OPTN Ethics Committee Meeting Summary November 17, 2022 Conference Call

Keren Ladin, PhD, Chair Andrew Flescher, PhD, Vice Chair

Introduction

The Ethics Committee met via Citrix GoToMeeting teleconference on 11/17/2022 to discuss the following agenda items:

- 1. Review and Discuss Multiple Listing White Paper
- 2. Normothermic Regional Perfusion (NRP) Workgroup Update

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

1. Review and Discuss Multiple Listing White Paper

The Chair provided an overview of the multiple listing white paper, including the scope, an overview of the ethical principles, data, and recommendations. Members were asked to provide feedback and will receive a draft for review within the next day.

Summary of discussion:

A member mentioned the geographic variability and emphasized the role that multiple listing could play in accounting for geographic disparities, such as quantity of transplant programs and transplant program behaviors. A member also noted that surgeon experience, staffing availability, and willingness to accept marginal offers are just a few of the many obstacles out of patient's control that influences a patient's decision to pursue multiple listing. The Chair emphasized that multiple listing should be reserved for clinically complex and otherwise hard to match patients. Members acknowledged the challenge of determining the characteristics for this population, agreeing that it is outside of the scope of the Ethics Committee and will need to be done by other OPTN committees. Members felt that attempts to remove obstacles for patients to access transplant should remain at the forefront, but if there are continued obstacles then patients should have the opportunity to multiple list.

A member brought up multiple evaluations and the interrelated role they play with each other. A member suggested that multiple evaluations could allow the patient to identify the transplant center that best meets their needs. Pursuing multiple evaluations does not infringe on autonomy as it does not impact a patient's ability to receive multiple organ offers simultaneously compared to single listed patients. In alignment with the Committee's *Transparency in Program Selection* white paper, this white paper could recommend transparent information be provided to patients prior to transplant evaluation for patients to identify the transplant program that is the best fit.

A member noted that patients may opt to multiple list if they feel their transplant center has not provided them with the services they need and are looking elsewhere to pursue transplantation. A member recommended that if a patient had not been transplanted within a certain time period that is proportionate to the average wait time in that area, then the transplant program should be required to remind patients of their ability to multiple list. The member suggested that not being transplanted within a certain proportion of the average wait time may be an indicator that a patient is medically complex. A member countered that the demarcation of time would vary drastically between transplant program and region. Due to this variability, some members agreed that they would feel uncomfortable removing the ability for patients to multiple list as there are extensive factors in allocation that are out of the patient's control. A member also noted that the transplant program has a vested interest in a patient remaining waitlisted at their hospital and could be biased in their recommendation or reminder of the option to pursue multiple listing.

A member noted that the disparities in data were not as significant as expected and anecdotally depicted in the media. While the data was preliminary, and should be viewed as such, the Committee should not support policies that are patterned in alignment with socioeconomic disparities. It is important for additional, more complex research to fully understand the extent of any disparities, but the early depictions do present some concerning patterns.

2. Normothermic Regional Perfusion (NRP) Workgroup Update

Staff reviewed the feedback of a poll the NRP workgroup took indicating their position on NRP, what additional information may be needed, and whether their perspective has changed during the group's discussions and deliberations. The NRP workgroup will continue to meet and begin writing the white paper in preparation for a special public comment period. The Ethics Committee will continue to receive regular updates of the workgroup's progress.

Summary of discussion:

A member inquired if there will be a heads up about the NRP white paper during the regional meetings. The Chair responded there may be a brief update at the regional meeting, but the team is still working through how this update may occur. The Committee wants to avoid engaging in preliminary discussions about NRP before the final white paper is completed and out for public comment.

Next Steps:

Members will receive a call for nominations sent via email. Members who are interested in the vice chair role are asked to submit a personal statement and updated curriculum vitae.

Upcoming Meetings

- December 15, 2022
- January 19, 2023
- February 16, 2023
- March 16, 2023
- March 31, 2023
- April 20, 2023
- May 18, 2023
- June 15, 2023

Attendance

- Committee Members
 - o Andrew Flescher
 - o Bob Truog
 - o Carrie Thiessen
 - o David Bearl
 - o Ehab Saad
 - o Erica Stohs
 - Felicia Wells-Williams
 - o George Bayliss
 - o Glenn Cohen
 - o Jen Dillon
 - o Keren Ladin
 - o Lynsey Biondi
 - o Megan Urbanski
 - o Melissa Anderson
 - o Sena Wilson-Sheehan

• HRSA Representatives

- o Edna Dumas
- o Jim Bowman
- SRTR Representatives
 - o Brynn Thompson
- UNOS Staff
 - o Catherine Parton
 - o Cole Fox
 - Houlder Hudgins
 - o James Alcorn
 - o Kim Uccellini
 - o Krissy Laurie
 - o Kristina Hogan
 - o Laura Schmitt
 - o Matt Belton
 - o Stryker-Ann Vosteen