

OPTN/UNOS Thoracic Organ Transplantation Committee
Meeting Minutes
September 27, 2018
Conference Call

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Introduction

The Thoracic Committee (Committee) met via Citrix GoToTraining teleconference on 09/27/2018 to discuss the following agenda items:

1. Fall 2018 Public Comment Review

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

1. Fall 2018 Public Comment Review

The Thoracic Committee (Committee) heard presentations for the following proposals and provided feedback.

Guidance on Pediatric Transition & Transfer

The Committee thanks the Pediatric Transplant Committee for the opportunity to provide feedback on their guidance document regarding transitioning and transfer of pediatric recipients to adult care. The group felt that generally, they have not had issues with transfer or transition, possibly because pediatric heart recipients are generally referred to an adult transplant program, versus a community provider. However, if a recipient only has access to a non-transplant cardiologist, members acknowledged challenges in keeping tabs on them and communication with the non-transplant provider. It makes it more challenging to catch indicators of rejection, or other adverse event, in a timely manner.

Some members opined that pediatric programs retain their patients for a long period of time, sometimes into their early 20's. Other members, especially those affiliated with a pediatric transplant program, acknowledged patients used to be referred to the adult program much later, but that has improved. Several members shared practices from their own program, including coordinator handoff processes, transition clinics and mentoring programs. One member suggested collecting information about underlying diseases for early diagnoses.

The following questions were asked and answered to the satisfaction of the committee:

- **Q: Was data for thoracic patients reviewed?**
A: The presenter confirmed it was, and that there was a low lost to follow-up for thoracic organ recipients, because they typically stay within the transplant system.
- **Q: Did the Pediatric Committee survey adult providers on best practices?**
A: No, they are seeking best practices from adult programs via public comment.

Frameworks for Geographic Distribution

The Committee thanks the Ad Hoc Geography Committee for the opportunity to comment on various geographic distribution frameworks to inform future allocation policy more consistent with the OPTN Final Rule. There was some confusion regarding committing to a fixed distance model now, as part of eliminating DSA from thoracic organ distribution, versus one of the frameworks proposed. UNOS staff clarified that fixed distance was selected as it is already used in thoracic organ distribution, and thus modifying it would be relatively easy. The community

was asked to provide feedback on a model that would be a more ideal way to distribute organs in a future state.

Thoracic organs are currently distributed via a fixed distance framework, so there was little discussion regarding this model. Members acknowledged a disadvantage of this framework was the hard stop at a determined geographic boundary. The Committee surmised that mathematically optimized distribution may be a more efficient way to distribute organs, in addition to being more fair and equitable. Members also agreed that this framework was more predictable, as programs would more or less still be working with the same OPOs they have a relationship with now.

There was some consensus around support for continuous distribution, but members grappled with the lack of evidence that this model would be any better than the current systems. They agreed it seemed more flexible and customizable. In addition, it appeared it would accommodate special populations well, such as pediatrics, sensitized candidates and other special disease groups. However, members commented that without any data or supporting evidence this would in fact be better, it was challenging to commit to this (or mathematically optimized) framework. It would have been helpful to provide more detail regarding the advantages and disadvantages of each framework, using an example for each organ. Members agreed it was difficult to evaluate the theoretical.

Finally, Committee members pondered whether the continuous distribution model would be feasible for heart. Heart, unlike lung, assigns medical urgency by status, not a continuous score. Would heart need-or would it be beneficial to-develop a heart allocation score first?

Upcoming Meeting

- November, 2018