

**OPTN Heart Transplantation Committee
Continuous Distribution Pediatric Waiting Time Workgroup Meeting Summary
March 22, 2024
Conference Call**

**Richard Daly, MD, Chair
J.D. Menteer, MD, Vice Chair**

Introduction

The OPTN Heart Committee's Continuous Distribution Pediatric Waiting Time Workgroup (Workgroup) met via Webex teleconference on 03/22/2024 to discuss the following agenda items:

- 1.) Discussion of Pediatric Waiting Time as Medical Urgency Attribute

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

1. Discussion of Pediatric Waiting Time as Medical Urgency Attribute

The Workgroup decided to send the proposal to the Heart Committee to receive more feedback.

The Workgroup heard a presentation from the Heart Committee Vice Chair (Vice Chair) about medical urgency and waiting time in pediatric groups. There is a concern that some pediatric candidates may remain on the waiting list for an extended amount of time without receiving a donor offer because of the limited number of pediatric donors. In addition, other pediatric candidates with higher medical urgency may be prioritized ahead of such candidates if waiting time is not addressed in continuous distribution. It was proposed that in the continuous distribution framework pediatric patients with a high urgency receive priority points based on waiting time to ensure such candidates are transplanted in a timely manner.

Summary of Presentation:

Goals:

- Determine if waiting time should accumulate points in the continuous distribution system for pediatric heart patients.
- Determine the suggested overall maximum impact waiting time should have.
- Determine the time scale in which points should accumulate.
- Make suggestions for a formula for determining point accumulation.

Waiting Time Justification:

- Pediatric Medical Urgency work previously undertaken aimed to bring the pediatric urgency system into better alignment with the adult system.
- Patients will be more granularly separated based on urgency in the Continuous distribution framework.

- An anticipated problem with the continuous distribution allocation framework being developed is that there is no sense of progression for many high urgency patients for whom there are very few donors.
- By using urgency as main source of points for given patient, new patients within former status 1A urgency can gain access above patients, also at 1a status, who have been waiting for a very long time at high urgency.
- Need to avoid situation where a pediatric candidate who has been listed for many months or even a year or more at high status (1a equivalents, in hospital) continues to be passed over due to new patients with slightly higher urgency score.
- Fairness of promoting waiting time as source of priority may be countered by concern that this promotes transplanting only stable patients. However, pediatric transplants will always be, on average, a long wait because of low donor numbers.

Parameters of a potential solution:

- Points awarded to recipients over time.
- Time cannot be the only parameter. Must include a factor proportional to urgency.
- Patients that move from high urgency downward (which is atypical) would get less urgency points but still receive waiting time points unchanged.

The following questions were considered:

- Agreement that waiting time should accumulate points?
- Agreement in the overall maximum impact waiting time should have?
- Agreement on the time scale in which points should accumulate (for many years at low urgency, for over a year at high urgency)
- Are there adjustments to the proposed formula that are suggested?
- Should this be considered for adult waiting time as well?

Summary of discussion:

Several members agreed with the proposed solution. One member brought up that waitlist mortality is higher in the first year. The Vice Chair responded that while this is a medical urgency issue, it is also an access to care issue. He also stated that this will help to support pediatric candidates' families. Also, the Vice Chair stated that some patients may experience long waiting periods for offers, which highlights the necessity of this change. Contractor staff reviewed the specifics of the data and transition of Continuous Distribution. Several Workgroup members wondered how many points should be allowed to accumulate and for how long, given that there are not often waiting periods of more than 2 years. The Vice Chair stated that other variables for points may be considered in the future.

The Vice Chair stated that the implications of Ventricular Assist Device (“VAD”) waiting periods on allocation are also being looked at outside of this pediatric workgroup, and the decisions from that would also be applicable to pediatrics on VAD. A Workgroup member asked about how points may apply to outpatient VAD recipients, and the Vice Chair requested more ideas from the Workgroup to bring that information back to the Heart Committee.

The Vice Chair asked if being an adult should disqualify a candidate from receiving points, as adults don't wait at high urgency for transplantation as long as pediatric candidates. The Workgroup considered if a

waiting time attribute would be beneficial to all heart transplant candidates. One member stated that including points could build a safety net for adult outlier candidates. A Contractor staff member noted the importance of clarifying whether this waiting time proposal applies to adults or not. A HRSA staff member asked if there would be an unintended risk for incentivizing joining the wait list to earn points, even if a candidate is not ready to join the waitlist. A member stated that normal medical guidance deters joining the waitlist early.

Next steps:

The Workgroup and the Heart Committee will discuss these topics further.

Upcoming Meeting(s)

TBD

Attendance

- **Workgroup Members**
 - J.D. Menteer
 - John Nigro
 - Melissa McQueen
 - Neha Bansal
 - Ryan Butts
 - Scott Auerbach
 - Jonah Odum
- **HRSA Representatives**
 - Marilyn Levi
 - Jim Bowman
- **SRTR Staff**
 - Yoon Son Ahn
 - Katie Audette
- **UNOS Staff**
 - Alina Martinez
 - Cole Fox
 - Eric Messick
 - Kaitlin Swanner
 - Laura Schmitt
 - Sarah Roche
 - Shelby Jones