

**OPTN Living Donor Committee
Social Media Patient Guidance Workgroup
Meeting Minutes
September 25, 2019
Conference Call**

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

Introduction

The OPTN Living Donor Committee (LDC) Social Media (SoMe) Patient Guidance Workgroup met via Citrix GoToMeeting teleconference on 09/25/2019 to discuss the following agenda items:

1. Review goal and timeline
2. Focus group feedback on survey
3. Preliminary survey results
4. Identify themes and next steps

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

1. Review goal and timeline

The Workgroup revisited their goal and timeline for the SoMe project. UNOS staff summarized the outreach methods used to distribute the survey.

Summary of discussion:

No discussion.

Next steps:

The survey will close on September 27 and the Workgroup will enter the development stage of this project in October.

2. Focus group feedback on survey

The Workgroup shared their own experiences with completing the survey.

Summary of discussion:

A member reported that the amount of time the survey took to complete was not burdensome. Members agreed that the survey's level of difficulty (ability to retrieve answers) would be dependent upon the role of the staff member completing it. Most members on the call distributed the survey to their program staff member who would be most qualified to complete it.

Next steps:

Workgroup members will follow-up with their staff members about the status of the surveys.

3. Preliminary survey results

UNOS Research presented preliminary survey results.

Summary of discussion:

A member asked for more detail on how cost would be a challenge for patients regarding their use of social media.

Next steps:

UNOS staff will develop a more detailed report that will show qualitative data in preparation for the October 2 full committee meeting. Staff will also reach out to those programs who indicated they would be willing to share their hospital's resources.

4. Identify themes and next steps

The workgroup discussed emerging themes and potential responses.

Summary of discussion:

No discussion.

Next steps:

The full report will be shared with LDC during the October 2, 2019 full committee meeting. Future scheduled Focus Group calls will be full Workgroup calls.

Upcoming Meeting(s)

- October 2, 2019 (Full- committee)
- October 16, 2019 (Social Media Workgroup)