

**OPTN Living Donor Committee
Meeting Summary
January 10, 2024
Conference Call**

**Nahel Elias, MD, Chair
Stevan Gonzalez, MD, Vice Chair**

Introduction

The OPTN Living Donor Committee (LDC), the Committee, met via WebEx teleconference on 01/10/2024 to discuss the following agenda items:

1. Announcements and Welcome
2. Scientific Registry of Transplant Recipients (SRTR) Presentation on Living Donor Collective Follow-Up and Discussion

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

1. Announcement and Welcome

The Chair of the Committee welcomed the group and informed members that the meeting was being livestreamed. He also reminded the Committee that their in-person meeting will take place in Houston, TX on February 9, 2023.

The Chair also called attention to the special public comment period for the Expedited Placement Variance Proposal out for consideration by the OPTN Executive Committee and described the OPTN Pre-Waitlist Data Collection efforts taking place in the OPTN Data Advisory Committee. He also asked for a volunteer to serve on the OPTN Operations and Safety Committee Extra Vessels Workgroup.

The Chair also announced that the OPTN President has requested a new committee effort to brainstorm out of the box ideas to promote efficiency and safely increase living donation. The Committee will focus on challenges to address, key stakeholders to address, and improvement ideas and will begin discussing this during the in-person meeting. The ultimate goal is to package the conversations into a report for the OPTN Board of Directors in June 2024.

Summary of discussion:

The Committee did not make any decisions.

A member volunteered for the Workgroup.

2. One Scientific Registry of Transplant Recipients (SRTR) Presentation on Living Donor Collective Follow-Up and Discussion

The SRTR presented about the Living Donor Collective and their follow-up rates and capacity.

Presentation summary:

Background:

- The Living Donor Collective aims to:

- Identify barriers to access for living donation
- Establish a better understanding of long-term risks
- Share best practices across transplant programs
- Share findings with living donor and stakeholder communities
- The SRTR shared some pilot findings, including:
 - The living donor candidate registrations
 - The time from evaluation to donation
 - And reasons for not donating
- Results from the pilot suggest that support for modifiable reasons for non-donation might increase donation opportunities and help address disparities.

