

**OPTN Living Donor Committee  
Social Media Project Workgroup  
Meeting Minutes  
June 20, 2019  
Conference Call**

**Introduction**

The OPTN Living Donor Committee (LDC) Social Media (SoMe) Administrative Challenges and Patient Guidance Workgroups met via Citrix GoToTraining teleconference on 06/20/2019 to discuss the following agenda items:

1. Brief Review of SoMe Focus Group goals, structure, and timeline
2. Overview of steps taken toward public comment
3. Outreach/Survey Questions Discussion
4. Project Brainstorming

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

**1. Brief Review of SoMe Focus Group goals, structure, and timeline**

United Network for Organ Sharing (UNOS) staff reviewed the SoMe project goals and timeline with workgroup members.

Summary of discussion:

UNOS staff reiterated the roles of each focus group. They explained the function of a guidance document. It does not enforce or implement policy, but is used as support and offer recommendations for best practices.

Next steps:

A draft paper will be required by mid-November in order to meet the final deadline on December 13, 2019.

**2. Overview of steps taken toward Public Comment**

UNOS staff reviewed the public comment process.

Summary of discussion:

The proposal goes out for public comment and regional meetings are held January through March 2020. At this point, a public comment analysis is conducted to develop a briefing paper to go to the OPTN Board of Directors. The Board of Directors (BOD) meeting will be held in June 2020.

Next steps:

SoMe project workgroups will continue to meet and gather evidence until September 2019. They will begin proposal development in October to meet the December 13 deadline.

**3. Outreach/Survey Questions Discussion**

The Workgroup discussed evidence gathering.

Summary of discussion:

The Workgroup will develop outreach questions on patient guidance and administrative challenges. These key questions will seek to understand hospitals' best practices when working with potential living

donors and the policies they use. Members can also use literature and feedback from association stakeholders as alternative sources to create questions.

Next steps:

Workgroup members and UNOS staff will formulate potential survey questions.

#### **4. Project Brainstorming**

The workgroup discussed topics for survey questions.

Summary of discussion:

Emerging themes included:

- Gathering existing data on the effectiveness of SoMe in bringing potential donors forward.
- If hospitals are seeing repeat living donors.
- Hospitals use of online living donor health history screening tools.
- Hospitals use and acceptance of websites that assist candidates in finding donors for a fee such as matchingdonor.com.
- If/how hospitals are actively educating patients on effective and safe use of social media to seek donors.
- Asking hospitals what materials they need in order to fill any gaps they experience that relate to SoMe and living donors.
- Gathering narrative on common troubling situations faced by hospitals and providing guidance on how to avoid or combat them.
  - The Workgroup reviewed a variety of crises they have personally faced at their experience.

Next steps:

Workgroup members and UNOS staff will draft survey questions by the next Workgroup calls

#### **Upcoming Meetings**

- July 17, 2019 – SoMe WG Call: Administrative Challenges Focus Group
- July 24, 2019 – SoMe WG Call: Patient Guidance Focus Group