated Placement Project Update

UNOS Research staff presented a 3-month post-implementation update to the Kidney Accelerated Placement (KAP) project for the committee's review and consideration.

#### Summary of Discussion

The KAP project focuses on the accelerated placement of hard-to-place kidneys through the UNOS Organ Center. The project uses data to identify donor "triggers" for accelerated placement as well as identify transplant centers that utilize hard-to-place kidneys. The project seeks to accelerate placement of these organs to those centers that utilize them.

#### Data Review:

- First 90 days of KAP project – July 18 through October 16
- A total of 3348 kidney match runs during this time
  - 746 of these donors were **KAP-eligible donors** (adult donors, KDPI 80+ at time of match submission)
  - The Organ Center attempted placement of 339 of these donors were at **KAP-eligible sequences** (national level sequences)
    - 56 of the 339 (17%) donors had a KAP-related acceptance
    - 66 kidneys placed during the **accelerated** portion of KAP
    - 5 kidneys placed after all accelerated centers refused the organ
  - Of the kidneys that were transplanted, 57.7% were transplanted into the accepting candidate during the Pre-KAP time period. This was 63.3% during the KAP time period
- Methodology is allocating to centers more likely to accept and transplant hard-to-place kidneys
- Candidates accepting kidneys are transplanted more often
  - No indication of kidney offers being "open/center offers"
- No decrease in time spent offering kidneys or associated cold ischemia time
- **Data & Safety Monitoring Council has no concerns with the project at this stage**
  - Will continue to monitor match offer time and cold ischemia time

A committee member asked if outcome data for the KAP organs will be available. This data will be incorporated on later reports. Another committee member asked if this was an extension of the COIIN program and it was clarified this is actually an improvement initiative from the Organ Center.

Committee members also commented that they would prefer the use of the term "non-utilized" or "not-utilized" instead of "discards".

#### Next Steps

Once more data is available, an update will be presented to the Committee.

### 4. Continuous Distribution Update and Analytic Hierarchy Process (AHP)

The Committee received an introductory presentation on Continuous Distribution, the Analytic Hierarchy Process (AHP) software, and the project plan for Lung Continuous Distribution.

#### Summary of Discussion:

The committee members were asked for their feedback on outreach efforts. Committee members suggested soliciting participation from donor groups and asking OPOs to send the AHP tool to their patients.

#### Next Steps

Committee members will be receiving invitations to participate in the AHP exercise. The Lung Committee will be using compiled data to develop a continuous distribution proposal to go out for future Public Comment.

### **5. Patient Services Update**

The Committee received a presentation on the UNOS Patient Services helpline including a summary of metrics of the types of requests typically received.

#### Summary of Discussion:

The Committee discussed how patients are notified of this resource. Transplant hospitals are required by policy to send the notify their patients at listing and send a copy of the *OPTN Contractor's Patient Information Letter* which contains the phone number. The Committee further discussed patient notification requirements and that OPTN Policy does not require patients be notified if they are deactivated. This issue continues to be a frequent inquiry on the Patient Services helpline.

### **6. Policy Oversight Committee Update**

The Committee Vice-Chair gave a Policy Oversight Committee (POC) Update

#### Summary of Discussion:

The Vice-Chair informed the Committee the POC has identified three strategic policy priorities:

- Continuous Distribution
- Efficient donor/recipient matching to increase utilization
- Improved equity for multiorgan and single organ candidates

The Committee then discussed cross-committee projects the PAC will be participating in including:

- Addressing Covert Factors Impacting Patient Decision-Making in Transplantation, OPTN Ethics Committee
- Revise PHS Increased Risk Criteria, OPTN Ad Hoc Disease Transmission Advisory Committee

The Vice-Chair encouraged committee members to reach out to other members on other committees if they have questions about any projects.

### **7. Communications Focus Group**

The Committee participated in a Communications Focus Group to determine what type of information patients need at different points of their transplant journey and how that information can be incorporated into the OPTN website. Committee members offered the following comments:

- There are lots of competing information sources
- There's a lack of broad awareness of OPTN or UNOS patient community
- Suggested an OPTN Patient Advocate or section of the website for patient specific content informed by the Patient Affairs Committee
- At the evaluation stage, the hospital should explain the different phases a patient will go through

- Patients want to validate information they are given and they want real world examples that relate to them

## **8. Open Session**

Committee members rotating off in June were recognized. The Committee closed the meeting with an open discussion. The Committee discussed committee member engagement and potential committee project ideas. A committee member suggested identifying proposal review team leads earlier in the cycle. The Committee also suggested moving the in-person meeting further into the Public Comment cycle to allow more time for proposal review.

The Committee also recognized the need for a collaborative communication tool. A committee member also suggested meeting face-to-face more regularly.

### Next Steps

In preparation for the next meeting, committee members will provide ideas for suggestions for the medical urgency proposal and share ideas on how to improve the At-a-Glance. Prior to the next meeting committee members were also asked to participate in the AHP exercise and complete a Communications Focus Group worksheet.

### **Upcoming Meeting**

- March 17, 2020 – Teleconference