Living Donor Collective Follow-Up: Current State

Figure 1: Living Donor Collective (LDC) vs OPTN Follow-Up

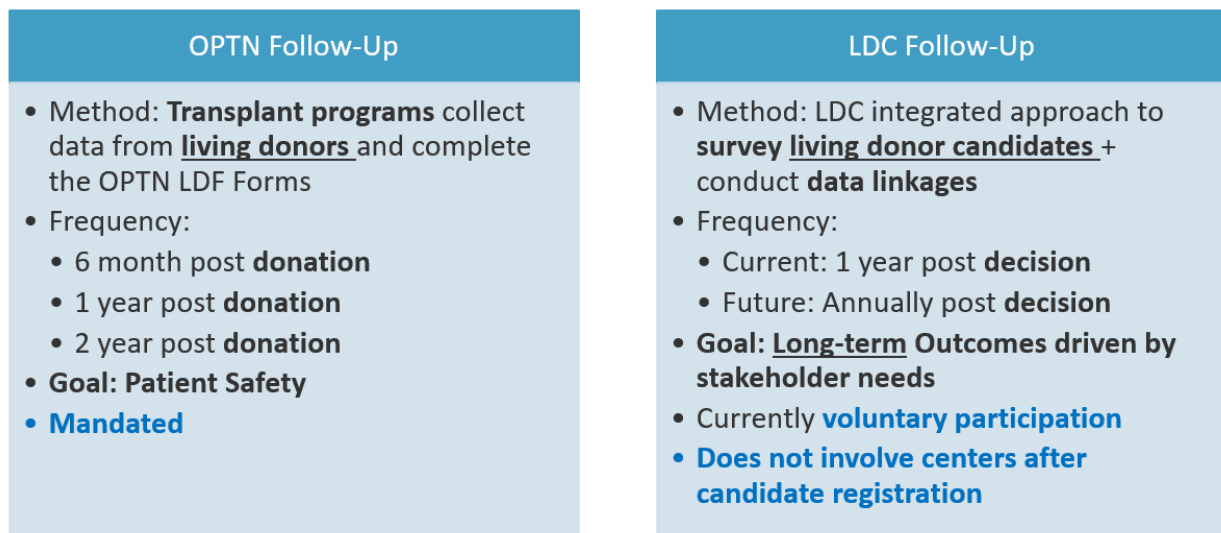


Figure 2: Follow-Up Survey Process

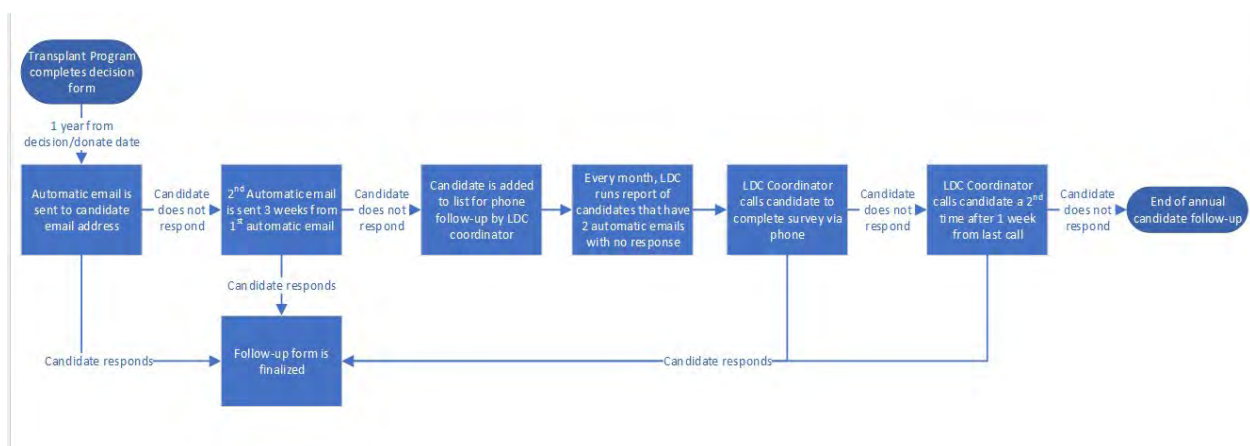


Table 1: LDC Follow-Up Rates

1-year Follow-up form	Number of attempts	Decision to donate center form	
		Yes	No
Completed	Overall	1197 (66.6%)	626 (40.2%)
	Initial automated email	612	182
	2nd <u>followup</u> : phone/email	233	127
	3rd <u>followup</u> : phone/email	114	148
	Additional engagements	235	169
Attempt ongoing	Overall	601 (33.4%)	931 (59.8%)

Table 2: LDC Participants Declining to Complete 1-year Follow-Up Form

Number of patients who directly declined to complete a 1-year follow-up form among finalized follow-up forms			
		Decision to donate	
		Yes	No
Question: Would you be willing to help us by answering a series of short questions going forward?	Declined	26	82
	Other	2	10

Living Donor Collective Follow-Up: Moving Forward

Figure 3: LDC Follow-Up Priorities Moving Forward

What follow-up survey data should we be collecting?

- Determine what long-term follow-up data is important to living donors, living donor candidates, and the medical transplant community

How do we improve follow-up survey data collection?

- New modalities: eg, phone caller-id; texting
- A sense of community, awareness, and excitement about being part of the LDC will improve participation

How can we further enhance data collection strategies?

- Leveraging linkages with other databases will enhance value of LDC even if survey engagement is incomplete

The SRTR also shared information about the Living Donor Steering Committee and the Site Steering Committee. Moving forward, they plan to:

- Update the LDC website: better landing site for living donor candidates to feel involved
- Inform LDC participants about findings

- Increase awareness & knowledge among living donor candidates who are enrolled in the LDC to improve follow-up survey response rates

They also shared the following opportunities for growth:

- New LDC team and leadership
- Task 5 Consensus Conference and the OPTN Concept paper on living donor data collection has increased awareness about need for the LDC and long-term data collection

And described the following challenges to overcome:

- Participation is currently only volunteers
- Limited staff resources
- Challenges enrolling transplant programs have taken time and energy away from follow-up efforts
- Concern about increased work for transplant programs

Summary of discussion:

The Committee did not make any decisions.

The Chair asked a clarification question about a figure in the presentation and thanked the SRTR for the presentation. The Chair also asked if outreach to participants is standardized, and SRTR representatives answered that the LDC provides materials but does not mandate that the outreach be standardized because participation is voluntary. A member asked if participants are informed of the purpose of the data collection and told that the data will not be shared with their insurance company. This member also asked if the SRTR performed analysis on the level of educational attainment of participants. An SRTR representative provided more detail on the opt-out process and the potential for data linkages. Another representative explained that the Living Donor Steering Committee will be re-working the brochures provided to participants with the varied levels of health literacy in mind.

A member encouraged the SRTR to consider reaching out to US census data collectors to gain additional information about barriers to data collection, noting that the challenges to obtaining complete and accurate data collection for the LDC and for the census would be similar. An SRTR representative responded that while the process for LDC and census data collection are quite different, this is an interesting point.

A member asked how many additional transplant programs have been recruited into the LDC, and an SRTR representative answered that about five transplant programs have ongoing efforts to join the LDC. A member inquired about the use of texting to achieve higher response rates, and an SRTR representative responded that they are exploring this avenue.

Next steps:

The Committee will continue to discuss during the in-person meeting. Members were encouraged to send any questions ahead of time.

Upcoming Meeting(s)

- Feb 9, 2024

Attendance

- **Committee Members**
 - Danielle Reuss
 - Anita Patel
 - Tyler Baldes
 - Annie Doyle
 - Hoylan Fernandez
 - Stevan Gonzalez
 - Dylan Adamson
 - Nancy Marlin
 - Nahel Elias
 - Henkie Tan
 - Laura Butler
 - Ginger Ireland-Hoffman
 - Ashtar Chami
 - Kelley Hitchman
 - Karen Ormiston
- **HRSA Representatives**
 - Marilyn Levi
 - Mesmin Germain
 - Vanessa Arriola
 - Shannon Dunne
 - Jim Bowman
- **SRTR Staff**
 - Katie Siegert
 - Ajay Israni
 - Avery Cook
 - Krista Lentine
 - Caitlyn Nystedt
 - Jon Snyder
 - Allyson Hart
- **UNOS Staff**
 - Sam Weiss
 - Meghan McDermott
 - Kieran McMahan
 - Sara Langham
 - Sam Weiss
 - Sara Rose Wells
 - Jen Wainwright