

**OPTN Living Donor Committee  
Meeting Summary  
October 26, 2020  
Conference Call**

**Heather Hunt, JD, Chair  
Titte Srinivas, MD, Vice Chair**

## **Introduction**

The Living Donor Committee (the Committee) met via Citrix GoToMeeting teleconference on 10/26/2020 to discuss the following agenda items:

1. SRTR Follow-Up Discussion on the Living Donor Collective
2. Policy Oversight Committee Update
3. New Project Discussion

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

### **1. SRTR Follow-Up Discussion on the Living Donor Collective**

The SRTR reviewed the goals, short-term and long-term plans, and challenges for the Living Donor Collective (the Collective) previously presented on the October 7, 2020 call. SRTR representatives also suggested ways the Collective and the Living Donor Committee could collaborate to improve donor follow-up including examining the living donor follow-up form (LDF) and working to better understand program processes and promote best practices. The SRTR representatives asked the Committee their thoughts on what data to collect, how best to collect it, and how to encourage program participation in the Collective.

Several Committee members appreciated the Collective's goal to integrate with electronic medical record software to ease data burden on programs. A Committee member commented collecting ongoing data on potential living donors who do not go on to donate could be difficult to collect. The Committee also commented long-term donor follow-up is very difficult for programs.

An SRTR representative informed the Committee that conducting long-term donor follow-up would be the responsibility of the Collective rather than the programs. Also, the Collective would not be able to collect laboratory data like what's included in the LDF.

A Committee member asked if the data collected through the Collective would be shared back to the program. The SRTR representatives clarified the data collected would be aggregate data and would not be program-specific.

Some Committee members suggested allowing donors to register themselves for the Collective. The Chair also recommended creating donor focus groups representative of different levels of donor engagement.

A Committee member asked if donors would be consented to be enrolled in the Collective. SRTR representatives answered there is education available on the Collective and clarified all data shared is protected information.

## **2. Policy Oversight Committee Update**

The Vice Chair presented an update from the Policy Oversight Committee (POC). The POC has three strategic policy priorities:

- Continuous distribution
- Multi-organ allocation
- Efficient donor/recipient matching to increase utilization

The Vice Chair reviewed the number of projects underway that fall under these priorities. There are a number of other projects that do not fall under these priorities that are still important to pursue.

The Vice Chair asked the Committee how they see committee projects relating to the strategic policy priorities and for any other feedback or questions. A member asked how the Committee could contribute to Continuous Distribution work. Another member commented the Committee should make sure living donors in need of transplantation don't drop down in prioritization in kidney policy. The member further commented one of the responsibilities of the Committee is to ensure when policies are being put forward that the unintended consequences for living donors are considered.

### Next Steps

The Committee members were asked to send any additional thoughts on the strategic policy priorities to the Vice Chair.

## **3. New Project Discussion**

The Committee continued discussion on new project ideas. The Committee reviewed the policy development process and three project ideas.

### *Clarifications to Modify Living Donor Policy to Include Living VCA Donors*

The Committee was reminded of public comments received on the *Modify Living Donation Policy to Include Living VCA Donors* proposal. There were questions raised on whether living VCA donors would be added to the list of organ types to be given prior living donor priority in kidney policy. Additionally, the Disease Transmission Advisory Committee recommended adding test timing requirements for chlamydia, gonorrhea, and trichomoniasis to match what was included in the original proposal for fungal screening. Based on these comments and a Committee member recommendation, the Committee was presented with a new project idea for a clarification proposal to expand prior living donor priority to cover all living donors and add the additional testing requirements to living donor policy for living uterus donors.

A member questioned whether living uterus donors should be added to the list of organ types eligible for prior living donor priority as uteri and other VCA are non-vital organs. A member responded the gift of living donation shouldn't be stratified based on whether the organ is vital. Additionally, the member commented the current list of organ types eligible for prior living donor priority in kidney policy includes the organs covered by living donation policy at the time. The member further commented a potential surgical risk of uterus donation is urinary tract injury which could possibly lead to eventual renal failure.

