

OPTN Transplant Coordinators Committee

Meeting Summary

September 30, 2020

Conference Call

Sharon Klarman, RN-BC, BSN, CCTC, Chair

Stacy McKean, RN, Vice Chair

Introduction

The Transplant Coordinators Committee met via Citrix GoToMeeting teleconference on 09/30/2020 to discuss the following agenda items:

1. Welcome & Icebreaker
2. OPTN Heart Transplantation Committee: Guidance and Policy Addressing Adult Heart Allocation (Public Comment Proposal)
3. OPTN Heart Transplantation Committee: Guidance Addressing the Use of Pediatric Heart Exceptions (Public Comment Proposal)
4. OPTN Executive Committee: COVID-19 Emergency Policies and Data Collection (Public Comment Proposal)
5. OPTN Committee Workgroups: TCC Member Updates
6. OPTN Minority Affairs Committee: Feedback on Socioeconomic Status Project
7. OPTN IT Update

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

1. Welcome & Icebreaker

The Committee members were invited to introduce themselves and share where they work as well as an exciting event or activity from the last six months.

Members were encouraged to participate in discussion. They were given an overview on how sentiment votes would be collected on the proposals presented. A sentiment vote summary will be shared at the conclusion of the meeting.

2. OPTN Heart Transplantation Committee: Guidance and Policy Addressing Adult Heart Allocation (Public Comment Proposal)

The Chair of the OPTN Heart Transplantation Committee provided a presentation on the public comment proposal *Guidance and Policy Addressing Adult Heart Allocation*.

Summary of discussion:

The Chair of the OPTN Heart Transplantation Committee shared that the Heart allocation policy changed in 2018. This proposal is intended to address issues that arose with policy implementation.

The purpose of this proposal is to amend policies to:

- Measure cardiac index at start of inotrope administration rather than submission of justification form, and increase qualifying timeframe at status from 90 to 180 days to reduce patient impact associated with measuring cardiac index (CI)

- Improve consistency of Status 1 criteria by changing initial qualifying and extension timeframes from 14 to 7 days to better reflect medically urgent status of these patients

The proposal also provides guidance to clarify type of information and level of detail that should be included in Status 2 exception requests.

Only transplant programs are anticipated to be impacted because they will be required to update Status 1 justification forms more frequently and enter the date of the candidates' inotrope administration on justification forms for Status 4 patients.

A committee member asked about the change to 7 days asking if there are patients who after 7 days are no longer meeting the criteria for Status 1. If it is unlikely that the patient will not remain meeting the criteria, this has the potential to add administrative burden. The Chair of the Heart Transplantation Committee commented that this change makes the timeline consistent with other status requirements and noted that this is a small patient volume, so inherently, there will be little burden.

A committee member commented that there is a lot of work required for these status justifications and supported that these patients need to be evaluated at this shorter timeframe emphasizing that these patients are supposed to be the most medically urgent.

A committee member supported the Status 2 guidance and agreed that many exception requests submitted may be inappropriate. The Chair of the Heart Transplantation Committee agreed that the guidance will increase consistency of review as well as create structure in what is submitted for review.

A committee member asked if there could be a standardized form for exception requests. The Chair of the Heart Transplantation Committee said there is a template included in the guidance. She suggested that this template could be added to a program's electronic medical records (EMR). She noted that using the template will help expedite the review process.

A committee member asked at what point the allocation policy be examined to see if there needs to be any adjustments. The Chair of the Heart Transplantation Committee commented that the allocation policy is continually examined. Typically, policy changes do not occur until after three or more years to allow for there to be enough data to analyze.

The Committee members submitted the following sentiment scores: 3 Strongly Support; 8 Support; 1 Neutral/Abstain; 0 Oppose; 0 Strongly Oppose.

Next steps:

3. OPTN Heart Transplantation Committee: Guidance Addressing the Use of Pediatric Heart Exceptions (Public Comment Proposal)

The Chair of the OPTN Heart Transplantation Committee gave a presentation on the *Guidance Addressing the Use of Pediatric Heart Exceptions* public comment proposal.

Summary of discussion:

Similar to adult, following policy changes in 2018, exception requests for candidate status did not decrease as intended. The purpose of this guidance is to increase consistency in pediatric heart exception request submission and review. This guidance will assist members of the National Heart Review Board for pediatric candidates once implemented in June 2021.

The guidance includes more clarity in status exceptions eligibility for the following diagnoses:

- Dilated cardiomyopathy
- Hypertrophic or restrictive cardiomyopathy

- Single ventricle heart disease
- Coronary allograft vasculopathy and retransplantation

A committee member commented that guidance for exception requests are extremely helpful. They noted that it will help save time to see if patients are eligible for exceptions prior to submission as well as what data to include rather than going back and forth with the review board.

A committee member offered to bring this proposal back to other coordinators they work with to see if they have any comments.

The Committee members submitted the following sentiment scores: 5 Strongly Support, 8 Support, 0 Neutral/Abstain, 0 Oppose, 0 Strongly Oppose.

4. OPTN Executive Committee: COVID-19 Emergency Policies and Data Collection (Public Comment Proposal)

UNOS staff gave a presentation on the *COVID-19 Emergency Policies and Data Collection* retrospective public comment proposal.

Summary of discussion:

There was a dip in transplant activity in the spring but numbers have rebounded since. When comparing this year to last, there are more deceased donor transplants.

The Executive Committee is authorized on taking emergency actions. These actions must go to public comment and cannot extend to more than 12 months. The original expiration date was set to 9/30/2020 but has been extended to end of December 2020. The Board of Directors (BOD) will consider public comment feedback at December BOD meeting.

