

**OPTN/UNOS Living Donor Committee
Meeting Minutes
January 9, 2019
Conference Call**

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

Introduction

The Living Donor Committee met via Citrix GoTo teleconference on 1/9/2019 to discuss the following agenda items:

1. Committee and Workgroup Updates
2. Guidance on the Use of Social Media by Transplant Candidates, Potential Donors and Transplant Hospitals
3. Kidney-Paired Donation (KPD) Policy Question
4. Living Donor Committee Project Update and Next Steps

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

UNOS staff announced the UNOS Research support staff would be transitioning to a new member of the UNOS Research staff. Committee members requested a data report on Living Donor follow-up to date. UNOS Research staff will compile the report within the next couple of months.

1. Committee and Workgroup Updates

The Chair opened the meeting for any committee or workgroup updates. A representative of the Patient Affairs Committee gave a brief update on the Patient Affairs Constituent Council (PACC) and Transplant Coordinators Constituent Council (TCCC) Proof of Concept pilot. The Executive Committee reviewed and discussed the proof of concept pilot. Going forward, only PACC will continue testing the structure under staff guidance and not TCCC. PACC will be looking at areas of increased engagement and increased understanding of complex proposals. The PACC is reassessing who will be continuing participation and will be breaking into workgroups.

2. Guidance on the Use of Social Media by Transplant Candidates, Potential Donors and Transplant Hospitals

Committee members reviewed and continued to revise the existing project form for the Living Donor Social Media Guidance project.

Summary of discussion:

Committee members identified the strategic goals the project would align with. UNOS staff explained the purpose of identifying a singular goal is to determine resource allocation and to also identify strategic alignment for the Board of Directors. The Committee discussed all of the strategic goals and ultimately supported aligning the project with *Strategic Goal 2: Increase the number of transplants*.

For potential controversies, some Committee members thought the guidance could potentially be interpreted as coercion. Specifically, guiding hospitals on how to counsel patients on the most appropriate way to use social media and identifying potential pitfalls.

Next steps:

Committee members were asked to send any additional related studies that could be added to the document. The Committee will also reach out to transplant hospitals that experience a lot of these types of cases to solicit their best practices.

UNOS staff will reach out to the liaisons for the Ethics and Transplant Coordinators Committees to gauge their interest in being involved in the project.

The Committee will review the project form and submit feedback on changes or suggestions. Once the form is completed, it will go to the Policy Oversight Committee for review.

3. Kidney-Paired Donation (KPD) Policy Question

A Committee member asked for clarification regarding OPTN Policy 14.6.B: Placement of Non-directed Living Donor Organs.

14.6.B Placement of Non-directed Living Donor Organs

Prior to determining the placement of a non-directed living donor organ, including non-directed organs from domino donors and non-domino therapeutic organ donors, the recovery hospital must obtain the match run of its waiting list candidates from its local OPO or the Organ Center. When a non-directed living donor organ is placed, the recovery hospital must document how the organ is placed and the rationale for placement.

This requirement does not apply to non-directed living kidney donors who donate a kidney through a Kidney Paired Donation (KPD) arrangement.

Summary of discussion:

The Committee member asked in the case of a KPD chain, does the last donor in the chain have to donate to the list. The specific policy language in question was "This requirement does not apply to non-directed living kidney donors who donate a kidney through a Kidney Paired Donation (KPD) arrangement". The Committee agrees this could be a potential gap in policy language and should be clarified.

Next steps:

The issue will be brought to the Kidney Transplantation Committee and KPD Workgroup to get their feedback and determine if language should be clarified.

4. Living Donor Committee Project Update and Next Steps

UNOS staff updated the Committee on the status of current projects.

Summary of Discussion

The *Clarifications on Reporting Maintenance Dialysis* proposal will be voted on by the Policy Oversight Committee on January 15, 2019 and then the Executive Committee on January 16, 2019.

Upcoming Meetings

- March 13, 2019, Teleconference
- April 1, 2019, In-person
- May 8, 2019, Teleconference
- June 12, 2019