

**OPTN/UNOS Transplant Coordinators Committee
Meeting Minutes
February 21, 2018
Conference Call**

**Sarah Nicholas, BSN, RN, CCTC, Chair
Sharon Klarman, RN-BC, BSN, CCTC, Vice Chair**

Introduction

The Transplant Coordinators Committee met via Citrix GoToTraining teleconference/ on 02/28/2018 to discuss the following agenda items:

1. Public Comment

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

1. Public Comment

Modifications to the Distribution of Deceased Donor Lungs

The OPTN/UNOS Transplant Coordinators Committee (TCC) received a presentation and discussed the Modifications to the Distribution of Deceased Donor Lungs proposal (Thoracic Organ Transplantation Committee). The Committee was in agreement that further research and discussions need to occur regarding the concepts of the proposal but this is a good first step. The following is a summary of the questions and comments committee members had for the presenter.

- It can be really difficult to transplant lung patients when listed for HR/LU because their heart may not be as critical as their lungs. Therefore, the heart goes elsewhere and it is much harder to match and get good quality lungs at baseline. Was there any consideration to give a higher allocation score for patients who are listed for HR/LU who have an LAS over 50? The reason for over 50 is because it's a high LAS and it's the UNOS cut off where you have to update the LAS score on a weekly basis. Patients who have that high of a LAS but the heart is not quite as critical die on the waitlist. The presenter responded that the threshold of 50 is important. The Thoracic has not thought about implementing this kind of scheme assuming that the LAS that high should be able to pull the heart anyway.
- The Thoracic Committee should talk to centers within the 250 nm to make sure they agree with taking highly sensitized patients out of sequence. It would be reasonable to develop a formula that could add points to a patients LAS by the review board. May not happen very often. The presenter stated this was actually one proposed solution. It is something the committee can consider. The reason it wasn't added to the proposal was because of the timeline to submit this proposal to the Board. It was also noted that most centers do not enter data on unacceptable antigens conventions. So there is currently no data to help support this model.
- There is concern with increased range to pull donors will likely be only patients with a high LAS. This is good and bad for obvious reasons but could see the benefit.
- Has the Committee considered how the 250 nm will affect coastal centers? The presenter answered this has and will continue to be considered by the Committee.
- One member stated that since the change in policy their center has had a huge difference in donor offers and blocked out of their local DSA which is difficult. This is causing multiple issues. There are more fly outs because of limited number of access to organs, having to send blood more often, and more travel further away is causing organ

wastage due to cold ischemic times. There is concern about organ quality and what centers will be able to offer their patients.

Improving Committee Structure concept paper

The OPTN/UNOS Transplant Coordinators Committee (TCC) received a presentation and discussed the Improving Committee Structure concept paper (Executive Committee). The Committee reviewed the four areas of concern outlined in the concept paper as a group and acknowledge the value of increasing greater public engagement within UNOS policy development. Greater engagement may increase broader understanding of policy proposals as well as integrate more diverse perspectives with the goal of producing more effective policies. However, under the proposed structure, the Committee feels UNOS is unlikely to achieve the important objectives it has articulated.

The Committee recognizes the instrumental values of accountability, transparency, participation, and inclusion. And while the proposed restructuring concept evokes potentially transformative notions of community engagement and empowerment, they risk being reduced in practice to limited forms of member input or technocratic reforms. Concerns were voiced regarding the potential for diluting meaningful work in an effort to broadly expand the size of the expert councils. Additionally, there was apprehension regarding the open membership structure which may make it more challenging to identify true content experts within large councils. A focus on participatory development seeking to make participation itself the driver of change by helping members take charge of policy development, may not foster any particular ties to formal accountability mechanisms. The Committee questioned how we would maintain quality and consistency within the expert council and ensure that the volunteers feel connected to the organization under the open membership model. In short, what is presented in the concept paper as a unified agenda instead appears from within the committee to be a set of goals that compete with each other for attention and resources. Our Committee questions whether the proposed changes really bridge longstanding operational divides within the OPTN committee structure, whether or not the proposal represents a unified agenda, and how deep the community commitment to these concepts truly are in practice. Overall, while the Committee applauds the goals set forth to increase participation and diversity, it does not feel that the current proposal is the most effective and desirable structure for OPTN/UNOS committees.

Upcoming Meeting(s)

- March 20, 2018 (Chicago, IL)

Attendance

- **Committee Members**
 - Sarah Nicholas
 - Sharon Klarman
 - Dawn Freiburger
 - Cathy McAdams
 - Christopher Schwartz
 - Christine Brenner
 - Debra Walczak
 - Doug Bremers
 - Erika Venniro
 - Shannon Tompkins
 - Barbara Jenkins
 - Marianne Butler-LeBair
 - Richard Cummings
 - Missy Holliday
 - Jamie Bucio
- **HRSA Representatives**
 - Raelene Skerda
- **SRTR Staff**
 - Alyssa Herreid
- **OPTN/UNOS Staff**
 - Angel Carroll
 - Kim Uccellini
 - Liz Robbins
 - Casey Humphries
- **Other Attendees**
 - Kevin Chan