

OPTN Pediatric Transplantation Committee

Meeting Summary

November 15, 2023

Conference Call

Emily Perito, MD, Chair

Rachel Engen, MD, Vice Chair

Introduction

The OPTN Pediatric Transplantation Committee (The Committee) met via WebEx teleconference on 11/15/2023 to discuss the following agenda items:

1. Welcome and Announcements
2. Setting the Stage: Lung Continuous Distribution
3. Six Month Monitoring Report: Lung Continuous Distribution

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

1. Welcome and Announcements

The Chair welcomed Committee members to the meeting and introduced the new Patient and Donor Affairs Representative.

2. Setting the Stage: Lung Continuous Distribution

The Committee received a presentation that provided an overview of continuous distribution.

Presentation summary:

Continuous distribution is a change in organ allocation from a classification-based system to a points-based system. This allows for candidates to be ranked based on their individual composite allocation score (CAS). Lung was the first organ to implement continuous distribution in March 2023. In lung continuous distribution, candidates who are registered on the waiting list before their 18th birthday receive 20 additional points. If a candidate turns 18 while on the waiting list, they will maintain those priority points until they are removed from the waiting list. In addition, candidates of small stature also receive points for height.

Recipients receive a percentage of points based on specific attributes. The attributes may include categories such as OPTN Waiting List survival, post-transplant survival, candidate biology, patient access, and placement efficiency. Those percentages are added together when an organ becomes available. While the scores are out of 100 points, it is rare for a candidate to receive more than 55 points.

Summary of discussion:

No decisions were made regarding this agenda item.

During a conversation on the methodology behind post-transplant survival metrics, a participant noted the intriguing use of a five-year timeframe, citing lung and pediatric survival curves that suggest a median survival slightly exceeding five years. Consequently, the participant speculated that approximately 40%-50% of patients might not surpass the five-year mark. In response, OPTN contractor

staff clarified that the intention was to optimize post-transplant survival, emphasizing that the five-year benchmark aimed to prioritize younger patients over older ones. While the participant expressed appreciation for the sentiment, he voiced skepticism about whether this approach would align with the actual outcomes in practice.

A member inquired about the feasibility of examining lung bone marrow patients and their calculated panel-reactive antibodies (CPRA). These cases pose a unique challenge as centers are required to make partial matches between recipients and donors, without the ability to specify unacceptable antigens. The member proposed incorporating this consideration into future deliberations, particularly as continuous distribution evolves. The Chair concurred, suggesting that it's a matter for contemplation by the Lung Committee. The OPTN contractor staff acknowledged the need for further investigation, indicating that there might be avenues to submit exception requests for biologically disadvantaged exception points.

A member inquired about the inclusion of certain attributes in continuous distribution that were previously under consideration but are now excluded. In response, OPTN contractor staff explained that attributes can differ across organs, and the customization is tailored to each organ to maintain appropriateness. While the general categories are consistent across all organs, the specific elements within these categories remain organ specific.

3. Six Month Monitoring Report Lung Continuous Distribution

OPTN contractor staff presented the results of the *Lung Continuous Distribution Six Month Monitoring Report*¹.

Presentation summary:

Compared to the pre policy era, in the post policy era:

- Fewer pediatric candidates were added to the OPTN Waiting List
- Similar number of pediatric:
 - Candidates ever waiting
 - Removals for death or too sick
 - Transplants
- Increased organ sharing from pediatric donors to adult candidates and vice versa
- Slight decrease in median distance traveled
- Increased prioritization on match runs

Summary of discussion:

No decisions were made regarding this agenda item.

A member proposed the inclusion of metrics for inactive time for other organs, emphasizing its significance, particularly for pediatric patients. They expressed anticipation about examining these metrics in the future, highlighting the movement of lung and other organs in continuous distribution. The member emphasized that additional data would prompt valuable discussions on the tradeoffs between efficiency and equity in organ allocation.

¹ Weiss, Samantha, and Chelsea Weibel. Rep. *Lung Continuous Distribution Six Month Monitoring Report*. OPTN, October 27, 2023.

An individual recognized the limited sample size in the presented data and emphasized the importance of ongoing monitoring as continuous distribution evolves. Expressing a commitment to continued learning, they urged the group to assess and identify opportunities for requesting additional consideration for extra points, both with other organs and specifically for the lung, in the future.

A member pointed out that despite an increase in offers for pediatric lung recipients, there's a concern that these offers may not align with the specific needs of the recipients. Drawing a parallel with kidney policy changes that elevated priority for pediatric patients, the member highlighted that while more offers were received, they might not have been the optimal ones for successful transplantation. The member expressed concern that the current data suggests a potential misalignment in prioritizing the right types of lungs for pediatric patients.

A member emphasized that despite pediatric candidates ranking at the top of the runs, organs are being allocated at a lower position on the list. This should prompt a critical examination of the reasons behind this discrepancy. It was suggested that the group should explore whether current organ matching is appropriate and if there are potential outliers such as physician behavior influencing the outcomes. The OPTN contractor staff agreed, acknowledging feedback about the overwhelming increase in overall offers and shared plans to introduce offer filters for lung continuous distribution in January to improve the relevance of offers.

Another member highlighted the need for filters tailored specifically to pediatric patients, drawing attention to the challenge faced with kidney offer filters that may not meet the unique requirements of pediatric recipients. They stressed the necessity of developing filters specifically designed for pediatric patients to enhance their utility and effectiveness.

A representative from the Lung Committee informed the group that there might be a forthcoming paper for public comment regarding lung filters. They encouraged members to actively contribute if they have specific considerations related to pediatrics that they would like to incorporate into the filters, emphasizing the importance of submitting public comments for meaningful input.

Upcoming Meeting(s)

- December 13, 2023

Attendance

- **Committee Members**
 - Emily Perito
 - Rachel Engen
 - Neha Bansal
 - Joe Brownlee
 - Dan Carratturo
 - Ryan Fischer
 - Namrata Jain
 - Geoff Kurland
 - JoAnn Morey
 - Caitlin Peterson
 - Danny Ranch
 - Gonzalo Wallis
 - Aaron Wightman
- **HRSA Representatives**
 - Marilyn Levi
- **SRTR Staff**
 - Avery Cook
 - Simon Horslen
- **UNOS Staff**
 - Alex Carmack
 - Kieran McMahon
 - Betsy Gans
 - Kaitlin Swanner
 - Chelsea Weibel
 - Samantha Weiss