

**OPTN/UNOS Ethics Committee
Meeting Minutes
May 18, 2017
Conference Call**

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

Introduction

The Ethics Committee met via Citrix GoToTraining teleconference on 05/18/2017 to discuss the following agenda items:

1. Current Projects
2. Kidney Paired Donation Conundrum

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. The lead author for a *White Paper Addressing Financial Incentives for Organ Donation* provided an update on the status of the project. She explained that when the original version of this 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. 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 July, 2017.

Over the past few months Committee members revised this white paper. The current draft of the white paper has been sent to some stakeholders for pre public comment feedback.

Next steps:

The Committee will consider any pre public comment feedback received regarding the white paper. A final draft will be posted for Committee members to review in advance of the next meeting (June 15, 2017). During the next meeting, Committee members will need to consider and potentially approve the paper for public comment.

Guidance Regarding Organ Donation by Competent Terminally Ill Donors

Summary of Discussion

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

The Committee considered and responded to feedback that had already been received from the leadership of the Living Donor Committee. The Committee chair comment that the term Imminent Death Donation (IDD) is being used differently by different groups. The white paper has been updated to include new expanded content comparing and contrasting IDD versus organ donation by competent terminally ill donors.

The Committee also supported changes to include using the phrase risks to living donors rather than harming living donors, and changes to the content addressing the doctrine of double effect.

Next Steps

The Committee liaison has meetings scheduled with the Operations and Safety and Minority Affairs Committees to receive feedback on this paper over the next two weeks. A final draft will be posted for Committee members to review in advance of the next meeting (June 15, 2017). During the next meeting, Committee members will need to consider and potentially approve the paper for public comment.

Honoring First Person Consent and Extending First Person Consent to Include DCD

Summary of Discussion

The lead author for this white paper provided an update on the status of this white paper and commented based on feedback from reviewers that there is now a cohesive version for the work group to consider when it meets by web conference next week.

The vice Chair reported that the Policy Oversight Committee (POC) considered the status of this project earlier in the week. Members of POC suggested using the word authorization rather than consent in the title of the white paper.

Next Steps

The Committee liaison will obtain the transcript of the POC meeting in order to provide other comments provided during that meeting. The workgroup developing this white paper will meet again on May 25th.

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.

The Committee vice Chair shared some feedback from the POC regarding this project including:

POC members expressed concerns that the paper will have no impact on policy or practice. Physicians will always be able to do this practice, so why even have a policy on this? It is unclear how this policy will help anyone. What kind of metrics can we use to determine whether this paper is helpful? What will this paper do to help address this problem? The paper sounds like it is conveying the idea that physicians would not be able to make treatment decisions for the best interests of their patient and that the paper is restricting the care that can be given.

This white paper could help raise awareness about gaming, other POC members expressed the belief that by UNOS not making any statement, UNOS will be silently condoning this practice, and that transplant providers may not even be aware of how their actions may raise ethical issues.

Definitely need to change the title. But avoid using 'gaming' in the title because that could have adverse effects in the transplant community and public. Perhaps something positive e.g., standardizing the application of allocation criteria across transplant hospitals.

Next Steps

The Committee liaison will obtain the transcript of the POC meeting in order to provide other comments provided during that meeting. The workgroup developing this white paper will meet again this afternoon and the meeting will include representative from the Thoracic Committee.

2. Kidney Paired Donation Conundrum

The founder and members of Living Donors Online want the Ethics Committee to support or require informing all potential donors about Kidney Paired Donation (KPD) as way to increase the number of transplants through an email campaign. The Committee liaison reported that the Living Donor Committee previously proposed a project to encourage transplant hospital to provide information at KPD to all potential living donors but the project was not supported by the POC. Members questioned why the project was not supported? The Committee liaison will investigate and have information to share with the Committee during its next meeting. A member surmised that this type of disclosure would not be supported by transplant hospitals that do not offer the option of KPD. The Committee chair stated he would support informing potential donors about KPD as a best practice but would not support requiring it as a new element of informed consent policy.

A member suggested that this type of disclosure should be a best practice for living donor programs. Paired donation is an important part of maximizing the number of transplants so it should be disclosed to potential donors. Otherwise transplant hospitals may be promoting their self-interest rather than what is best for the transplant candidate.

Next Steps

The Committee will discuss this topic again during its next meeting.

Members were encouraged to plan to participate on the next meeting when the Committee will consider if its white papers should be sent for public comment.

The meeting was adjourned.

Upcoming Meetings

- June 15, 2017