

**OPTN Living Donor Committee  
Meeting Minutes  
December 11, 2019  
Conference Call**

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

## **Introduction**

The OPTN Living Donor Committee (the Committee) met by teleconference on December 11, 2019 to discuss the following agenda items:

1. Donate Life America (DLA) Living Donor Registry Project
2. Social Media (SoMe) Paper Discussion
3. Cross- Committee Updates
4. Open Forum

### **1. Donate Life America (DLA) Living Donor Registry Project**

The Living Donor Committee was given an overview of DLA's new Living Donor Registry Initiative.

#### Summary of discussion:

Representatives from DLA introduced their organization and the new Living Donor Registry and Testing initiative. Their goal is to establish a registry for living donor prospects through their donor registry. According to DLA data, if 1% of all people who register to be a deceased donor showed interest and 50% actually donated, 7,500 more lives could be saved. A member asked why DLA chose 50% as their benchmark, as under 15% of potential living donors actually end up donating. Another member asked if this initiative was only focused on kidney donation. The presenter answered kidney is the focus for now due to the overwhelming need, but that DLA would look to move into living liver donation as well.

The DLA representative described the operational details of the Living Donor Registry and Testing initiative in steps:

1. Express interest through the National Donate Life Registry.
2. Complete online health screen questionnaire.
3. Collect saliva sample.
4. Return sample for lab analysis.
5. Potential donor shared with transplant program thorough United Network for Organ Sharing (UNOS) connectivity.
6. Follow- up by transplant program.

This initiative is not an official medical or psychological evaluation, considered informed consent, or matching system. These processes still fall under the role of the transplant hospital.

A member asked if the Centers for Medicare and Medicaid Services (CMS) will have to regulate this initiative. The presenter answered that CMS does not have jurisdiction over non-profits. Another member asked that if a potential living donor wanted their medical information, such as their blood

type, would DLA be able to provide this to them? The presenter responded that they would take this question back to their workgroup.

A member asked how hospitals are to handle the large influx of potential living donors this new registry could create. Other members agreed that their hospitals struggle to process the number of interested potential living donors through the current system. The DLA representative reported that an interim solution could be to get more nearby programs involved in order to decrease the amount of burden placed on one or two centers in a specific area. A member commented that this initiative can be closely tied with the Committee's Social Media Guidance Document project, as it discusses administrative burden as a challenge. This member also advised DLA to be thoughtful of how they store patient information. Another member commented that the National Kidney Registry (NKR) should be involved and that a long-term vision of this project could be to work with the UNOS Kidney Paired Donation (KPD) project.

## **2. Social Media (SoMe) Paper Discussion**

The Committee received an update on the current state of the SoMe paper.

### Summary of discussion:

The final draft of the paper is complete and will need to be approved by the executive team and HRSA. The Committee will vote on the final paper to go to Public Comment on January 8, 2020. The Committee plans to solicit specific feedback from the community on additional challenges and effective practices they've experienced due to Social Media campaigns. The Committee would also like to ask what materials or guidance programs have developed that they would be willing to share. They also want to focus on receiving feedback that separates patient guidance from effective center practices.

## **3. Cross-Committee Updates**

The Committee received an update on the project to update OPTN Policy 14 to include living VCA donors.

### Summary of discussion:

The Committee will review the purpose and goals of this project during their next meeting. The project workgroup will form with representation from the Living Donor, Ethics, and VCA Committees.

## **4. Open Forum**

The floor was opened for any remaining comments or questions.

### Summary of discussion:

A member asked for a CMS Independent Living Donor Advocate (ILDA) guidelines update. The committee will be updated on these guidelines during the next call.

## **Upcoming Meetings**

- January 8, 2020 (teleconference)
- February 12, 2020 (teleconference)