

**OPTN Living Donor Committee  
Meeting Minutes  
June 12, 2019  
Conference Call**

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

**Introduction**

The Living Donor Committee (LDC) met via Citrix GoToTraining teleconference on 06/12/2019 to discuss the following agenda items:

1. Center for Medicare and Medicaid Services (CMS) “Transplant Program Survey Activity Transition” Response Letter Update
2. Social Media (SoMe) Project

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

**1. Center for Medicare and Medicaid Services (CMS) “Transplant Program Survey Activity Transition” Response Letter Update**

United Network for Organ Sharing (UNOS) staff gave an update on the letter in response to the new CMS “Transplant Program Survey Activity Transition” regulations. They reported that there are some concerns on misaligned and incremental CMS requirements when compared to the Organ Procurement and Transplantation Network (OPTN) requirements.

Summary of discussion:

Additional concerns to others already expressed have to do with specific compliance requirements when transplant programs perform living donor services with other hospitals. A modification has been requested in order to identify services that do not require this specific compliance, such as kidney paired donation (KPD) exchanges.

The next portion of the response focused on time requirements for an interview with an Independent Living Donor Advocate (ILDA). If the current requirement stays in place, there are concerns that potential living donors will not be screened early enough in the assessment process and that they will have limited access to living donor resources. There is also concern surrounding the CMS regulation that the ILDA must not be associated with the transplant program in any capacity, even on a temporary basis. This can cause staffing and resource issues. It was noted that efficient living donor screening is important potential living donors and that allowing hospitals some judgment within the parameters of the OPTN requirements can ensure screening is done in a way that protects against practices that delay or frustrate potential donors.

Next steps:

The response letter is being finalized. Once approved by the Executive Committee, it will be submitted on behalf of the OPTN and shared with Committee members. The next Executive Committee meeting is on August 1, 2019.

**2. Social Media Project**

A committee leader explained the structure of the Social Media (SoMe) project. Three focus groups have been created. One group will focus on developing a white paper introduction that will serve as the

basis of knowledge for this project. The other two groups will write sections centered on patient guidance and administrative challenges. All three of the group's products will come together to draft an OPTN guidance document for Spring 2020 public comment. Members who would like to participate in the project have indicated which focus group they would like to join. Engaged stakeholders from the Transplant Coordinator and Ethics Committees were invited to collaborate with the Committee on this project. Members were asked to review selected studies and look for any others that would inform the SoMe project. It was noted that a work product that will be most useful to transplant hospitals with diverse patient populations will depend on diverse input from all committee members.

#### Summary of discussion:

A committee member spoke on the evidence gathering process for the SoMe project. He asked when community outreach becomes formal enough to be considered a survey and need approval from the Office of Management and Budget. He reported needing more information on this from the OPTN. UNOS staff will work to gather this information and report back to the Committee.

The member leading the white paper development group walked the Committee through a draft paper outline. Discussed themes are as follows:

- Disparity in patient access.
- Patient privacy implications.
- Consequences of unregulated social media content.
- Early public expressions of interest made by potential living donors.
- Potential competition for living donors.
- Action taken when a candidate has multiple living donor applicants.
- Psychological distress.
- Increased risk of directed donation to candidates with certain characteristics.
- Transplant hospital administrative burden.
- Opportunities.

#### Next steps:

The SoMe Project Workgroup will hold a kickoff call on June 20, 2019 to discuss details of the project. They will begin to develop key questions to ask transplant hospitals regarding challenges they face and best practices used when working with potential living donors that come forward as a result of social media.

#### **Upcoming Meeting**

- July 10, 2019 - Full OPTN Living Donor Committee Call (Teleconference)