

**OPTN Living Donor Committee  
Social Media Administrative Challenges Workgroup  
Meeting Minutes  
September 18, 2019  
Conference Call**

**Randy Schaffer, MD, Chair  
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## **Introduction**

The OPTN Living Donor Committee (LDC) Social Media (SoMe) Administrative Challenges Workgroup met via Citrix GoToMeeting teleconference on 09/18/2019 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, 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 if there is way to require programs to enter their program name and region on the survey after viewing results that showed that quite a few of the responding programs had not entered this field. UNOS staff responded that this survey question had been made optional.

Another member referenced a preliminary result that reported almost 1/3 of patients did not voice challenges they have faced regarding their use of social media campaigns. This member questioned as to why patients were not sharing challenges and if transplant programs are asking about them.

Next steps:

UNOS staff will run and develop a more detailed report that will show qualitative data in preparation for the October 2 full committee meeting.

**4. Identify themes and next steps**

The workgroup discussed emerging themes and potential responses.

Summary of discussion:

Members discussed the possibility of two staff members from the same program with different roles answering the survey. They were interested in examining the differences in responses should this occur. Members also wanted to look at larger volume programs and compare their reported transplant rates to years past.

Next steps:

The full report will be shared with LDC during the October 2, 2019 full committee meeting.

**Upcoming Meeting(s)**

- October 2, 2019 (Full- committee)
- October 16, 2019 (Administrative Challenges Workgroup)