

**OPTN/UNOS Patient Affairs Committee  
Meeting Minutes  
August 21, 2018  
Conference Call**

**Darnell M. Waun, MSN, RN, Chair  
Garrett W. Erdle, MBA, Vice Chair**

**Introduction**

The Patient Affairs Committee (PAC) met via Citrix GoToTraining teleconference on 08/21/2018 to discuss the following agenda items:

1. Public Comment Review
2. UNOS Ambassador Program
3. Education: Allocation 101 in 5 minutes or less
4. Committee Report: Liver and Intestinal Organ Transplantation Committee

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

**1. Public Comment Review**

Following opening remarks by the Committee Chair, UNOS staff reminded the public comment teams to complete their review of the summaries that have been posted to Basecamp. The team leaders will provide an overview of the summaries following the presentations during the August 27, 2018 meeting in Chicago.

**2. UNOS Ambassador Program**

The UNOS Public Relations and Marketing Director provided an overview of the UNOS Ambassador program. This program is designed to engage living donors, donor families, and transplant recipients with UNOS. Ambassadors serve as community volunteer advocates for UNOS who share their personal stories and spread the message about UNOS and organ donation. One Committee member asked if there was a hierarchy among the 1317 ambassadors. UNOS staff noted that there have been some discussions about creating "Super Ambassadors" that could potentially represent each region.

UNOS staff noted that there is a DVD available as part of kit that is intended to provide a structured and consistent message. Most of the Committee members expressed an interest in the kits and there was a suggestion to post the video to Basecamp. One Committee member suggested the video be played during the in-person meeting. UNOS staff noted that the agenda is full but there is the potential to show the video during the social event being held the evening before the meeting. Finally, one Committee member made a recommendation to develop a webinar aimed at leaders of the various support groups around the country.

**3. Education: Allocation 101 in 5 minutes or less**

UNOS staff provided a brief overview of the organ allocation process. This included an overview of the factors used in organ allocation. These include such factors as blood type, medical urgency, survival benefit, waiting time, and other medical factors. UNOS staff noted that not all organs use every factor and each organ type has its own individual allocation policy.

UNOS staff noted that the computer system applies the allocation policies and other factors to determine the order that candidates will receive offers. UNOS staff also noted that geography is also used in allocation and there are currently 11 regions and 58 DSAs (donation service areas). This issue will be addressed in more detail during the in-person meeting.

#### 4. Committee Report: Liver and Intestinal Organ Transplantation Committee

The Committee was provided with an update on the project to eliminate the use of DSAs and Regions in liver and intestine allocation. The Committee has submitted a modeling request to the SRTR and plan to distribute a proposal during a special public comment period in October in order to submit a final proposal to the Board of Directors in December 2018. This proposal will replace DSAs and regions with concentric circles based on the distance from the donor hospitals.

The Committee members posed the following questions:

- Does OPO performance impact the Median MELD at time of transplant in DSAs? Are there initiatives to address disparities in performance? UNOS staff noted that this issue is not part of the upcoming proposal.
- Is MELD calculated the same nationwide? UNOS staff noted that MELD is calculated nationally.
- Can you help us understand how HHS and OPTN got sued and the basis thereof? UNOS staff noted that this question can be addressed during the in-person meeting.
- Does UNOS have a publicist that can rustle up a media campaign? UNOS staff noted that UNOS does have a communications department but there is currently only limited information about what initiated the need to address geography within such a short timeline.
- What is the maximum time for livers? One Committee member noted that the maximum cold ischemia time is 12 hours but it is preferred to keep it down to 6-8 hours. He noted that with the use of planes and proper logistics it is possible to use larger circles.
- Isn't concentric circle method what is used by lungs? UNOS staff noted that concentric circles are currently used in lung allocation.

The Committee members posed the following comments:

- While the 500 mile circles even out the disparity, Region 5 still has a significantly higher MELD/PELD score for transplant as well as the largest waitlist.
- The concentric circles include a lot of "ocean area."
- A couple of Committee members noted that from a donor family perspective they supported whatever method gives their loved ones organs the best chance for survival, (transplanted, not discarded), and also doesn't cause the donation process to be extended too long.
- Do patients care about the messaging? UNOS staff noted that this was an interesting thought.
- There are many places in the country that already have organs traveling 500 miles from a donor hospital
- It has to be easy to explain to patients!
- Patient communication – recommend some combination of transplant centers, online/social media as well as general marketing in hospitals.

The following questions were submitted via the chat feature but the Committee did not have the opportunity to discuss:

- Is the committee concerned about artificially inflated MELD scores once DSAs are removed?
- How does increased travel via flights impact cost? Does this more negatively impact smaller centers who cannot absorb increased costs of flying in organs for their patients? Will this then decrease access for patients who live in rural areas?

- Do the circles put patients at risk?
- Can we really consider an organ a "national resource?"
- Will kidney allocation follow this model in the future?

### Next Steps

UNOS staff requested that Committee members respond to the specific feedback requested, what messaging would reassure patients, and whether we agree with the strategy that would be helpful for the Liver Committee. UNOS staff also noted that the average candidate and donor family member will not participate in the public comment process so it is important for this patient group to voice their opinions.

### **Upcoming Meeting**

- August 27, 2018 (Chicago, Illinois)