

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

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

Introduction

The Ethics Committee met via Citrix GoToTraining teleconference on 03/16/2017 to discuss the following agenda items:

1. Current Projects
2. Plans for April 3rd Committee Meeting

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

1. Current Projects

White Paper Addressing Financial Incentives for Organ Donation

Summary of discussion:

The Ethics Committee (the Committee) Chair opened the meeting and explained that the *White Paper Addressing Financial Incentives for Organ Donation* had been withdrawn from public comment. He explained that after the white paper was released for public comment some respondents considered it to be a directive for OPTN leadership to lobby for modification of the National Organ Transplant Act (NOTA) to allow for financial incentives for organ donation. The Committee intended the white paper to start a conversation about potential research through a pilot study and acknowledged that NOTA would need to be modified for such research to occur. The white paper specifically asked for feedback regarding if a pilot study should or should not be supported. Committee leadership ultimately decided it would be best to withdrawal the white paper from public comment for revision and to plan to send the white paper for public comment in August 2017.

Next steps:

The Committee Chair will annotate the document to identify and suggest content for revision.

The white paper will be discussed at the April 3, 2017 meeting.

Guidance Regarding Organ Donation by Competent Terminally Ill Donors

Summary of Discussion

The lead author for this white paper commented that she has been receiving inconsistent feedback regarding revisions to the white paper.

The Committee discussed several categories of living donors listed in the summary and goals section of the paper. The Committee supported changing the current language to read and include individuals whose illness would not put them at greater risk for an adverse outcome, or whose illness would not put the individual at an unreasonable risk based on evaluation by the recovery hospital. The Committee supported changing language to read whose organ would be of sufficient quality to provide benefit to the recipient. Members commented that a terminal illness may effect the medical quality of an organ but that organ may be sufficient or adequate for a recipient.

The Committee had an extensive discussion regarding if this white paper should address physician assisted suicide. A member commented that physician assisted suicide is legal in some states in this country and it will likely expand in the future. A member commented that if physician assisted suicide is not addressed in the white paper then it could appear that the Committee failed to consider the topic or it could imply that the Committee supports organ donation prior to assisted suicide because it was not specifically addressed.

Some members were concerned that addressing organ donation prior to physician assisted suicide would make the white paper too controversial.

The Committee discussed several options for addressing physician assisted suicide, including 1) addressing assisted suicide in the white paper but stating the Committee does not have a formal position on the topic at this time, and 2) asking if assisted suicide should be addressed in the white paper during public comment.

The Committee discussed if hospital staff should be able to refuse to participate in a living donor organ recovery if the donor may be considering assisted suicide.

Members discussed a research article entitled *Seriously Ill Patients as Living Unspecified Kidney Donors: Rational and Justification* (Transplantation 2015_99(1)232-5). This article reports living donation by patient with life-threatening disease, but the article may not be applicable because these living donors donated their organ well in advance of their death.

The Committee decided to continue this discussion at its April 3, 2017 meeting.

Next Steps

The lead author will update the white paper to reflect areas of consensus reached during this meeting. The lead author will prepared an updated draft of this white paper.

White Paper Addressing the Escalation of Treatment for the Purpose of Advancing a Patient's Status on the Transplant List

Summary of Discussion

The lead author for this white paper reported that members working on this project have had two meetings by conference call and reviewed a first draft of the document during the most recent meeting.

Members discussed physician autonomy versus patient autonomy and agreed that patients typically accept whatever is recommended by their physician. Consequently, a patient may not know that they may be a participant in gaming the allocation system. Any allocation system that permits gaming may be a flawed allocation system. Allocation systems should not use subjective measures and allocation criteria should be difficult to manipulate. Any gaming undermines equity in the transplant system.

Members discussed examples of gaming which included moving a transplant candidate to the intensive care unit to raise their priority for transplant, although ICU care may not actually be needed or justified. A member mentioned that the introduction of the MELD score lead to a decrease in ICU use because the MELD score was a less subjective method of determining priority for transplant.

Members discussed that systematic gaming has the potential to undermine public trust and the collegiality in the transplant community. A member reported that some medical centers in Germany were gaming to improve access to transplant. Some involved were convicted, events were publicized and contributed to 15% drop in donations/transplants the following year.

Next Steps

The Committee will continue its discussion during the April 3, 2017 meeting. Representatives from the Thoracic Committee will be invited to participate in future workgroup calls.

2. Plans for April 3rd Committee Meeting

Summary of Discussion

The Committee will meet on April 3, 2017 at the Chicago O'Hare Hilton. Meeting material will be posted on the Ethics Committee SharePoint site no later than March 20, 2017, and will be updated as the meeting date approaches.

Committee members were instructed to complete and submit at least one new committee project worksheet in advance. Committee leadership will review the proposed projects and select some projects for discussion during the April 3rd 2017 meeting.

Next Steps

Members should complete and submit at least one new committee project worksheet during the next week.

The meeting was adjourned.

Upcoming Meetings

- April 3, 2017