

**OPTN Heart Committee
Continuous Distribution Pediatric Waiting Time Workgroup
Meeting Summary
December 1, 2023
Conference Call**

**Richard Daly, MD, Chair
J.D. Menteer, MD, Vice-Chair and Workgroup Lead**

Introduction

The Heart Workgroup (“Workgroup”) met via WebEx teleconference on 12/01/2023 to discuss the following agenda items:

1. Overview of Continuous Distribution (CD) & Pediatric Medical Urgency

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

1. Overview of Continuous Distribution (CD) & Pediatric Medical Urgency

The workgroup worked on determining point and time accumulation for the waitlist and medical urgency as well as continuous distribution for hearts in the pediatric population.

Summary of discussion:

To start the discussion, a member noted that adjusting the distance factor with the time component should be addressed to ensure there is parity within the new system. Included in the parity discussion was the idea that subpopulations may be at risk and should be considered. The Chair remarked that this was noted when developing CD. The Vice Chair introduced the proposed formula to the workgroup and noted that the allocation of points over time could be a solution to providing parity. A workgroup member questioned whether aspects of the formula were for additional medical urgency points or if it was for a separate attribute. The Chair made note that this the allocation of points to medical urgency or access to care points is what the workgroup should focus their discussion on. In response, the workgroup agreed that accumulation of waiting time should count.

Turning towards the discussion on the proposed formula, a workgroup member mentioned whether there exists a way to fine-tune the numbers with data sets from the OPTN Contractor. Other members note that some of the numbers seem arbitrary and that there should be a process for testing real time data or taking various snapshots of the data to analyze it before agreeing on numbers for the formula. An SRTR member noted that this could help the workgroup decide on what is most relevant, while the tool is being developed. Another member noted from a patient perspective that allowing numbers to accrue to 100 could devalue the entire system and undermine hope in patient populations, noting that a cap to the wait time accrual points could be necessary. However, the Chair noted that the downside to capping it is patients would not be able to measure progress.

Another member suggested that a logjam could occur if everyone can move up to 100 points. The Chair responded by noting that it would take a long time for the logjam to occur. The Chair also noted that they could present the public with the values prioritization exercise (VPE) to analyze what people think. Another member noted that the new formula would be easier to understand in a model. Another

workgroup member noted that it may be hard to have someone compete against VA ECMO (Veno-Arterial Extracorporeal Membrane Oxygenation), which is the first status 1 criteria for adults. The workgroup closed with an agreement to table the conversation and reconvene in the new year with data sets.

Next steps:

The workgroup will work toward adjusting the formula in CD for pediatric patients.

Upcoming Meeting

- To be determined

Attendance

- **Workgroup Members**
 - J.D. Menteer, MD, Chair
 - Richard Daly, MD, Vice Chair
 - Fawwaz Shaw
 - John Nigro
- **HRSA Representatives**
 - Jim Bowman
- **SRTR Staff**
 - Grace SRTR
- **UNOS Staff**
 - Cole Fox
 - Holly Sobczak
- **Other Attendees**
 - Carol Wittlieb-Weber
 - Scott Auerbach
 - Brian Feingold
 - Gonzalo Wallis
 - Ryan Butts
 - Neha Bansal
 - Jonah Odum
 - Melissa McQueen