

**OPTN/UNOS Ethics Committee
Meeting Minutes
November 16, 2017
Conference Call**

**Elisa Gordon, PhD, MPH, Chair
Keren Ladin, PhD, Vice Chair**

Introduction

The Ethics Committee met via Citrix GoToTraining teleconference on 11/16/2017 to discuss the following agenda items:

1. Living Organ Donation by Person's with Certain Life-limiting Illness
2. White Papers in Development
3. Proposed New Projects

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

1. Living Organ Donation by Person's with Certain Life-limiting Illness

The Committee Chair provided an update on the status of an Ethics Committee (Committee) white paper.

Summary of discussion:

The Chair explained that there have been some substantive changes to the white paper to address concerns of the Living Donor Committee. The changes should clarify that the Ethics Committee is saying it ethically acceptable for people with certain life-limiting conditions to the living donor but other groups would need to address questions concerning risk and medical acceptability.

Some of the changes included:

- Removed references to physician assisted suicide
- Reinforced need for potential donor and transplant hospital to agree on level of risk
- Emphasized that other Committees would need determine if new guidance or policies would be needed and to determine level of risk and clinical eligibility

Updated draft will be reviewed by subgroup of OPTN/UNOS Broad (Board) to recommend if the white paper should be on the consent agenda or be a discussion item at the upcoming Board meeting.

Committee leadership sent a written response to Not Dead Yet to address comments received during public comment.

Next steps:

The white paper should be considered by the Board in early December.

2. White Papers in Development

The Committee the discussed the status of two white papers in development.

Summary of discussion:

The white paper addressing the Manipulation of Therapeutic Strategies to Advance Candidate Priority Status will be sent to the Thoracic, Liver, Kidney, Transplant Coordinators and

Transplant Administrators Committees for pre-public comment. The lead author for this white paper is scheduled to present it to the Thoracic Committee on November 30th.

The Committee will review and address all responses and consider if the white paper should be sent for public comment during the December 21st meeting.

The white paper addressing Guidance for Honoring First Person Consent and Extending First Person Consent to Include DCD has been sent to the OPO Committee for pre-public comment feedback.

A member questioned if the white paper should use the word consent versus authorization. Members supported waiting for feedback from the OPO Committee.

The Committee will consider all responses and consider if the white paper should be sent for public comment during the December 21st meeting.

A member raised questions regarding the financial incentives white paper that was not released for public comment. The member commented that a lot of work had been invested in the development of the white paper and questioned if it could be converted to an academic publication? The Committee agreed to investigate options through a future conference call.

3. Proposed New Projects

The Chair lead a discussion of projects that had been recommended during the October 2nd meeting.

Guidance related to Current Multi-Organ Allocation Policy and Practice

The Committee worked on this project previously (2016). Ethics was requested to address this topic and then later was directed to stop work on the project. In the work that has occurred to date, it has been difficult to address specific types of multi organ allocation. A member questioned if the Committee could get data on the frequency and outcomes for multi-organ transplants. A member volunteered to lead development of this white paper.

Eligibility of Intellectually Disabled Individuals for Transplant

The Chair commented that this is a timely topic and it might be possible to address the topic during a review and update of the exiting white paper addressing transplant candidacy. A member was identified to lead this project. A member questioned if it might be possible to survey transplant programs to help determine the scope of the problem. The liaison explained that UNOS has tight restrictions on surveys, but suggested it might be possible to ask the Transplant Coordinators and Transplant Administrators Committees for feedback on the scope of this problem.

Organ Transplantation in Undocumented Migrants to the United States

The member that originally suggested this project was asked to clarify the specific question or problem to be addressed. He explained that the transplant community could benefit from a statement addressing how to handle potential transplant candidates who are illegal aliens. He explained that eligibility for transplant is typically dependent on having insurance coverage to help cover the cost of the transplant and post-operative care. He questioned what should happen if an illegal alien has insurance or is financially independent and able to cover the cost of the transplant and post-operative care. Should being an illegal alien be a reason for not

considering someone as a candidate for transplant? Some members opined that this topic could be very controversial and suggested a standalone white paper on this topic might be the best approach.

Stipends to Living Donors from Medicare Funding

The Chair voiced concerns that this project is similar in scope to the recent financial incentives white paper that was not supported by HRSA. Members did not support work on this topic at this time.

Next steps:

The proposed projects to address *Eligibility of Intellectually Disabled Individuals for Transplant* and *Organ Transplantation in Undocumented Migrants to the United States* will need to be considered by the Policy Oversight Committee.

4. Consider Revising the Ethics Committee Charge

Upcoming Meeting

- December 21, 2018
- Spring 2018 Full Committee Meeting - April 9, 2017 – Chicago O'Hare Hilton