

**OPTN Living Donor Committee
Meeting Minutes
May 8, 2019
Conference Call**

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

Introduction

The Committee met via Citrix GoToTraining teleconference on 05/08/2019 to discuss the following agenda items:

1. Living Donor Data Report Follow-Up
2. New Centers for Medicare and Medicaid Services (CMS) “Transplant Program Survey Activity Transition” Regulations
3. Social Media Project

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

1. Living Donor Data Report Follow-Up

United Network for Organ Sharing (UNOS) staff presented a follow up to the preliminary draft data report that was presented to the Committee on April 1, 2019. The follow up was based on a request from the Committee to further analyze some key aspects of living donor short-term outcomes reported to the Organ Procurement and Transplantation Network (OPTN) via living donor registrations and the Living Donor Follow-up (LDF) form.

The Vice Chair suggested continuing to discuss this draft data report as an ongoing agenda item for further discussion, analysis and consideration of the appropriate content and form for further distribution.

2. New Centers for Medicare and Medicaid Services (CMS) “Transplant Program Survey Activity Transition” Regulations

UNOS staff informed the Committee of the recently updated and released “Transplant Program Survey Activity Transition” CMS guidelines. UNOS staff, committee leadership and the living donor community have identified some of the new regulations are not aligned with OPTN policy or common practice.

The Living Donor and Transplant Administrator Committee leadership are drafting a response letter on behalf of the OPTN to be sent to CMS regarding the issue. The response letter will focus on the following areas of the new guidelines:

- Independent Living Donor Advocate (ILDA) interview timing (prior to initiation of evaluation)
- Change of ILDA role as it relates to education
- Conflict of interest for ILDAs
- Associated hospital

The Committee expressed great concern over the new regulations and the feasibility of implementing them in every day practice. One committee member asked if the OPTN has had any conversations with CMS regarding these new guidelines. UNOS staff did not know of any communication between the two organizations regarding this issue.

Once the response letter is drafted it will be sent to the OPTN Executive Committee for approval.

3. Social Media Project

UNOS staff gave the Committee an update on the project and summarized the Committee members who have volunteered to work on three key areas:

Short white paper: challenges and opportunities that patients' use of social media to find potential living donors presents for transplant hospitals

- Transplant hospital effective practices: advising patients about the safe and effective use of social media
- Transplant hospital effective practices: efficiently managing the administrative challenges that arise when patients' social media campaigns generate a substantial number of potential living donors

The Committee further discussed these areas of interest, goals, and timelines for the project moving forward. The Committee also discussed creating a project specific workgroup and the need for focused meetings outside of the regular committee meetings.

UNOS staff also informed the Committee the Ethics Committee and Transplant Coordinators Committee have both expressed interest in getting involved in this project.

Next Steps

UNOS staff will continue refining the list of volunteers for these areas of interest and a project timeline to be reviewed on the next committee meeting.

The white paper group of volunteers will also develop an initial draft of the document to review at the next committee meeting. The teams working on effective practices for transplant hospitals will develop a high level preliminary plan for discussion about outreach to hospital transplant programs to solicit best practices. UNOS staff will also get clarification on what feedback mechanisms will need Office of Management and Budget approval going forward.

Representatives from the Ethics Committee and Transplant Coordinators Committee will be invited to the next Committee meeting.

Upcoming Meetings

- June 12, 2019
- July 10, 2019
- August 14, 2019

Attendance

- **Committee Members**
 - Jennifer Brieman
 - Nahel Elias
 - Jane Forbes
 - Steven Hays
 - Macey Henderson
 - Heather Hunt
 - Krista Lentine
 - Carolyn Light
 - Jayme Locke
 - Laurie McDonald
 - Rita McGill
 - Randy Schaffer
 - Pooja Singh
 - Jessica Spiers
 - Heather Wertin
 - Vaughn Whittaker
- **HRSA Representatives**
 - Marilyn Levi
 - Raelene Skerda
- **SRTR Staff**
 - Katie Audette
 - Bert Kasiske
- **OPTN/UNOS Staff**
 - Nicole Benjamin
 - Scott Castro
 - Lindsay Larkin
 - Leah Slife
 - Elizabeth Suskind