Introduction

The OPTN Living Donor Committee (LDC) Social Media (SoMe) Patient Guidance Workgroup met via Citrix GoToMeeting teleconference on 07/24/2019 to discuss the following agenda items:

1. Review and Refine Questions
2. Open Forum

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

1. Review and Refine Questions

The Workgroup narrowed the possible questions for the patient guidance portion of the Social Media Project survey.

Summary of discussion:

Workgroup members discussed and drafted potential survey questions specific to identify effective practices for transplant hospitals to advise patients about the safe and effective use of social media. Survey question topics included:

- Potential expectations set by the transplant hospital for patients regarding social media campaigns
- The transplant hospital’s internal guidelines for patients
- Challenges patients have identified regarding the use of social media campaigns
- Patient education

Next steps:

UNOS staff will work to organize and streamline questions. The Patient Guidance Workgroup’s survey questions will be combined with the Administrative Challenges Workgroup’s questions to be reviewed as a whole. Once finalized, the survey will be sent to the UNOS internal survey review team for review before distribution.

2. Open Forum

Workgroup members shared their recent experiences with living donors and social media.

Next Steps:

The Workgroup will continue to discuss their experiences with social media and living donors to provide insight for the project.
Upcoming Meeting

- August 28, 2019