Another member asked what the original intent of the prior living donor priority policy was when it was drafted. A member answered the original intent was to acknowledge the donor's gift with priority points in kidney allocation.

Some members expressed uncertainty if all types of living donors should qualify for the priority in kidney policy as there is a shortage of available kidneys. A member responded the number of prior living donors

that go on to receive kidney transplant is small and there has been limited push back on this policy before as it was not felt to alter the outcome of kidneys at the national level.

A member commented the Kidney Committee should be consulted on this subject. Other members commented prior living donor priority should also be discussed for other organ types.

The Committee will continue discussion on the next call and requested data on prior living donors who have undergone transplant for kidney and other organ types.

#### *Evaluating Exclusion Criteria*

The Committee had previously discussed a project idea to holistically review existing exclusion criteria in OPTN policy which may result in policy changes.

The Committee reviewed current exclusion criteria and available data related to exclusion criteria including:

- Current fields on the living donor-registration form (LDR) related to exclusion criteria
- Number and percent of living kidney and liver donors with history of cancer
- Cancer-free interval reported for living kidney and liver donors with history of cancer
- Diabetes status indicated on LDR for living kidney donors
- Treatment for living donors with diabetes indicated on the LDR
- Number and percent of living kidney donors with history of hypertension
- Method of control reported for living kidney donors with history of hypertension

A committee member asked if there is any international data available on living donors with diabetes. Another member answered the KDIGO guidelines make reference to international data.

A committee member asked if there is data available on deceased donor transplants with donor-derived melanoma post-transplant.

A member commented the data doesn't show who is excluded from donation due to exclusion criteria.

The Committee brainstormed on additional data that could be included in a data request:

- Data on transplants with donor-derived melanoma post-transplant
- Institutional data for hypertensive donors
- International data on outcomes of donors with diabetes

#### *Living Donation in Multi-Organ Transplant*

The Committee had also previously discussed a project idea to evaluate how living donation could play a role in multi-organ transplant.

The Committee reviewed available data from the simultaneous liver-kidney (SLK) policy monitoring report including:

- Kidney after liver (KAL) registrations from May 31, 2017 - December 31, 2019
- Number of KAL transplants since SLK implementation

A member asked if there was any data for living donation in simultaneous liver-kidney (SLK) transplant. Staff responded there have not been any donors that have donated liver and kidney at the same time.

The Committee brainstormed on additional data that could be included in a data request:

- Data on those who qualify for safety net; time to transplant and proportion of those still waiting for transplant

- Data on living donation in other organ combinations

The Committee discussed both project ideas and were asked to indicate their preference for the Committee's primary focus. 11 Committee members indicated support for the *Evaluating Exclusion Criteria* project and 5 indicated support for the *Living Donation in Multi-Organ Transplant* project.

#### Next Steps

The Committee will select a primary project focus on the next call.

#### **Upcoming Meeting**

- November 18, 2020 (teleconference)

## Attendance

- **Committee Members**
  - Nahel Elias
  - Katey Hellickson
  - Omar Garriott
  - Stevan Gonzalez
  - Carol Hay
  - Roberto Hernandez
  - Heather Hunt
  - Vineeta Kumar
  - Carolyn Light
  - Angie Nishio Lucar
  - Mark Payson
  - Randy Schaffer
  - Aneesha Shetty
  - Pooja Singh
  - Jessica Spiers
  - Mary Beth Stephens
  - Titte Srinivas
- **HRSA Representatives**
  - Marilyn Levi
  - Adriana Martinez
  - Arjun Naik
  - Raelene Skerda
- **SRTR Staff**
  - Michael Conboy
  - Chris Folken
  - Bertram Kasiske
- **UNOS Staff**
  - Sarah Booker
  - Matt Cafarella
  - Lindsay Larkin
  - Kerrie Masten
  - Matt Prentice
  - Michelle Rabold
  - Tina Rhoades
  - Susan Tlusty
- **Other Attendees**
  - Krista Lentine