OPTN Heart Committee
Educational Emails Subcommittee
Meeting Summary
February 23, 2022
Conference Call

Shelley Hall, MD, Chair

Introduction
The Educational Emails Subcommittee met via Citrix GoToMeeting teleconference on 2/23/2022 to discuss the following agenda items:

1. Introduction
2. Message focusing on use of exception requests for Status 2 assignments

The following is a summary of the Subcommittee’s discussions.

1. Introduction
The Subcommittee reviewed the members who are participating and reviewed the purpose of the emails while establishing who the target audience is. They also highlighted the pathway for obtaining member feedback and questions following the dispersement of the educational emails.

Summary of discussion:
A member asked if this would be an appropriate place to highlight the concerns that the OPTN Heart Committee has with the Establish Eligibility Criteria and Safety Net for Heart-Kidney and Lung-Kidney Allocation policy proposal out for public comment from the OPTN Ad Hoc Multi-Organ Transplantation Committee. The Chair clarified that the appropriate pathway to provide feedback on another Committee’s policy proposal is through public comment. The Chair noted that these emails will be focused on topics relevant to OPTN heart policy.

The Chair added that these emails ought to be succicent and short with minimal links, emphasizing the need to provide the community with consumable information. It would also be beneficial to link to the OPTN Committee page with the directive to contact their regional representative with questions or feedback.

2. Message focusing on use of exception requests for Status 2 assignments
The Subcommittee discussed the primary points to be used for the Status 2 Exception Request guidance.

Summary of discussion:
A member referenced literature about Status 2 Exception patients having equal outcomes as patients who met criteria without exception, stating that physicians seem to be doing a good job of identifying patients who need a higher status but are not meeting criteria for some reason.1 A member suggested noting the explicit component the program is wanting to be reviewed for an exception. This will help

direct those are reviewing the applications to the most relevant information. The Chair agreed with this and echoed that the point of the email is not to tell the community they should or should not use the process, but instead provide guidance on how to use it appropriately.

A member suggested providing clarification on ventricular tachycardia, specifically that ATP does count as an event. The member noted that this could be an issue that needs consideration in other areas than the exception request, but noted that this has come up in the exceptions. The Chair suggested using an example in the email that ‘A patient had one shock and one ATP but did not initially qualify because they did not have three events.’ A member suggested covering ATP, and other atypical things, in a subsequent email.

The Chair suggested developing an introductory paragraph that outlines the magnitude of the issue and shares statistics on the total volume of Status 2 exception requests. The email should also highlight the relevant details of current state of the patient, the patient’s equivalent risk profile to Status 2 patients, and the hyperlink to the existing guidance document.

A member inquired if there was a way to find out if certain centers were overusing the exception request process and if that information could be shared back to them. UNOS staff responded that the OPTN has exception data by regions and suggested against using center-specific data to avoid singaling out specific programs. A member noted that it could be beneficial for centers to have a better understanding of how their exception practice falls in comparison to others. The member emphasized that some centers may be underutilizing them while others may not be taking the exception guidelines as seriously. A member added that it could be beneficial to understand, from the programs, how often they utilize exceptions to provide insight on center behavior and inequities. The group discussed this briefly, and while beneficial in general, that information would be unreliable and not relevant for this email specifically.

In terms of the program specific exception request data, the Chair responded that the Committee would only be able to include publicly available information in the email and suggested using the volumes per region information from the monitoring report. A member inquired if the Committee could include statistics on the number of Status 2 exception requests versus the number of Status 2 form completions. This information is available in the monitoring report and can be included in the email. UNOS support staff noted that if there is a need for additional data for future educational emails then the Committee could look into potentially making a data request.

A member noted that it could be beneficial to show the change in volume since the new heart allocation system was implemented, noting that perhaps volume has changed as the community has become more comfortable with the exception request process. The Chair pushed back that it may be hard to tell if changes in volume were due to centers having a better understanding of the process or other factors.

A member added that they find exception requests with the medication included in the body of the narrative to be most helpful. This member noted that while it makes the narrative longer, it is easier to have all of the information in one place as opposed to scrolling down to consider the medication with respect to the narrative. They agreed that the email could include tips for an effective narrative. A member volunteered to develop the first round draft for the group to review.

The next email will focus on atypical events. Members suggested including education restrictive cardiomyopathy, hyperthrophs, and ATP.

Next steps:
Members are asked to circulate any articles that would be pertinent for this email and share ideas for future educational emails.
Upcoming Meetings

- To be determined
Attendance

- **Subcommittee Members**
  - Amrut Ambardekar
  - JD Menteer
  - Jennifer Carapellucci
  - Jonah Odim
  - Michael Kwan
  - Shelley Hall

- **HRSA Representatives**
  - Jim Bowman

- **SRTR Staff**
  - Grace Lyden
  - Yoon Son Ahn

- **UNOS Staff**
  - Eric Messick
  - Keighly Bradbrook
  - Krissy Laurie
  - Laura Schmitt
  - Sara Rose Wells
  - Susan Tlusty