

**OPTN Ethics Committee  
Meeting Summary  
February 16, 2023  
Conference Call**

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

## **Introduction**

The Ethics Committee met via Citrix GoToMeeting teleconference on 2/16/2023 to discuss the following agenda items:

1. Welcome, Updates, and Housekeeping
2. Regional Meeting Debrief
3. Update on Normothermic Regional Perfusion (NRP) White Paper & Discussion

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

### **1. Welcome, Updates, and Housekeeping**

The Chair welcomed members to the call. Staff provided a few staffing updates and information about the upcoming in-person meeting in March. Information about how the Committee will submit comments about the relevant proposals out for public comment was provided to members. Staff also gave a reminder about the Winter 2023 Regional Meeting schedule for those presenters who have not yet had their meeting.

#### Summary of discussion:

Members asked for more details about the public comment proposal review process, and staff explained that members will submit their thoughts via email, which will then be collected and compiled into a formal comment for final member review.

#### Next steps:

Members will review their assigned public comment proposal and submit their thoughts via email.

### **2. Regional Meeting Debrief**

Members shared their experiences so far with presenting the Ethical Evaluation of Multiple Listing white paper out for public comment.

#### Summary of discussion:

A member described how some participants felt that the slide deck was confusing, especially where organ-level specificity is not provided. Another member shared that they had heard a lot of feedback from liver transplant professionals, including considering patients who reside in states without liver transplant programs, patients who reside in areas that have long wait times who can multiple list in an area with lower waiting times and patients who want to list at both a deceased donor liver program and a living donor liver program. The Chair responded that the waiting time concern is currently being addressed by continuous distribution development, and that the Committee must address the system at large. A member added that while it is true that the Committee must address the entire system, it

cannot lose sight of the individual experiences of both clinicians and their patients in areas with high waiting time on the list. The Chair also asked for liver clinician input on why a patient would need to multiple list when wishing to pursue both living and deceased donor options. A member answered that because liver centers may not necessarily do both types of transplantation, it would make practical sense for a patient to multiple list. Another member shared that a patient spoke up at their presentation and stated that they were concerned about the conclusions in the paper considering that programs are not highly transparent in their selection criteria. Another patient at that meeting shared that one way to improve patient access to multiple evaluations is to encourage programs to accept prior labs and other evaluations as part of their process. A member shared that at veteran hospitals in the US, transplant candidates are limited to listing at two centers. Another member clarified that this depends on the candidate insurance and is not true across the board. New York also limits multiple listing as a part of state law. A regional meeting participant asked for more granular data on pediatrics.

A member shared some helpful tips for preparing for the regional meeting presentations, including to re-read the paper several times. Staff showed the regional sentiment to date. The sentiment showed mixed feedback. When the final sentiment is available, it will be incorporated into the public comment analysis.

#### Next steps:

A public comment analysis will be conducted. After this, the Committee will discuss any revisions or clarifications needed to the white paper in the March in-person meeting.

### **3. Update on Normothermic Regional Perfusion (NRP) White Paper & Discussion**

The Chair informed the Committee that the NRP Workgroup is still in the process of writing the white paper, with Ethics Committee members as their primary authors. Staff showed an overview of the outline and shared a few details about each section. The Chair asked members for comments, suggestions, objections, and any other feedback they have to share.

#### Summary of discussion:

A member shared that the Workgroup may want to revise the use of “do no harm,” as someone who has been declared dead is not subject to the same do no harm concerns as living persons. The Chair responded that this subject will be addressed delicately and carefully in the paper. The paper will frame things into what we do and do not know at this time. A member suggested following up with colleagues from the United Kingdom and other countries for an update on NRP in their experiences. A member shared that they have reached out to many programs and organ procurement organizations (OPOs) that currently use NRP to ask about their protocols and practices. Members discussed informed consent and the appropriate information and language to share with donor families. A member asked if there have been any instances of centers declining NRP organs, and another member shared that this has happened and continues to happen. The Chair affirmed that NRP practices and procedures are a patchwork, both in the US and overseas.

### **Upcoming Meetings**

- March 16, 2023
- March 31, 2023
- April 20, 2023
- May 18, 2023
- June 15, 2023

## Attendance

- **Committee Members**
  - Bob Truog
  - Carrie Thiessen
  - David Bearl
  - Ehab Saad
  - Erica Stohs
  - Felicia Wells-Williams
  - George Bayliss
  - Glenn Cohen
  - Jen Dillon
  - Keren Ladin
  - Sanjay Kulkarni
  - Megan Urbanski
  - Sena Wilson-Sheehan
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
- **SRTR Representatives**
  - Bryn Thompson
- **UNOS Staff**
  - Cole Fox
  - Kieran McMahon
  - Kim Uccellini
  - Kristina Hogan
  - Laura Schmitt
  - Stryker-Ann Vosteen