# OPTN Continuous Distribution of Lungs Meeting Summary November 21, 2019 Conference Call

## Erika Lease, MD, Workgroup Chair

### Introduction

The Continuous Distribution of Lungs Workgroup met via Citrix GoTo teleconference on 11/21/2019 to discuss the following agenda items:

1. Continuous Distribution: Discuss candidate size, ex vivo perfusion and population density

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

## 1. Continuous Distribution: Discuss candidate size, ex vivo perfusion and population density

The Workgroup continued their discussion regarding candidate's size, and possible factors to include in a composite allocation score, including candidate size, ex vivo perfusion and population density.

#### Summary of discussion:

#### Candidate Size

The Workgroup discussed the findings and outcomes in the article titled "Short Stature and Access to Lung Transplantation in the United States: A Cohort Study" by Sell, Bacchetta, Goldfarb et. al. There was concern from several members about the number of eligible donors available to candidates within certain height brackets. One member stated that they would not give a smaller candidate more of a priority based on donor eligibility because this may be overestimating the candidate's disadvantage. This member noted that in the article, the relative proportion of candidates to recipients is much higher for smaller patients. From this discussion, other members commented that perhaps the Workgroup should take into account who candidates are competing against and the ratio of availability of donor organs. For example, what is the relative proportion of blood type B candidates to the overall pool, and what is the relative proportion of donors that these candidates could access compared to a blood type O candidate? In this way, the Workgroup was concerned about how to adjust for the decreased likelihood of different candidates being transplanted at different height ranges. Clarification was provided that this issue is currently being looked into in order to determine a candidate's equity and access to transplantation.

One Workgroup member suggested using height as the only factor, and to adjust a candidate based on their relative risk for not getting transplanted and having shorter stature. Another member stated that it would be interesting to look at the ratio of candidates to available donors whom are close to the candidate's height, in order to determine their relative risk. However, this member noted that in the article, they were concerned how the Workgroup would ensure a candidate's chances of getting an organ are comparable to others, if said candidate has access only to a subset of the donor pool. In this way, the member advocated that the Workgroup develop a consistent approach when determining the methodology of each attribute.

Other Workgroup members suggested that a candidate's underlying disease should be taken into account. For example, one member stated that short candidates with interstitial lung disease (ILD) and

short stature are twice affected negatively. A suggestion was to include underlying disease as well as height, because certain diseases that candidates have may not be reflected in their LAS score. An example of this would be to risk stratify candidates by height, and by either obstructive or restrictive. However, most Workgroup members agreed that they would need more data to support stratifying candidates this way.

Several Workgroup members noted that the article did not take into account donor hospital location and competition between hospitals.

In the end, the Workgroup agreed to only use height for now, until further data is available. The Workgroup agreed to continue discussing candidate height and methodology at a later continuous distribution call.

## Ex Vivo Perfusion

During public comment and previous workgroup conversations, members have asked whether and how ex vivo perfusion should be incorporated into continuous distribution. Ex vivo perfusion 1) permits organs to travel further distances with less impact due to ischemic time and 2) reconditions injured donor lungs for transplant. However, it is not always known whether a lung will be perfused at the time that the match is run. There were four approaches the Workgroup discussed:

1. Require members to submit information about which lungs they would perfuse so that the OPTN could predict which lungs are perfused. The OPTN could then have different rating scales similar to how we have different rating scales for pediatric and adult donors.

- 2. Assume that all lungs are perfused.
- 3. Assume that no lungs are perfused.
- 4. Revise the ischemic time rating scale for lungs that are perfused and reallocated.

There were some concerns from members, including the need to consider that a transplant center may "intend to pump lung", but then decide they don't need to. Another member was concerned that the Workgroup would be assuming that a center is going to have the equipment and machinery necessary for perfusion. One member commented that transplant centers should decide whether to perfuse a donor lung, and was concerned that indicating a candidate for perfusion into the total composite allocation score may become a slippery slope. Clarification was provided that the OPTN is currently collecting limited amounts of information on perfusion, mainly on the DDR about whether the left or right lung was either perfused (intended or performed); additionally on the TCR data has been collected about whether the lung was perfused (single or double lung) and location of the perfusion. However, there is no ex vivo lung perfusion data collected at the time of match. Due to the above concerns, members agreed on the third approach (assume that no lungs are perfused) until more data is collected that would allow for the Workgroup to determine whether perfusion should impact allocation.

## **Population Density**

Members of this workgroup have asked whether and how population density could be incorporated into the composite score. The concern stated was that patients near an airport would be over-prioritized. The Workgroup discussed whether to add points for population density to the composite allocation score, and if adding points, what problem would be solved through the use of population density points.

There was concern from one Workgroup members that population density does not correlate well with donor availability (such as in New York). Many member stated that population has always been an issue between different regions of the U.S. (population density versus potential donor availability density).

One Workgroup member stated that in terms of equity, the OPTN should analyze the ratio of available donors to the number of candidates competing for those donors. Many members agreed that knowing where candidates and donors are would be more relevant than population density. A member advocated for building in "eligible deaths" and some measure of disease prevalence that would allow the OPTN to balance inequities in the U.S. (example: inequities have been driven by ESRD prevalence and prevalence of donors available to meet those needs). However, there was some concern as to looking at disease prevalence because organs may end up flying to richer areas of the country because there are lower rates of listing in poorer areas of the country. Yet, the member insisted that the OPTN must be willing to discuss how to address the donor-side of the equation if you are looking to balance supply and demand. In this way, you may need to create a reasonable construct that balances out the factors but doesn't create a benefit for members to inflate their numbers of candidates on the waiting list so that they can get organs offers. An SRTR staff member agreed, but emphasized the importance of sorting candidates for allocation versus improving equity across the country.

Another Workgroup member stated that they should be aware of the issue of population density because some centers might not have a potential donor hospital nearby. For example, if you give priority to a candidate that can drive vs. fly, then those will disadvantage people living in rural areas. Also, if a candidate loses priority in a continuous manner immediately from the donor hospital, then population density is very important to consider. In this way, if distance is going to be a priority, then population density should be considered in order to comply with the OPTN Final Rule. Clarification was provided that the Workgroup had discussed travel costs, not travel distance.

In the end, the majority of the Workgroup decided not to include population density at this time. Instead, the Workgroup will monitor access across the country (urban and rural areas). Also, members suggested collecting actual offer data (important to look at offers and donors). However, it was noted in the end that OPOs will need to determine a better metric for "eligible donors" before that measure can be incorporated into a continuous distribution system.

## Next steps:

The next topics the Workgroup will focus on include waiting time and the use of age.

## **Upcoming Meetings**

- December 11<sup>th</sup>
- December 18<sup>th</sup>