

**OPTN/UNOS Ethics Committee
Meeting Minutes
June 15, 2017
Conference Call**

**Peter Reese, MD, Chair
Elisa Gordon, PhD, MPH, Vice Chair**

Introduction

The Ethics Committee met via Citrix GoToTraining teleconference on 06/15/2017 to discuss the following agenda items:

1. Current Projects

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

1. Current Projects

- White Paper Addressing Financial Incentives for Organ Donation
- Living organ donation by persons with certain fatal diseases who meet the criteria to be living organ donors
- Guidance Honoring First Person Consent and Extending First Person Consent to Include DCD
- Standardizing Treatment According to OPTN Allocation Criteria (Gaming)

Summary of discussion: White Paper Addressing Financial Incentives for Organ Donation

The Ethics Committee (the Committee) vice Chair opened the meeting. She explained that this white paper had been sent to Committee members in advance for review and asked if there were any questions regarding the white paper. She explained that the goal of this meeting would be to reach consensus and to consider if the white paper should be sent for public comment.

The Committee reviewed pre public comment feedback regarding the white paper from the Living Donor Committee which included:

- Most LDC members opined that this white paper is premature, financial neutrality and removing disincentives for living donation should be addressed before considering financial incentives.
- So much still needs to be done and evaluated to remove disincentives, to spend effort on financial incentives seems a mistake
- The Ethics Committee should consider if there is an ethical obligation to remove disincentives first before considering the ethics of financial incentives
- The way the paper is framed its give the impression that issues with disincentives have been solved.

Committee members commented that there was no reason work on disincentives and possible financial incentives could not occur simultaneously. The organ shortage is a multifactorial problem and all options should be considered.

The Committee discussed some potential changes to the white paper to address concerns from the Living Donor Committee. The Committee liaison cautioned the group against making

changes to the document and suggested addressing the concerns of the Living Donor Committee in the background material for the white paper.

The Committee unanimously supported sending the white paper for public comment with a roll call vote. Vote 15:0:0

Next steps:

The background material for the white paper will be updated. Current plan is for this white paper to be presented at regional meetings to begin in early August.

Summary of Discussion: Living Organ Donation by Persons with Certain Fatal Diseases who meet the Criteria for Living Organ Donors

The Committee discussed the current status of this white paper. A draft of the white paper was provided to several Committees (Living Donor, Operations and Safety, Minority Affairs) for pre-public comment feedback.

The Operations and Safety Committee provided the following comments:

- One member stated that this distinction could get a little slippery. The act of donating kidney could actually add to the progression of the illness. One member stated as long as act of donation does not necessarily hasten the death it would be acceptable.
- Members noted that some of the definitions are somewhat confusing because the terms are so similar. Members asked about the timeline used to help define fatally ill versus terminally ill potential donors. Some members indicated that they were not sure the timeline is needed. The timeline could be confusing if you have an 80 year old that has a fatal illness with a 10 year expected death.
- This type of donation could be a great opportunity for people to give who are ill, but could also raise trust issues in certain communities.
- Medical staff should not raise the options of organ donation with type of potential donor. If medical staff raise the topic it could erode public trust.
- The feedback was generally supportive, and there was support for sending the white paper for public comment.

The Living Donor Committee provided the following comments:

- Recommendations are quite brief but are too strong. Public input necessary before making recommendations. Consider changing recommendations as follows:
- If this concept is supported in public comment, the OPTN should consider if individuals with certain fatal disease should be considered for living donation.
- If supported by the OPTN, the OPTN should determine how to address the problem which could include determining which policies for living donor informed consent, psychosocial and medical evaluation and follow-up should not be necessary for or appropriate for individuals with certain fatal diseases who wish to be living organ donors.
- The OPTN should take steps to remove disincentives and undue scrutiny of transplant hospitals that undertake the recovery of organs from individuals with certain fatal diseases who wish to be living organ donors.

The Committee consider the pre public comment feedback but did not support making changes to the white paper.

The Committee unanimously supported sending the white paper for public comment with a roll call vote. Vote 15:0:0

Next Steps

The background material for the white paper will be updated. Current plan is for this white paper to be on the consent agenda at regional meeting to begin in early August.

Summary of Discussion: Honoring First Person Consent and Extending First Person Consent to Include DCD

The lead author for this white paper provided an update. She explained that a draft of the white paper had been sent to several OPO representatives for comment, and some have responded with helpful information on what happens when the family does not support a first person consent for donation. The Committee reviewed some of the feedback received to date.

The paper originally contained scenarios but the scenarios has been problematic so they have been removed. The white paper does not need to address approaching the family for donation.

The law on this topic is clear, but there is some variation on how it is handled state to state. This paper may need to be a statement supporting honoring first person consent rather than an ethical analysis.

Next Steps

The work group will continue to refine the white paper. The OPO, Operations and Safety and Transplant Administrators Committees will be asked to review the white paper and to provide feedback.

Summary of Discussion: Standardizing Treatment According to OPTN Allocation Criteria

The title for this white paper was recently changed. The paper needs to avoid the term “gaming” because it has a negative connotation. The lead author for this white provided an update. The workgroup had met my web conference earlier in the week. The workgroup decided not to include scenarios to demonstrate escalation of care for each organ type.

Next Steps

The work group will continue to refine the white paper.

Due to overabundance of items for next public comment period only two white papers will be sent for public comment. The Committee will finalize the two remaining white paper for a future public comment period.

The Committee Chair offered some personal observations regarding the end of his term of service on the Committee. He commented that the Committee has had more direction, organization and oversight. He thanked members for their high quality work, and increased involvement and their leadership over the past year.

The meeting was adjourned.

Upcoming Meetings

- To be determined