

**OPTN Living Donor Committee
Social Media Workgroup
Meeting Minutes
October 16, 2019
Conference Call**

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

Introduction

The OPTN Living Donor Committee (LDC) Social Media (SoMe) Workgroup met via Citrix GoToMeeting teleconference on 10/16/2019 to discuss the following agenda items:

1. Whitepaper Update
2. Social Media (SoMe) Survey Report- Discussion
3. Identify Themes for Guidance

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

1. Whitepaper Update

The committee discussed their plan for the whitepaper writing process.

Summary of discussion:

A draft of the whitepaper was sent out to the Workgroup. More volunteers with specific expertise are needed to write sections of the paper.

Next steps:

These additions to the paper are needed by the end of this week or early next week.

2. Social Media (SoMe) Survey Report- Discussion

The committee reviewed the SoMe survey results and asked follow up questions.

Summary of discussion:

Members had a conversation about publication of the survey. They voiced the desire to publish their findings and plan to find out more about how they can carry this out.

UNOS staff followed up on a survey result question on the count of social media referrals versus the number of referrals approved for donation. Staff explained that outliers in this graph were free response and that some had entered question marks behind their answers. Some of these survey responses could have been quoted from tracking systems, while others may just be a guess. UNOS staff added that many centers did not submit responses for this question or only answered the number of referrals they received. Members noticed that there was a wide range of center effectiveness and non-effectiveness within the responses to this question. They wondered what practices the highly effective centers were using and what issues the less effective centers were facing.

Next steps:

The Workgroup had no further questions on survey data results at this time.

3. Identify Themes for Guidance

The Workgroup began to construct an outline for the SoMe Guidance Document.

Summary of discussion:

UNOS staff reviewed the format of the guidance document. A member suggested focusing on the topic of access to social media. This member asked what programs could do to understand and assist patients who face this challenge. They suggested that programs should create actionable plans to optimize patients' ability to access and use social media. A member suggested having an automated system that could create a social media page for those seeking a living donor. This system would make it easy for transplant candidates to tell their story without having to spend hours online. This could be especially helpful for those who have limited access to technology or knowledge of social media.

Another member suggested alternatives to connection through technology, especially for those living in rural parts of the country. This member highlighted the importance of face to face connections through gatherings where communities can connect and learn about one another's needs. Members asked how programs can optimize patients' connections to their networks in order to be access transplantation through living donation.

Next steps:

Members volunteered to write sections of the paper. The final product is due on 12/13/19. Progress on the paper will be reviewed on 10/28/19 with a more complete draft ready for internal review by 11/13/19.

Upcoming Meetings

- October 28, 2019 (In- Person)
- November 13, 2019 (Teleconference)