

## **OPTN Heart Transplantation Committee**

### **Meeting Summary**

**January 17, 2023**

**Conference Call**

**Rocky Daly, MD, Chair**

**JD Menteer, MD, Vice Chair**

### **Introduction**

The Heart Transplantation Committee met via Citrix GoToMeeting teleconference on 1/17/2023 to discuss the following agenda items:

1. Continuous Distribution: Review
2. Continuous Distribution: Consideration of Congenital Heart Disease and Hypertrophic/Restrictive Cardiomyopathy as a potential attribute

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

#### **1. Continuous Distribution: Review**

The Chair provided a review of continuous distribution, with a focus on the development of the Composite Allocation Score (CAS). The Chair emphasized the role and impact of the various attributes within each goal, and how the goals will be weighed against each other in the CAS. The Chair suggested the Committee be deliberate in deciding which goal the attributes will align with and consider how they could be combined with existing attributes, such as medical urgency.

#### Summary of discussion:

A member inquired if exceptions will continue to be a component of heart policy in continuous distribution. Staff clarified that exceptions will still occur in continuous distribution, but they will be for a certain percentage of available points for a specific goal and likely have a different impact than the current system. A member suggested developing a stronger monitoring component that would deter centers from potentially misusing the system.

#### Next steps:

Staff will provide more details and context on exception requests at a future meeting.

#### **2. Continuous Distribution: Consideration of Congenital Heart Disease and Hypertrophic/Restrictive Cardiomyopathy as a potential attribute**

In an effort to review potential attributes for continuous distribution, the Committee has divided into small groups to consider attributes in depth and present their findings and recommendations to the full Committee. As such, the small group assigned to congenital heart disease and hypertrophic/restrictive cardiomyopathy presented their findings and recommendation for inclusion as an attribute within the medical urgency goal. Instead of adding Congenital Heart Disease (CHD) and Hypertrophic/Restrictive Cardiomyopathy (HCM/RCM) as separate attributes, the group recommended including them as part of the waitlist mortality rates which will inform patient medical urgency.

#### Summary of discussion:

### *Congenital Heart Disease (CHD)*

A member inquired how these points would play into a patient's CAS. Staff clarified that the CAS score is developed through a combination of attributes that embody each goal, noting that the patient's medical urgency would remain consistent but the CAS could change across offers as placement efficiency varies. A member inquired if there would be an opportunity to reevaluate the existing qualifying criteria for each status, specifically with regard to intra-aortic balloon pumps (IABP). Staff confirmed that medical urgency will occur on a continuum that will be mapped to waitlist mortality and other evidence. The Chair brought up the existing CHD guidance document as the baseline evidence to support the Committee's decision.<sup>1</sup> The Chair recommended transitioning the criteria from the guidance document into policy. The presenter noted that this recommendation would likely reduce the number of exception requests for these patients since the criteria are already widely agreed upon within the community. Members were asked to vote in the chat if they support including CHD as an attribute. The Committee unanimously voted in favor.

### *Hypertrophic/Restrictive Cardiomyopathy (HCM/RCM)*

A member recommended including language such as 'to show that sufficient attempts at medical or interventional therapy.' Currently, this language is not included in the guidance document but there is language that indicates the qualifying criteria needed for this type of exception. Members considered whether it was necessary to add language like this to this attribute recommendation, noting that it should be a common practice amongst physicians but the added due diligence could be beneficial. A member suggested adding a check box attestation for this, but another member countered that is not a common practice for other clinical criteria for heart.

A member inquired if there are instances where regional review boards have denied patients for exceptions despite using the criteria outline in the HCM/RCM guidance document.<sup>2</sup> While this data is not available off hand, members have not encountered instances where this has been the case given the clear guidance and objective nature of the qualifying criteria. Members agreed with the content of the existing guidance document as well as the considerations from the small group. Members were asked to vote in the chat if they support including CHD as an attribute. The Committee unanimously voted in favor.

#### Next steps:

The small group will make some updates to their document based on today's discussion and the additional data requested. Once there is a final version, staff will circulate the document to the full Committee for review.

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<sup>1</sup> OPTN Heart Committee, *Review Board (RB) Guidance for Adult Congenital Heart Disease (CHD) Exception Requests*, December 2017, [https://optn.transplant.hrsa.gov/media/2349/thoracic\\_guidance\\_201712.pdf](https://optn.transplant.hrsa.gov/media/2349/thoracic_guidance_201712.pdf).

<sup>2</sup> OPTN Heart Committee, *Review Board Guidance for Hypertrophic/Restrictive (HCM/RCM) Cardiomyopathy Exception Requests*, October 2018, [https://optn.transplant.hrsa.gov/media/2637/thoracic\\_guidance\\_review\\_board\\_hcm\\_rcm\\_201806.pdf](https://optn.transplant.hrsa.gov/media/2637/thoracic_guidance_review_board_hcm_rcm_201806.pdf).

### **Upcoming Meetings**

- February 8, 2023
- February 21, 2023
- March 21, 2023
- March 29, 2023
- April 18, 2023
- May 16, 2023
- June 20, 2023

## Attendance

- **Committee Members**
  - Adam Schneider
  - Amrut Ambardekar
  - Cristy Smith
  - Dmitry Yaranov
  - Earl Lovell
  - Fawwaz Shaw
  - Glen Kelley
  - Hannah Copeland
  - JD Menteer
  - Jennifer Carapelluci
  - Jennifer Cowger
  - Jonah Odim
  - Jose Garcia
  - Martha Tankersly
  - Nader Moazami
  - Rocky Daly
  - Tamas Alexy
  - Timothy Gong
- **HRSA Representatives**
  - Jim Bowman
  - Marilynyn Levi
- **SRTR Staff**
  - Grace Lyden
  - Katie Audette
  - Monica Colvin
  - Yoon Son Ahn
- **UNOS Staff**
  - Alina Martinez
  - Eric Messick
  - Holly Sobczak
  - James Alcorn
  - Kelsi Linbald
  - Krissy Laurie
  - Sara Rose Wells
- **Other Attendees**
  - Daniel Yip