

**OPTN/UNOS Patient Affairs Committee**  
**Meeting Summary**  
**October 20, 2014**  
**Chicago, Illinois**

**Kristie Lemmon, MBA, Chair**  
**John Fallgren, RN, BS, Vice Chair**

*Discussions of the full committee on October 20, 2014 are summarized below and will be reflected in the committee's next report to the OPTN/UNOS Board of Directors. Meeting summaries and reports to the Board are available at <http://optn.transplant.hrsa.gov/> .*

**Committee Projects**

**1. Clarify Policy Language and Process for Individual Wait Time Transfer**

The Subcommittee presented draft policy language for a proposed update to Policy 3.6.C Waiting Time Transfer. The Committee was concerned about providing protections for persons who are eligible for transplant, but do not accrue waiting time because they have been removed from the initial program before being registered at the receiving program. This results in a period of time when the candidate is not on either waiting list and cannot receive organ offers. The Committee was especially concerned about instances when the transfer occurs due to extenuating circumstances, such as a change in insurance providers or a change in preferred transplant providers within an insurance network. The Committee also identified instances when there is a delay in transfer of waiting time due to administrative delays or errors.

After discussion and a brief review of related policy, the Committee voted to move forward with the current public comment proposal; voting to accept the proposed policy language as presented.

The Committee decided to gather more information on the issue of loss of waiting time during the waiting time transfer process. The Committee will submit a request to review available data on this issue. The Committee will also survey the TAC and TCC regarding current clinical practice in waitlist management when a candidate moves from one program to another and chooses to transfer waiting time.

The proposal is scheduled to go out for Public Comment in January, 2015.

**2. Update to What Every Patient Needs to Know (WEP)**

The WEP Update Subcommittee presented an update on it's work since the last full Committee meeting. The Subcommittee stressed that this is an update, and not a rewrite. The Subcommittee presented a high-level overview of the types of changes that the project will focus on. WEP went through a complete redesign in 2010. The Subcommittee wanted to ascertain whether the current subjects were still in line with what is most relevant to patients currently going through the transplant process. Each Subcommittee member was tasked with asking their cohort the following question; "What do you know now, that you wish you had known when you began the transplant process'. One Subcommittee member queried multiple patient Facebook pages and received responses from 65 persons. The results were presented as part of the discussion. The Committee supported the Subcommittee's recommendations to

maintain the current format and tone of WEP, make updates and incorporate a new look. The Subcommittee should have completed recommended changes by January, 2015. The project is scheduled for completion in May 2015.

### **Committee Projects Pending Implementation**

- 3. None**

### **Implemented Committee Projects**

- 4. None**

### **Review of Public Comment Proposals**

#### **5. Proposal to Allow Collective Patient and Wait Time Transfers**

The Committee received a presentation on the Operations and Safety Committee (OSC) Proposal to Allow Collective Patient and Wait Time Transfers. The Committee recommended that the transplant program(s) involved be required to provide updates on each patient at pre-determined time intervals until the transfers are complete. This recommendation is in lieu of the states update at 90-days post-transfer. The Committee voted on the proposal. See the results below:

For – 16, Against – 0, Abstain - 0

### **Other Significant Items**

#### **6. How Policy is Born**

The Committee received a presentation on the OPTN Policy Development process. The Committee is comprised primarily of laypersons, This is an interactive presentation, designed to introduce both patients and transplant professionals to the OPTN and it's work.

#### **7. TCC Inactive Waitlist Proposal Update**

The Committee has followed and summarily supported the TCC proposal to require transplant programs to notify candidates of their status as inactive on the waiting list at pre-determined intervals. Based upon the feedback received, the TCC decided not to go forward to public comment. Instead the TCC has opted to convene a workgroup to consider other options for impacting this issue. The TCC has invited The Committee to become a part of this workgroup.

#### **8. KAS Patient Education Module**

The Committee has been involved in developing resources to educate patients about the new Kidney Allocation System (KAS). The latest resource for patients is an online module that explains the changes that KAS makes in the system and how these changes may benefits some patients. Input from the Committee was used in developing the module.

#### **9. ESRD Patient Referral Guide**

The Committee received an update from the members of the MAC ESRD Patient Referral Workgroup. The Workgroup invited the Committee to give feedback on issues that might discourage patients from early referral for transplant evaluation. The Committee divided into small groups and responded to this question: 'Can I be referred for transplant if .....'. Responses were divided into 3 buckets:

- Medical/Health Characteristics
- Personal Resources
- Social Characteristics

The results will be shared with the ESRD Patient Referral Workgroup.

#### **10. Guidance Document for VCA Authorization**

The Committee received presentations on Vascular Composite Allograft (VCA) transplant during the Spring In-person meeting, and at a subsequent conference call. The Committee has also reviewed the VCA Authorization Guidance Document. The Committee verbalized feelings of discomfort regarding some of the VCA discussion and concern regarding the reaction of the general public to VCA. During today's discussion, the Committee stressed the importance of developing a sensitive, compassionate education program for the general public. The Committee also suggested approaches that would be impactful, based on the input received from their discussions in the community. The Committee will continue to be involved with the VCA Committee.

#### **Upcoming Meeting**

- December 4, 2014