

# OPTN Data Advisory Committee Meeting Summary May 10, 2021 Conference Call

# Rachel Patzer, PhD, Chair Sumit Mohan, MD, MPH, Vice Chair

#### Introduction

The Data Advisory Committee (DAC) met via Citrix GoToMeeting teleconference on 5/10/2021 to discuss the following agenda items:

- 1. Project to Update Refusal Codes
- 2. Update Vascularized Composite Allograft (VCA) Policies and Data Collection

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

### 1. Project to Update Refusal Codes

The Vice Chair provided an overview of the DAC sponsored project to update the primary and secondary refusal reason drop down options in the offers detail section of DonorNet<sup>®</sup>. The members were asked to vote on whether to recommend the proposal be sent to the Board of Directors for review and approval.

### Summary of discussion:

The Vice Chair shared that the updated refusal codes are intended to improve data collection to allow more actionable insights into why an offered organ is refused. Feedback from 11 OPTN committees and over 100 community members who provided comment through a request for feedback posted to the OPTN website were incorporated into the proposed list of refusal codes.

The Chair asked if users will still be able to submit a primary and secondary reason. The Vice Chair commented that this process will not change and the user will still be able to submit up to two reasons for refusal. The Chair asked how missing data will be managed. UNOS staff confirmed that entering a primary refusal reason is required.

The Vice Chair commented that education will be provided to members to assist in the implementation of the new codes. He also shared that there is a plan to monitor the use of codes to allow the DAC to suggest additional modifications if a need is identified.

Members questioned the separation of "donor size- height" and "donor size- weight." A member commented that the Workgroup discussed that height is typically assessed for lung offers, and weight for heart offers. A member of the public commented that organs are typically refused for the size of the organ and although organ size may be related to a donor's height and weight, these factors may not be the primary reason for refusal. The Ex Officio member agreed and commented that there are a lot of size issues relative to the organ and not the donor.

Members suggested replacing the height and weight codes to "donor size mismatch" or "donor/recipient size mismatch." A member commented that height and weight are still considered when considering the acceptance of an organ for thoracic transplant. The Ex Officio member questioned how specifying height and weight adds more value to the database than collecting refusals due to organ size. Ultimately, the members agreed to combine the two refusal codes relating to donor height and weight into a refusal code that describes "organ size." UNOS staff shared that currently, the refusal code in production relating to donor size is "donor size/weight" which was used for approximately 3.5% of refusals in 2019-2020.

Following the meeting, members received a revised list of proposed refusal codes that combined "donor size- height" and "donor size- weight" into "organ size." All members approved the revised list of refusal codes by email vote (16 yes; 0 no; 0 abstain).

## 2. Update Vascularized Composite Allograft (VCA) Policies and Data Collection

The Vice Chair of the VCA Committee provided an overview of a project to update VCA data collection in DonorNet<sup>®</sup>.

## Summary of discussion:

This project, sponsored by the VCA Committee, intends to modify data collection on graft failure to better represent the unique nature of VCA transplants, as well as uterus transplant outcomes. The VCA Vice Chair commented that in VCA transplantation, graft removal is not always indicative of graft failure in all cases and therefore needs to be defined. This proposal seeks to and add and modify VCA specific data fields in TIEDI, DonorNet<sup>®</sup>, and Waitlist<sup>SM</sup>. VCA is currently being programmed into UNet but is not yet implemented.

The Chair asked about the timing of data collection and whether the proposed fields would be required. The VCA Vice Chair commented that the timing of data collection would be consistent with other organ types. Graft failure or function would be collected at the same time points as the other organ types. A member asked if graft failure would be defined differently for different VCA transplantation types as well. The VCA Vice Chair commented that the definition of graft failure for extremities would differ from uterus. The VCA committee is still developing graft failure definitions as well as reasons for graft failure.

# **Upcoming Meeting**

• June 3, 2021

#### Attendance

## • Committee Members

- o Anna Mello
- Benjamin Schleich
- Colleen Flores
- Daniel Stanton
- Farhan Zafar
- Heather Hickland
- Kristine Browning
- Lauren Kearns
- Macey Levan
- Melissa McQueen
- o Rachel Patzer
- Sandy Feng
- Sumit Mohan

### HRSA Representatives

- Adriana Martinez
- Chris McLaughlin
- SRTR Staff

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- Bert Kasiske
- Michael Conboy
- Nick Salkowski

#### • UNOS Staff

- Brooke Chenault
- Carly Engelberger
- Kaitlin Swanner
- Kayla Temple
- Kiana Stewart
- Kimberly Uccellini
- Lauren Mauk
- o Leah Slife
- Lindsay Larkin
- Matt Prentice
- Nicole Benjamin
- o Ross Walton
- Sarah Konigsburg
- o Sarah Taranto
- Sharon Shepherd
- Susan Tlusty
- Other Attendees
  - o Jamie Bucio
  - o Sandra Amaral