

**OPTN Living Donor Committee
Meeting Summary
October 7, 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 10/07/2020 to discuss the following agenda items:

1. SRTR Presentation on Living Donor Collective

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

1. SRTR Presentation on Living Donor Collective

SRTR Representatives presented an overview of the Living Donor Collective project to the Committee.

Summary of data:

The goals of the Living Donor Collective (the Collective) project are to:

- To ascertain why candidates for living donation do not donate
- To better understand the long-term risk of volunteering to be a living donor

The project began in 2017 as a pilot project funded by HRSA and as of 2019 has collected information from 10 kidney programs and six liver programs. In 2020, HRSA outlined plans to expand the pilot project to a full registry involving participation of all U.S. living donor transplant programs.

Currently the Collective conducts follow-up surveys to donors but in the future the Collective will be expanding donor follow-up methods in order to compare donors donating vs. not donating over time.

The SRTR representatives then presented trends found in deceased and living donor kidney transplants. The data shows since approximately 2002, living kidney donation numbers have remained relatively constant with no significant upward or downward trends.

Evaluation of the OPTN Living Donor Follow-Up (LDF) data shows there are gaps in data collection on clinical and lab data, and the gap increases as donor follow-up time increases (ex. 75 percent of programs submitted clinical data and 70 percent submitted laboratory data on the 24 month follow-up).

The Collective is facing two barriers to data collection:

- Willing participation of transplant programs
- How to perform the follow-up

The SRTR detailed benefits for participation of living donor programs in the Collective, both to donor candidates and programs.

- Benefits to donor candidates:
 - Information on risks and outcomes
 - Information on resources, e.g. NLDAC

- Benefits to transplant programs:
 - Secure information comparing each program's evaluation, selection, and outcomes to those of other programs
 - Help obtaining follow-up information on donors

The SRTR also presented a suggestion for the OPTN could replace the 12 and 24-month LDF data (i.e. long-term data) requirement with participation in the Collective.

Finally, SRTR representatives concluded:

- Living donations have not kept pace with the need for transplants
- Lack of a better understanding of long-term outcomes that matter to patients and providers may be limiting living donations
- Only a comprehensive registry can provide adequate information on long-term outcomes after living donation
- The Collective pilot has successfully registered candidates and donors
- A path forward should be found to include all living donor programs in the LDC

Summary of discussion:

The Committee was asked their thoughts on what measures will encourage the participation of living donor programs in the Collective. Committee members asked if participation in the Collective would require a duplication of information submission. An SRTR representative stated the goal is to eventually have streamlined data sharing between the Collective and the OPTN. A Committee member suggested they may get more participation from programs if the Collective can remove redundancies in labor intensive follow-up forms but still sharing the knowledge that there will be follow-up. The Committee agreed the overall goal should be to make sure data is collected and the role of the Collective in that goal should be defined.

Next Steps

The Committee and SRTR representatives will continue discussion during the October 26 meeting.

Upcoming Meetings

- October 14, 2020 (teleconference)
- October 21, 2020 (teleconference)
- October 26, 2020 (teleconference, formerly in-person meeting)

Attendance

- **Committee Members**
 - Aneesha Shetty
 - Angie Nishio Lucar
 - Carol Hay
 - Carolyn Light
 - Heather Hunt
 - Jessica Spiers
 - Mark Payson
 - Nahel Elias
 - Omar Garriott
 - Rita McGill
 - Roberto Hernandez
 - Stevan Gonzalez
 - Vineeta Kumar
 - Randy Schaffer
 - Pooja Singh
 - Titte Srinivas
- **HRSA Representatives**
 - Shannon Dunne
 - Adriana Martinez
 - Arjun Naik
 - Raelene Skerda
- **SRTR Staff**
 - Katie Audette
 - Bertram Kasiske
 - Michael Conboy
- **UNOS Staff**
 - Lindsay Larkin
 - Matt Cafarella
 - Matt Prentice
 - Sarah Booker
 - Tina Rhoades
- **Other Attendees**
 - Krista Lentine