

**OPTN Lung Transplantation Committee
Meeting Summary
September 1, 2022
Conference Call**

**Marie Budev, DO, Chair
Matthew Hartwig, MD, Vice Chair**

Introduction

The Lung Transplantation Committee (the Committee) met via Citrix GoTo teleconference on 9/1/2022 to discuss the following agenda items:

1. Welcome and agenda
2. Update on multi-organ change to lung, heart, and heart-lung match runs
3. Public comment presentation: *Transparency in Program Selection*
4. Discuss new project: Standardize Six Minute Walk

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

1. Welcome and agenda

UNOS staff and the Chair welcomed the Committee members. UNOS staff noted public comment feedback is positive so far, and Committee members should request feedback from colleagues.

Summary of discussion:

There was no further discussion by the Committee.

2. Update on multi-organ change to lung, heart, and heart-lung match runs

UNOS staff provided an update to the Committee regarding a visual enhancement to heart, lung, and heart-lung match runs for those candidates who also need a liver and a kidney. The new visual cue indicates that OPO is required to share at least one of the additional organs (liver or kidney).

Summary of discussion:

A Committee member asked why the OPO would not be required to offer a liver and a kidney. UNOS staff explained the policy was designed for candidates needing two organs but will take this concern back to the OPTN Multi-Organ Transplantation Committee. The Chair stated that triple organ transplantation is rare and if it is needed this could be handled in conversation with the OPO but may not be indicated in the visual cue. Another member stated this change is a way to flag for a multi-organ transplant and help reflect when another organ is needed.

3. Public comment presentation: *Transparency in Program Selection*

A member from the OPTN Ethics Committee presented on a white paper that aims to ensure patient autonomy and shared decision-making through the transplant process. The paper examined the distinction between information and data that would aid in patient decision making, the role patients should have in determining which information they are interested in, and the education resources that can be provided to ensure that patients understand the information provided. The OPTN Ethics Committee member explained the Committee found that the ethical principles of organ allocation

support increased transparency, challenges that may arise when increasing transparency can be mitigated and should not deter centers from increasing transparency, and information ought to be provided in a way that is accessible and patient centered.

The OPTN Ethics Committee member asked for feedback on:

- What factors are important to patients when selecting a transplant program?
- Do patients and transplant professionals think that it is important to share program specific listing criteria prior to transplant evaluation?
- What best practices have transplant programs developed for increasing transparency?
- Does the transplant community think this information, shared with patients, would strengthen the provider-patient relationship, and/or provide better care for patients?

Summary of discussion:

A Committee member commented that they support this as a concept, but has concerns logistically, such as the small number of absolute contraindications to lung transplantation, the differences between patients that cannot be ruled out for evaluation, and the constant reevaluation of risks that transplant programs are willing to accept with patients. The OPTN Ethics Committee member stated this white paper was written with the intention of providing format for ten questions a patient should ask when attending the initial organ (kidney) evaluation, while programs should be clear that criteria continue to change. The Chair expressed concern about how to clarify the dynamic nature of lung transplant criteria.

Another member voiced concern regarding the inequity between patients who will have access to this information and stated the most vulnerable population will use this information the least. The member also noted the multitude of factors considered for thoracic organs, such as varying levels of risk factors. The OPTN Ethics Committee member stated the paper addresses differences in computer literacy, availability, and speed.

A member stated that different programs have different criteria to accept patients, and different programs should be willing to refer patients to other programs who are a better fit for that specific patient. The member agreed that sometimes their transplant program will not register a patient for transplant because of multiple comorbidities but suggested that lung transplant programs could at least publish their absolute contraindications to transplant, like a body mass index (BMI) above a certain score. The OPTN Ethics Committee member stated the challenge is getting it out to the general population and not just transplant professionals. Another member stated this information needs to be accessible to the physicians that refer patients to a program. The member expressed concern that the paper will not be useful because the only patients comparing programs are those who are affluent, well connected, and informed. The OPTN Ethics Committee member stated that it may take a long time to reach every audience.

The OPTN Ethics Committee member noted this is not policy and how the paper is incorporated is up to individual programs if the paper is approved by the board in December. The Chair stated this white paper shows everyone what information should be provided to every patient and doctor by transplant centers, which helps promote equity.

4. Discuss new project: Standardize Six Minute Walk

The Chair stated the Committee will take on a new project that works to standardize how transplant programs perform the six minute walk due to its variability between programs. The Chair explained the walk can be standardized by policy, guidance, data definition or data collection, or a combination of these methods. She noted this project will align with the strategic plan by proving equity in access to transplants. The Committee would aim to send a proposal out for public comment in August 2023.

Summary of discussion:

The Chair explained that Committee leadership is looking for feedback on the key metric for this project. Multiple members noted the variability between programs and their patients and the inability to measure progress because of this. A member suggested measuring this by comparing the six minute walk scores provided for dually listed patients from each transplant center, but the Chair voiced concern over the small number of dually listed patients and the variation between a patient having a good day and a bad day. Another member expressed concern over capturing risk level that centers are willing to take since less sick patients will have better distances at more conservative centers. A member suggested controlling for severity of illness using pulmonary function testing (PFT), diffusing capacity for carbon monoxide (DLCO), supplemental oxygen, etc. and use this to determine the outlier centers. A member expressed concern that it would be hard to control for severity of illness since frailty is such a huge component impacting how patients perform on the six minute walk, and frailty is not measured well.

Another member suggested examining the variance at each of the centers before and after implementation, since the centers will have their own unique distances that should become more consistent. The Chair noted there is variability in the patient population within a center from months, weeks, and days, and a member responded that the Committee could look at standard deviation within a center since method should not change by a surgeon. A member pointed out the variability between pulmonary rehabilitation at each center that could impact patient scores.

Next steps:

- The Committee decided to use qualitative feedback as the key metric for the six minute walk project.

Upcoming Meeting

- September 15, 2022, 5PM-6:30PM EST, teleconference

Attendance

- **Committee Members**
 - Marie Budev, Chair
 - Erika Lease
 - Brian Armstrong
 - Cynthia Gries
 - Dennis Lyu
 - Edward Cantu
 - Errol Bush
 - John Reynolds
 - Kelly Willenberg
 - Marc Schecter
 - Maryam Valapour
 - Matthew Hartwig
 - Serina Priestley
 - Stephen Huddleston
 - Julia Klesney-Tait
- **HRSA Representatives**
 - Jim Bowman
 - Marilyn Levi
- **SRTR Staff**
 - David Schladt
 - Katherine Audette
 - Nick Wood
- **UNOS Staff**
 - Kaitlin Swanner
 - Cole Fox
 - Taylor Livelli
 - Holly Sobczack
 - Krissy Laurie
 - Susan Tlusty
 - Tatenda Mupfudze
- **Other Attendees**
 - George Bayliss