

**OPTN Living Donor Committee
Meeting Summary
December 8, 2021
Conference Call**

**Heather Hunt, JD, Chair
Nahel Elias, MD, Vice Chair**

Introduction

The OPTN Living Donor Committee (the Committee) met via Citrix GoTo Meeting teleconference on 12/08/2021 to discuss the following agenda items:

1. Upcoming UNet Change: Multi-factor Authentication
2. Living Donor Education Efforts
3. Discussion: Living Donor Data Collection

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

1. Upcoming UNet Change: Multi-Factor Authentication

The Committee received an update regarding the upcoming multi-factor authentication for UNet.

Summary of discussion:

There were no comments or questions.

2. Living Donor Education Efforts

The Committee received an update on the ongoing living donor education efforts.

Summary of discussion:

Current living donor education curriculum:

- Psychiatric Evaluation of the Living Donor
- Insight into Living Donor Evaluation
- Evaluation Criteria and Informed Consent for Living Liver Donors
- Evaluation Criteria and Informed Consent for Living Kidney Donors
- Infectious Disease Verification of the Living Donor
- Living Donation: Including Vascularized Composite Allograft (VCA)

An education series related to cultural competence and living donation is upcoming. The series will address defining cultural competence and the benefits to living donation, assessing cultural competence within living donor programs, and applying cultural competence practices.

The Vice Chair asked if living donor education is available in Spanish. Staff responded that the education offerings are not available in other languages, but will look into expanding.

3. Discussion: Living Donor Data Collection

The Committee continued discussing living donor data collection.

Summary of discussion:

The Chair emphasized that long-term data collection is necessary in order for potential living donors to provide informed consent. The Chair added that long-term outcomes would help potential living donors communicate with their families about their decision to donate.

A member expressed concern about requiring transplant programs to collect long-term data on living donors. The member explained that transplant programs cannot require living donors to visit for follow-up appointments. The member stated that long-term data on living donors may be skewed due to the living donors who participate in extended long-term follow-up may be individuals who place a lot of emphasis on their health. Another member agreed and added that there is difficulty having living donors follow-up at one-year post transplant. The member stated that living donors moving is an issue when trying to continue follow-up communication.

Another member stated that their transplant program focuses on setting the expectation for living donors to be committed to long-term follow-up. The member stated that clear communication with living donors prior to transplant as well as dedicated staff help ensure continued follow-up. The member stated that it may not be possible to collect all the data that is sought, even with dedicating resources to aid in collection.

A member stated that the experience of the living donor is very important. The member asked how to collect data on more subjective topics such as living donation experience. The member stated that asking a living donor whether they would choose to be a living donor again after having gone through the experience is very valuable information to inform other potential living donors.

Another member stated that a timeframe of “long-term” needs to be decided. The member stated that expanding follow-up to five-years or ten-years is a helpful first step. The member added that data on potential living donors that did not go on to donate is very important. The member stated that it will be important to figure out how to combine all the living donor data being collected by various transplant programs and organizations as to not duplicate data collection efforts.

The Vice Chair suggested integrating data from the Centers for Medicaid and Medicare Services (CMS) on renal failure patients given that those patients are registered as end stage renal disease (ESRD) patients.

The Chair stated that data should be collected that is both beneficial to medical professionals as well as living donors and their families. A member agreed and added that collecting mental health and experiential data is important. The member stated that mental health data may not need to be included in long-term follow-up as there are various other influences, however, mental health data collected during the immediate post-transplant period may be beneficial.

Another member stated that it would be beneficial to have data regarding later onset diseases that are further complicated by having a single kidney. The member added that data on the effect of COVID-19 on prior living donors may be important.

A member stated that living donor follow-up should be extended to have specifics for each type of living donation, not only living kidney and liver donors.

Upcoming Meetings

- January 12, 2021 (teleconference)
- February 9, 2021 (teleconference)

Attendance

- **Committee Members**
 - Angie Nishio Lucar
 - Camille Rockett
 - Doug Penrod
 - Heather Hunt
 - Henkie Tan
 - Katey Hellickson
 - Nahel Elias
 - Omar Garriot
 - Roberto Hernandez-Alejandro
 - Tyler Baldes
 - Vineeta Kumar
 - Yee Lee Cheah
- **SRTR Staff**
 - Bert Kasiske
 - Christian Folken
 - Krista Lentine
- **UNOS Staff**
 - Heather Carlson-Jaquez
 - Lauren Motley
 - Leah Slife
 - Lindsay Larkin
 - Meghan McDermott
 - Mike Ferguson
 - Rebecca Goff