

**OPTN/UNOS Living Donor Committee
Meeting Minutes
December 12, 2018
Conference Call**

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

Introduction

The Living Donor Committee met via Citrix GoTo teleconference on 12/12/2018 to discuss the following agenda items:

1. Staffing Update
2. Kidney Paired Donation (KPD) Workgroup Update
3. Clarifications on Reporting Maintenance Dialysis
4. Living Donor Committee Project Update and Next Steps

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

1. Staffing Update

The Chair announced effective December 2018, the committee support will transition from a single point-person to a team of UNOS staff including a Transplant Community Administrator, a Policy Analyst and a Policy Associate.

2. Kidney Paired Donation (KPD) Workgroup Update

A representative of the KPD Workgroup gave a brief review of the KPD projects currently on hold.

Summary of discussion:

In February of 2018 the KPD Workgroup reviewed the KPD Deceased Donor Chains (DDC) project and agreed to continue forward to modeling, optimization, and simulation. In March of 2018, the KPD Workgroup met to begin discussion for goals, metrics and constraints of the DDC models. This project is currently on hold while the Kidney-Pancreas (KP) Workgroup works on their geography allocation project.

From February to March of 2018 the KPD Workgroup also reviewed the Repairing of OPTN KPD Chains project. This project is also currently on hold while the Kidney-Pancreas (KP) Workgroup works on their geography allocation project.

One Committee member asked what data is available for kidney-paired donation. The KPD Workgroup representative clarified all data is available within the UNOS system, but not if a different system was used.

Next steps:

The projects will be revisited by the KPD Workgroup once the KP Workgroup's geography project is finalized.

3. Clarifications on Reporting Maintenance Dialysis

UNOS staff monitored Committee dialogue and comments on Basecamp and created revised mock-ups of the Patient Safety Portal form.

Summary of discussion:

The Chair recommended adding example text for the “specify” option under “Kidney complications since”. Another Committee member suggested making “regularly administered dialysis” its own checkbox instead of a sub-question, as well as reducing redundancy of some questions.

Next steps:

UNOS IT staff will continue to clean up the form and reduce redundancy in the questions. The proposal will go to the Policy Oversight Committee and Executive Committee in mid-January and then the spring public comment cycle.

4. Living Donor Committee Project Update and Next Steps

The Committee discussed other project priorities.

UNOS staff updated the Committee on the status of various projects. The Living Donor Self-Assessment Tool project has been deprioritized due to other priority projects, and there may be other organizations better positioned to develop such a tool. The Living Donor Vascularized Composite Allograft (VCA) projects are in the pipeline for future work in collaboration with the VCA Committee.

Summary of discussion:

UNOS staff presented some key updates on the status of the Living Donor Social Media Guidance project as well as some draft language from the Committee.

Current Working Title:

“Preparing for the Challenges and Opportunities of Patient Use of Social Media to Find Living Donors: Transplant Hospital Best Practices”.

Problem Statement:

- Members have raised concerns about disparity in patient access to and use of Social Media in a safe and effective ways to find a living donor. Members have similarly identified administrative challenges - and opportunities - that result from Social Media campaigns that generate a significant influx of potential living donors. The problem is rooted in the following factors:
 - The U.S., unlike other countries, has not provided guidance or principles about the use of social media to identify potential living organ donors and related issues.
 - Transplant patients are not uniformly educated about the communication tool in general, about how to use it safely, effectively and legally, or about the risks and benefits of using it to find a living donor.
 - Transplant hospitals have widely disparate approaches to interacting with patients about the use of social media as a communication tool to identify potential living donors.
 - The wide variation in transplant hospital approaches to discussing the use of social media with patients could increase the disparity across patient groups in access to transplant via living donation.
 - Successful social media campaigns can result in an influx of potential living donors, which creates administrative challenges and opportunities for transplant hospitals.

Targeted/Impacted/Vulnerable Populations:

- Patients in need of a kidney or liver transplant, particularly those for whom a living donor is a medically appropriate treatment option.
- Living donor transplant programs—specifically, coordinators?
- Various patient populations, including those defined by socio-economic status, race, age and/or technological access or sophistication, are generally considered to be disadvantaged in the use of social media to find living donors.
- Transplant hospitals have disparate approaches as to whether and/or how to engage with patients about using social media to express their need for potential living donors. This ranges from proactive assistance, to provision of tools to facilitate patients' safe and effective use of social media, to virtually no discussion. The variation in transplant hospital practices may increase disparities across various patient populations identified above in their ability to express their need for a living donor using contemporary communication channels and consequent access to living donor transplantation.

Collaboration

- The Committee plans to collaborate with various OPTN committees as well as stakeholder professional societies and patient advocacy organizations.

Potential Controversy/Barriers

- Potential controversy could arise if there is a misimpression that the project creates obligations on transplant hospitals to implement specific actions.
- Potential controversy could arise around social media as a communication channel to look for living donors increasing disparities in living transplantation among patient populations, i.e., those patients who have no access to computers, internet access or public libraries that make such tools available for use at no cost. An objective of the project, however, is to identify and share transplant hospital practices that have accounted for and addressed the needs of such patient populations.
- As is the case currently, there is the potential for concern about transplant hospitals steering potential living donors who express interest in donating to a particular patient as a result of a Social Media campaign to other transplant patients. The potential for this to arise, however, exists currently with potential living donors who come forward in response to a patient's expression of need for a living donor through any communication channel (i.e., car sign, billboard, etc.). Further, potential living donors may and do, on their own initiation and without any undue influence by a transplant hospital, elect to donate to another transplant patients after exploring living donation for a patient who executed a social media campaign.
- Some transplant hospitals may be assisting with or encouraging transplant candidates to use social media while other transplant hospitals may not support the use of social media to match transplant candidates and potential donors.
- The potential for transplant hospitals to engage in “bait and switch”, (i.e., steer potential living donors who express interest in donating to a particular patient to other transplant patients).
- The potential for transplant hospitals to be disinclined due to practical or other considerations to discuss social media with patients and the consequent disadvantage (sustained disparities) that would flow to their patients relative to patients at other centers.

UNOS staff encouraged the Committee to clarify and elaborate on key points of the project form. The Committee should not only specify who but also when they plan to collaborate and seek input from OPTN committees and external stakeholders. The Committee should also identify the strategic goals the project would align with and how.

Next steps:

The Committee will finalize the project form to clarify key points. The project will proceed to the Policy Oversight Committee (POC) and Executive Committee for approval in early 2019 for potential inclusion in the fall 2019 public comment cycle.

Upcoming Meetings

- January 9, 2019, Teleconference
- March 13, 2019, Teleconference
- April 1, 2019, In-person