

**OPTN Ethics Committee
Meeting Minutes
September 19, 2019
Conference Call**

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Introduction

The Ethics Committee (the Committee) met via Citrix GoToTraining teleconference on 9/19/2019 to discuss the following agenda items:

1. Social Media Project Update
2. Public Comment Proposal: Kidney Allocation Proposal
3. Public Comment Proposal: Expedited Liver Proposal

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

1. Social Media Project Update

The Committee heard an update on the Living Donor Committee's project regarding social media use by candidates to solicit donations or potentially find living donors.

Data summary:

Two members of the Ethics Committee are helping the Living Donor Committee with this project by providing the ethical perspective. The Living Donor Committee issued a survey to different transplant programs on social medial presence and solicitations for donations. It hopes to use this survey to inform a guidance document that will go out for public comment in the Spring 2020. The survey went out to all living donor programs regardless of urbanicity or volume level. Data from the survey will help inform a practical tool kit that Ethics Committee members are helping to create.

The guidance document or white paper that the Living Donor Committee will sponsor includes discussion of the potential challenges in disparity in access to tools on the internet. Specifically, people with visual or hearing disabilities may have challenges in using or participating in certain social media, as could those lacking in computer skills. The group is also looking into the fact that social media is information sharing that isn't confidential or regulated, and this could push the burden of correcting misinformation to the transplant program. The paper will also look into the potential public pressure a living donor could face if the associated candidate put out a broad call for donations through a social medial site.

Summary of discussion:

A member asked about the disparity in access to transplant part of the project and whether the ultimate recommendations of the Living Donor Committee would include support for programs providing tool kits for candidates and donors to use to maximize their potential social networks. The presenter noted that sections of the paper are still being assigned, but it is a focus of the paper to discuss literacy with computers, social media, and soliciting for support through social media. The group is waiting for the results of the survey to come back because the survey will help identify what current practices are regarding the education of candidates on appropriate social media use, and what transplant programs

identify as important to receive guidance on. Once the survey is reviewed, the group will create a toolkit based on that feedback.

A Committee member asked whether the workgroup considered the equitable implications of social media usage providing support to “appealing” cases and exacerbating concerns about fairness and perpetration of disparities. The member noted that procedures and policies can promote or discourage this type of behavior. While the survey will be useful to ascertain current practice, certain normative questions exist that are not necessarily dependent on the survey results, and should be considered.

Next steps:

The Committee members on the workgroup will continue to keep the Committee informed.

2. Public Comment Proposal: Kidney Allocation Proposal

The Committee reviewed a Kidney Committee proposal to remove DSA and region from kidney allocation.

Summary of Discussion

The Committee suggested that the Kidney Committee better illustrate the current prioritization of prior living donor and pediatric groups to show how those groups will receive more priority in the proposed allocation changes. Committee members had several questions about medical urgency and what the changes would mean for transplant programs and patients. Specifically, the Committee asked where medically urgent candidates would be prioritized in kidney allocation. Staff incorrectly stated that medically urgent candidates are prioritized above all allocation classifications, but clarified to the committee subsequently that medically urgent candidates would be prioritized above 99% sensitized candidates but below 100% sensitized candidates.

Staff clarified that the Kidney Committee is looking for feedback on medical urgency criteria in particular. Committee members questioned what would happen if members of a review panel for medical urgency disagreed on whether a particular candidate met the criteria. Staff explained the Kidney Committee is still deciding what criteria is included, and the process for establishing medical urgency. Review of medically urgent candidates could be prospective or retrospective. A Committee member noted that retrospective review would benefit the patient (who wouldn't have to wait to receive a medically urgent status). However, the Committee member questioned what repercussions there would be for a transplant program that transplanted a candidate under medically urgent status who was determined under subsequent retrospective review to be non-medically urgent. Staff thanked the Committee member and emphasized that this feedback is exactly what the Kidney Committee is looking for in reviewing its options post public comment.

Overall the Committee supported the Kidney Committee's proposal, with 27% strongly support, 53% support, and 20% neutral/abstain. No Committee members indicated opposition.

Next Steps

The Committee's feedback will be summarized and posted on the OPTN public comment site.

3. Public Comment Proposal: Expedited Liver Proposal

The Committee reviewed an OPO Committee proposal to provide expedited liver offers.

Summary of Discussion

A Committee member asked about the information related to the biopsy that would be available for expedited offers, and how far the offers would go. The presenter clarified that expedited offers would

not occur in cases where the decline reason relates to the candidate. Instead, expedited offers would center on center decline because of biopsy results and those biopsy results would be made available. OPOs would have 30 minutes to call their more aggressive programs, but at the end of the 30 minutes, the OPO must offer to the program with the highest acceptance rate. Another Committee member asked whether the Committee will collect data overall on center rate of acceptance and decline. The presenter clarified that the data will be collected at 6 and 12 month intervals. Committee members expressed approval of collecting the data, and encouraged the OPO Committee to review those programs that may receive expedited placement offers but not accept the offers, which would not be efficient. Overall the Committee supported the proposal: 29% strongly support, 50% support, 21% neutral/abstain. No Committee members indicated opposition to the proposal.

Upcoming Meeting

- October 15, 2019 (Chicago, IL)