The reasons these actions were implemented were to increase patient safety, reduce burden, reduce disadvantages that some candidates may have faced, and provide members with a way to communicate COVID-19 testing status and results.

A committee member commented that there have been a lot of questions about donors with known history of COVID-19 and tracking the recipient of the organs. As COVID rates increase, more donors will have a history of COVID-19 and may be recovered. The committee member asked if testing should include antibody testing and noted that the antibody testing is inconsistent. UNOS staff shared that they can enter antibody testing results for deceased donors and that multiple tests can be added in DonorNet®. Another committee member asked if there is there a plan to analyze type of testing and issue recommendations. UNOS staff responded that testing is being monitored.

A committee member commented that UNOS' response to COVID-19 was timely and that once the testing is more consistent, the fields should become mandatory. On the Transplant Registration Form (TRF), there should be data collected on if the patient has been infected with COVID-19 since last form submission. Data could be collected on living donors that are declining to come into labs due to concerns around COVID 19. They also commented that additional guidance would be helpful.

A committee member from the Midwest commented that they are seeing COVID-19 numbers increase. Patients are still not coming in and are being served via Telehealth. They suggested allowing the submission of forms with all fields optional so partial data could be collected and commented that retrospective data entry will cause burden.

A committee member suggested that a standard registry for COVID-19 data would have been helpful to assist in answering patient questions regarding outcomes.

A committee member asked where they could access the amnesty information. UNOS staff provided a link to the proposal.

A committee member asked how this will impact the Scientific Registry of Transplant Recipients (SRTR) data. UNOS staff said that reporting timeframes will be adjusted.

The Committee members submitted the following sentiment scores: 2 Strongly Support, 12 Support, 0 Neutral/Abstain, 0 Oppose, 0 Strongly Oppose.

Next steps:

Members were encouraged to submit additional comments to UNOS staff by email.

5. OPTN Committee Workgroups: TCC Member Updates

Members who represent TCC on workgroups gave an update on recent workgroup activity,

Summary of discussion:

Ethics Committee: Facilitating Patient Navigation Workgroup

- Several recent meetings have been canceled
- Goal is to provide patients with information that should be considered to help make informed decisions pertaining to the donation and transplantation process via a white paper
- Workgroup has reviewed current patient materials and identified that there are still gaps in information that can be addressed

Policy Oversight Committee: Provisional Yes Workgroup

- Data is being reviewed
- Group is focused on offer filters
- Filters will allow for the more marginal organs to be offered to centers that will accept them sooner

OPO Committee: Multi-Organ Policy Review Workgroup

- Goal is to update multi-organ allocation policy
- TCC member was unable to attend last meeting

Operations & Safety Committee: Broader Distribution Data Collection Workgroup

- Workgroup is looking at broader sharing efficiency
- Examining how data is collected
- Discussing how can travel and logistics be improved

Data Advisory Committee: Refusal Codes and Late Turndowns Workgroup

- Reviewing refusal codes
- The goal is to update and improve refusal codes to increase granularity in understanding why organs are turned down

Data Advisory Committee: Implementation Advisory Task Force

- Goal is to improve integrity and quality of form submission and data
- Form data will be locked
- Education will be created to support any changes

6. OPTN Minority Affairs Committee: Feedback on Socioeconomic Status Project

The Committee heard an update from the Minority Affairs Committee (MAC) on their revisions to *Data Collection to Access Socioeconomic Status and Access to Transplant*.

Summary of discussion:

A committee member stated that she would be more supportive of the annual income range revision than having to collect one specific number in the unrevised proposal. This member also suggested that the MAC look into collecting data at the time of registration and again at the time of transplant. They also asked if the MAC would consider providing transplant programs with education and tools for collecting income data from patients.

A Board member agreed with the TCC member and added that the MAC could look into using other data to help identify low SES candidates, such as if they collect Medicaid or live in government subsidized housing.

7. OPTN IT Update

The Committee heard about some new technology projects from UNOS IT.

Summary of discussion:

Offer Filter Pilot

A committee member asked if the offer filter pilot would be expanded to other organs. UNOS IT reported that this year the focus would be on kidney and asked what other organs would benefit from participating in the pilot. A committee member answered that this could be useful for liver, especially for liver programs who are more conservative and filter at offer level.

New Tools: COVID RUM

A committee member commented that transplant coordinators could benefit from a summary/tutorial of how to apply these new reports into real life practice.

Upcoming Meetings

- October 21, 2020 (teleconference)
- November 18, 2020 (teleconference)

Attendance

- **Committee Members**
 - Angele Lacks
 - Alexandria Dillard
 - Brenda Durand
 - Donna Campbell
 - Hannah Murry
 - Jaime Myers
 - Jill Campbell
 - JoAnn Morey
 - Lisa Gallagher
 - Maria Casarella
 - Melissa Walker
 - Natalie Blackwell
 - Randee Bloom
 - Sergio Manzano
 - Sharon Klarman
 - Stacy McKean
 - Susie Ditsworth
- **HRSA Representatives**
 - Christopher McLaughlin
 - Raelene Skerda
- **UNOS Staff**
 - Lloyd Board
 - Shannon Edwards
 - Chelsea Haynes
 - Sarah Konigsburg
 - Eric Messick
 - Elizabeth Miller
 - Kelley Poff
 - Kaitlin Swanner
 - Susan Tlusty
 - Ross Walton
 - Sara Rose Wells
 - Anne Zehner
- **Other Attendees**
 - Shelley Hall
 - Irene Kim