

**OPTN Patient Affairs Committee
Meeting Summary
March 17, 2020
Conference Call**

**Darnell Waun, MSN, Chair
Garrett Erdle, MBA, Vice Chair**

Introduction

The Patient Affairs Committee (PAC) met via teleconference on 03/17/2020 to discuss the following agenda items:

1. Medical Urgency Amendment Discussion
2. At-A-Glance Review
3. Continuous Distribution Exercise Feedback

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

1. Medical Urgency Amendment Discussion

The Committee continued their discussion on a possible amendment to the OPTN Kidney Transplantation Committee's *Addressing Medically Urgent Candidates in New Kidney Allocation Policy* proposal out for public comment.

Summary of Discussion

Based on collective feedback, the Committee proposed the following changes to the proposal:

- A prospective rather than retrospective review
 - Have a randomly selected transplant center within 250 miles review the documents requesting a patient be listed as "Medically Urgent"
 - This approach is similar to what already occurs, so would help increase transparency without adding additional burden
- Limit the definition of Medically Urgent to only those with total loss of access for dialysis
- If the above are implemented, sequence Medically Urgent at the top of the list

The Committee discussed the retrospective review of cases as proposed. Many felt that this was inadequate to prevent the potential for candidates being inappropriately assigned this status. There was discussion of keeping some form of the current system of approvals intact, perhaps by having one other randomly selected hospital in the 250NM circle do a prospective review of the case. This would be in addition to the retrospective review. There was also general agreement that if a candidate is facing only days of survival without a transplant, they should get first priority in the allocation sequence. The Committee also stressed that being engaged in the policy development process much earlier on projects like these that have a patient component would result in their questions and feedback being addressed prior to public comment.

Next Steps

The Committee decided not to draft a formal amendment but will forward their comments and concerns to the Kidney Committee for consideration.

2. At-A-Glance Review

The Committee was asked for feedback on the current “At-A-Glance” structure included in the proposals out for Public Comment. The Chair commented the language should be simplified more for general audiences. Another committee member suggested there should be a separate document that summarizes what the public needs to know prior to reading the proposal, as a primer to the subject area. Committee members suggested adding more key terms to the glossary section.

Next Steps

Committee members were encouraged to send any additional thoughts or comments to staff prior to drafting the next round of documents.

3. Continuous Distribution Exercise Feedback

The Committee was asked for feedback on the Continuous Distribution exercise discussed at the last committee meeting. Committee members thought it was an intuitive process and the results were intriguing. A Committee member commented the exercise might be difficult to complete by someone who is not familiar with transplant.

Upcoming Meeting

- April 21, 2020 – Teleconference

Attendance

- **Committee Members**
 - Garrett Erdle
 - Sarah Koohmaraie
 - Marvin Lim
 - Stephanie Little
 - Earl Lovell
 - Molly McCarthy
 - Elizabeth Rubinstein
 - Jim Sharrock
 - Julie Siegel
 - Darnell Waun
 - Phil Williams
 - Chris Yanakos
- **HRSA Representatives**
 - Jim Bowman
 - Adriana Martinez
 - Melanie Deal
 - Raelene Skerda
- **UNOS Staff**
 - Matt Cafarella
 - Lindsay Larkin
 - Sara Rose Wells
 - Shannon Edwards
 - Alison Wilhelm