

**OPTN Thoracic Committee
Pediatric Heart Workgroup
Meeting Summary
January 28, 2020
Conference Call**

Ryan Davies, MD, Chair

Introduction

The Pediatric Heart Workgroup of the Thoracic Committee met via Citrix GoTo teleconference on 01/28/2020 to discuss the following agenda items:

1. Discussion of Guidance Document and Associated Information

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

1. Discussion of Guidance Document and Associated Information

The Pediatric Heart Workgroup is developing a guidance document for review boards and transplant centers regarding heart transplant candidate exceptions for pediatric status 1A.

On this call, Workgroup members discussed potential qualifying criteria for exceptions for two categories of candidates: 1) dilated cardiomyopathy (DCM) candidates, and 2) hypertrophic or restrictive cardiomyopathy (HCM/RCM) candidates.

Summary of discussion:

DCM Candidates

The Chair noted that DCM candidates generally have low waitlist mortality and high frequency of using exceptions. Accordingly, the Workgroup's intent is to limit the use of exceptions among DCM candidates to those at particularly high risk to maximize the number of candidates who get a transplant within an appropriate amount of time.

First, the Workgroup discussed older pediatric DCM candidates that have access to adult donor hearts. The Chair noted that these candidates tend to receive organ offers relatively quickly, and most of the candidates in this category that need 1A status meet the existing criteria. The Workgroup discussed whether there are any other circumstances in which these candidates should qualify for an exception. Members agreed that if a transplant center has a candidate in need of ventricular support but deems it high risk to insert a device, then it would be reasonable to give that candidate a 1A exception. However, members noted that it is challenging to define contraindications to ventricular assist device (VAD) insertion and that treatment should not dictate a candidate's status, meaning that programs should not avoid giving a candidate a VAD solely to elevate the candidate's status. The Chair stated that the Workgroup should be able to identify some objective criteria that would indicate a candidate's need for priority, like right heart failure.

Members discussed whether use of two inotropes should qualify a candidate for an exception, or if such a request would be rejected because the candidate should be on a VAD. Members expressed concerns that including this criterion would place candidates in competition for offers with sicker adult candidates, like those on extracorporeal membrane oxygenation (ECMO); that it would elevate the

status of candidates with less medical urgency for a transplant; and that it would create a disincentive for the use of VADs. However, members also agreed that the guidance should not disadvantage candidates at centers that are not comfortable inserting VADs. To address this concern, the Workgroup noted that their guidance would not stop a center from requesting an exception for candidates receiving two inotropes, and that such requests could be reviewed on a case-by-case basis. Additionally, the Workgroup agreed that transplant centers could provide hemodynamic criteria justifying the use of a second inotrope to ensure the second inotrope was not used solely to make a candidate eligible for an exception. The Workgroup agreed to reference the Heart Subcommittee's work on adult heart allocation guidance to inform the Workgroup's exception guidance for pediatric candidates.

Next, the Workgroup discussed 1A exception eligibility for younger pediatric DCM candidates. The Chair noted that the primary distinguishing factor between the older candidates and the younger candidates is their smaller size, which can increase the risk of using mechanical support (e.g. VAD). Members referenced data published by Jennifer Conway finding that candidates under 5 kilos carry higher risk for use of mechanical support, and agreed that candidates between 5 to 10 kilos likely carry similar risk. One member proposed that if a candidate is under 10 kilos and on multiple inotropes and/or intolerant to feeding, then the candidate should qualify for an exception. Another member proposed that if a candidate is under 5 kilos and on a single inotrope and/or in need of noninvasive respiratory support like hyponasal cannula, Bilevel Positive Airway Pressure (BiPaP), or Continuous Positive Airway Pressure (CPAP), then the candidate should have 1A status. Members agreed to add criteria related to noninvasive respiratory support to help distinguish a candidate's relative health. For candidates over 10 kilos, the Chair suggested giving 1A status to those with contraindications to mechanical support.

HCM/RCM Candidates

The Chair referenced a recent study showing that the pediatric heart allocation changes implemented in 2016 potentially hurt some HCM/RCM candidates, as their waitlist mortality when not using a 1A exception was higher than expected. Formerly, requiring one or more inotrope could qualify a candidate for 1A status, but the 2016 changes eliminated inotrope use as qualifying criteria. The Chair suggested that programs may have been using inotropes to qualify HCM/RCM patients for 1A status and that waitlist mortality increased because that access point is no longer available. Members agreed that since pediatric candidates with RCM are rare and have a worse prognosis than adults, many of these candidates should be listed at status 1A. Members agreed that RCM candidates with syncopal events, refractory ventricular arrhythmias/implantable cardioverter defibrillator firing, elevated pulmonary vascular resistance, and/or inotrope treatment should be listed at 1A status. For HCM candidates, members agreed that increasing frequency of arrhythmia is an indication that the candidates should be elevated to 1A status.

Next steps:

The Chair will draft guidance regarding status 1A exceptions for DCM and HCM/RCM candidates for the Workgroup to review and discuss. The Chair told Workgroup members that the next call will focus on guidance for re-transplant patients and whether there are subsets of candidates at particularly high risk.

Upcoming Meeting

- February 25, 2020