

OPTN Living Donor Committee Social Media Project Administrative Challenges Workgroup Meeting Minutes August 21, 2019 Conference Call

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

Introduction

The OPTN Living Donor Committee (LDC) Social Media (SoMe) Administrative Challenges Workgroup met via Citrix GoToMeeting teleconference on 08/21/2019 to discuss the following agenda items:

- 1. Review and Refine Survey Introduction
- 2. Survey Distribution Planning
- 3. Drafting Administrative Challenges Section Outline

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

1. Review and Refine Survey Introduction

The Workgroup gave their thoughts on an introduction to the SoMe Survey written by UNOS Staff.

Summary of discussion:

The Workgroup's suggestions included:

- A concise introduction that uses bullet points instead of paragraph format.
- Rephrasing of a section to make it known that this survey is optional.
- Refinement of wording.

Next steps:

UNOS staff will refine the introduction and send to Workgroup leadership for approval. Staff will then pass it on to communications for final approval and follow up about making the survey accessible on the UNOS website.

2. Survey Distribution Planning

The Workgroup discussed methods of survey distribution.

Summary of discussion:

Goals for Feedback:

• Members favored distributing the survey to as many programs as they could.

Key Programs for Outreach:

• UNOS staff suggested using survey staff data that showed numbers of living donor workups for each program to help select where the survey should be sent. Members liked the idea of distributing the survey to higher volume centers.

- The Workgroup suggested presenting the project and survey at regional meetings, to the Transplant Coordinators Committee (TCC), and the Transplant Administrators Committee (TAC).
 - UNOS Staff reported that it might be difficult to present the survey at regional meetings, as these have already begun. It was noted that TCC and TAC do have upcoming meetings.

Committee Member Participation

- UNOS Staff suggested that workgroup members distribute surveys to their own programs and others within their networks. Members of the workgroup thought this was a good idea.
 - Another member suggested a more formal distribution plan so the survey would get into the hand of the program staff member who could answer most accurately.
 - UNOS staff reported that this could be done through our membership records.
- A Workgroup member suggested using list serves to locate the correct coordinators and administrators to fill out the survey.

Next steps:

The survey will be ready for distribution in early September. Key living donor staff that work at various programs will be identified and asked to complete the survey. UNOS staff will contact the TCC and the TAC to ask these committee members for participation.

3. Drafting Administrative Challenges Section Outline

The Workgroup discussed some expected themes for the Administrative Challenges section of the guidance document.

Summary of discussion:

Expected Themes:

- Purposes, challenges, and best practices.
- Massive influxes of potential living donors in a short period of time.
- Education of donors.
- Staff burden- time and financially.
- Responding to the media.
- Ethical issues and grey area.

Next steps:

The Workgroup will continue this discussion and begin to draft an outline.

Upcoming Meeting

• September 18, 2019