

**OPTN/UNOS Living Donor Committee**  
**Meeting Minutes**  
**January 10, 2018**  
**Conference Call**

**Krista Lentine, MD, PhD, Chair**  
**Randy Schaffer, MD, Vice Chair**

**Introduction**

The Living Donor Committee met via Citrix GoToTraining teleconference on 1/10/18 to discuss the following agenda items:

1. Kidney Donor Learning Center
2. Updates on Current Projects
3. Proposed New Committee Projects
4. Living Donor Collective

The following is a summary of the Living Donor Committee's (the Committee) discussions.

**1. Kidney Donor Learning Center**

Summary of discussion:

Several staff members from UNOS Communications joined the meeting to provide an overview of the new Kidney Donor Learning Center. Communications staff explained that the Transplant Living website has been redesigned to make it easier for mobile users to access information on the site. Historically, the website has been receiving 40,000 unique visits each month. UNOS Communications reported that they collaborated with patients, stakeholders, focus groups and the Patient Affairs Committee during the redesign of the website.

An online survey provided insights into areas or content on the website that needed improvement. Some survey respondents erroneously thought they could use the Transplant Living website to register to become a living donor or to check their position on the Waitlist.

The Transplant Living website includes a new mini site called the Kidney Donor Learning Center. This mini site includes donated living donation related educational materials under the purview of Health Literacy Missouri (HLM). This site will receive additional updates in the next few months to include the addition of transplant center map that will allow users to search for transplant programs by the type of organ transplant procedure performed.

A Committee member asked if the site could include a tool for prescreening self-assessment tool for potential donors to help them determine if they are ready or meet the general criteria required to be a living donor. UNOS Communications staff was receptive to this idea and recommended that the Committee should develop a set of screening questions that could be tested with a focus group. A funding source for adding a self-assessment tool would be required.

Next steps:

The Committee may prepare a set of screening questions that could be included on the Kidney Donor Learning Center website. This proposed project may need Policy Oversight Committee approval.

## **2. Updates on Current Projects**

Lay Person Version of the Psychosocial and Medical Evaluation Policy Requirements

### Summary of discussion:

A single lay person resource that addresses living informed consent and psychosocial and medical evaluation has been sent to UNOS Communications.

### Next steps:

UNOS Communications has been asked to coordinate the development of a Spanish version and to have the English and Spanish versions posted to the OPTN website.

## **3. Proposed New Committee Projects**

New social media resources

### Summary of discussion:

People are increasingly using social media to promote living donation, and in some cases misusing it. There are not standard, guidelines or wide-spread strategy to minimize disparities across population in its effective, safe and ethical use.

It will be important to reduce disparities among patients with different technological savvy, financial capacity, and ability to tell their story. The Committee agreed that the guiding principle for this project should be to reduce disparities to the maximum extent possible.

The proposed project would include a patient resource and a transplant professional resource. The patient resource would provide guidance for patients and their family and friends on the safe and effective use of social media, executed in a way that seeks to neutralize variation in patients' technological and financial capacities. Additionally, this resource could direct patients and their family and friends to additional resources that have been developed by transplant hospitals.

The patient resource could include:

- Instructions on building a social media page
- What information to share and not to share
- Clarity on keeping it legal (no exchange of value)
- Sample boilerplate on "how to tell your story"
- What and when to tell your transplant hospital about your social media efforts to allow it to be prepared
- Setting reasonable expectations

The professional resource could provide information to transplant professionals that enhances their ability to guide patients in the safe and effective use of social media, executed in a way that seeks to neutralize variations in patient's technological and financial capacities. The resource would share information about practices transplant centers have found to be effective in managing living donor activity generated on social media (for example increased living donor screening and evaluation volume, heightened need to evaluate motives, potentially inappropriate arrangements by and between strangers who connect on social media).

The professional resource could address:

- Topics where guidance of best practices provide the greatest value
- Managing traffic (inquiries, evaluation, etc.) generated by social media
- Answering patient questions regarding how to tell their story
- Help candidates who have never used social media

- Assessing motivation of potential donors who meet a transplant candidate online
- How to integrate social media in the transplant candidate education process
- What resources already exist, and if those resources should be endorsed or promoted
- Transplant centers role in the use of social media

Next steps:

The workgroup addressing this project will meet on January 24<sup>th</sup>.

#### **4. Living Donor Collective**

##### Summary of discussion:

A representative from the Scientific Registry of Transplant Recipients (SRTR) announced that the Office of Management and Budget (OMB) approved their proposed project to register all potential living donor candidates evaluated at transplant programs including those that become donors, are suitable but do not donate, or found not suitable to donate. Under the proposed project the SRTR will obtain follow-up information and make reports to the transplant programs and to the general public. SRTR is finalizing work on its web based data collection system, and will begin collecting data at pilot sites in the next few months.

##### **Upcoming Meeting**

- February, 2018