

Meeting Summary

OPTN Living Donor Committee
Meeting Minutes
November 13, 2019
Conference Call

Randy Schaffer, Chair, MD Heather Hunt, Vice Chair, JD

Introduction

The OPTN Living Donor Committee (the Committee) met by teleconference on November 13, 2019 to discuss the following agenda items:

- 1. Social Media Draft Review
- 2. Donate Life America Registry Update

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

1. Social Media Draft Review

A Committee member presented progress on the Social Media (SoMe) guidance document draft.

Summary of discussion:

This member has edited the document to be more concise as the Committee suggested during their inperson meeting. A section describing the survey tool will be added.

A member asked how the Committee plans to organize and present the survey results. Another member responded that if the Committee presents the full survey results on the OPTN website, the material is no longer considered novel and likely cannot be published into journals. This member added that the inclusion of the full survey to the OPTN guidance document may make it long and less readable. Members would like to strategize on how to describe the survey results in the SoMe guidance document and publish the survey outside of the OPTN website for viewing by a wider audience. A member reported that the goal of this OPTN project is to provide general guidance and that this can be accomplished through narrative as opposed to utilizing charts from the survey.

A stakeholder reminded the Committee that they do need to add some survey data to the guidance document in order to support the narrative. A member reported that ideally, the OPTN guidance document and separate survey publication would happen simultaneously. This member reported that the OPTN SoMe guidance document is the Committee's first priority and simultaneous publication would alter the project's established timeline.

A member asked for guidance on the ethical challenges section. The committee decided to report on current ethical concerns and reference principles established by the Ethics Committee's work in order to elaborate on potential solutions.

Next steps:

The committee called for volunteers to edit sections of the document down to narrative and themes in order to determine if this format delivers the same impact as a section containing survey data details. A

combination of existing literature, experiences, and qualitative results will be utilized for the guidance document's narrative.

2. Donate Life America Registry Update

Summary of discussion:

A member informed the Committee that Donate Life America will give a presentation on the development of the living donor registry during a future meeting.

Upcoming Meetings

- December 11, 2019 (teleconference)
- January 8, 2019 (teleconference)