

OPTN Living Donor Committee

Meeting Summary

April 10, 2024

Teleconference

Nahel Elias, MD, Chair

Stevan Gonzalez, MD, Vice-Chair

Introduction

The Living Donor Committee (the Committee) met via Webex Teleconference to discuss the following agenda items:

1. Welcome and Announcements
2. Decision Point: Transition of OPTN Follow-Up
3. Report to the OPTN Board of Directors on Enhancing Living Donation

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

1. Welcome and Announcements

The Chair welcomed Committee members to the call. The incoming Vice Chair was announced and introduced to members.

2. Decision Point: Transition of OPTN Follow-Up

First, staff overviewed the project progress to date and then explained progress on decision-making for how to transition the OPTN follow-up requirements for living donors. The Committee discussed and decided to proceed with removal/transition of OPTN follow-up at 24-months, but retain (and review) follow-up at 12-months.

Presentation Summary:

The project combines two elements: the granular review of living donor data elements and living donor candidate data collection and policy updates. Following discussion at the in-person meeting, the project has a new working title of "Update and Improve Efficiency in Living Donor Data Collection."

The Committee will discuss and decide how to transition the existing OPTN living donor follow-up requirements to the Scientific Registry of Transplant Recipients' (SRTR) Living Donor Collective in a way that serves the goals of the Committee, the project, and the community. Following discussion in the in-person meeting, the Committee had three different viable solutions for how to transition follow-up:

1. Remove/transition 12-and 24-month follow-up from OPTN at the time of proposal implementation
2. Remove/transition 24-month follow-up from the OPTN at the time of proposal implementation, and retain 12-month follow-up
3. Remove/transition 24-month follow-up, develop a truncated 12-month follow-up form to collect critical information

The goal is to come to consensus on which of these options to proceed with for the project proposal. Staff reminded members of information about the data collection by OPTN and the SRTR's Living Donor Collective presented in prior meetings.

Summary of discussion:

The Chair explained that there was prior Committee consensus to retain 6-month follow-up, and that all of the options under consideration include removal of the 24-month follow-up, so the Committee should discuss when the transition should happen with regards to the 12-month follow-up. The Chair also stated that collaboration with the SRTR to ensure adequate and appropriate data collection will be important.

A member supported removing the 24-month follow-up but retaining the 12-month follow-up due to difficulties in collecting data and addressing the burden on transplant centers. This member explained that this would show responsiveness to public comments about caring for living donors, and that a truncated 12-month follow-up form would just create more confusion for centers. The Chair emphasized these points, especially that the living donor can return to their center in the event of any health challenges following donation at any time point. The Vice Chair agreed, stating that changing the format of the follow-up does not change the ability of the center to care for the living donor.

The Vice Chair reminded the Committee that the project includes review of and updates to the OPTN data collection forms for living donation. In terms of developing a truncated 12-month follow-up form, this effort may get at the idea of a truncated form by ensuring that all the data elements collected on the 12-month follow-up are reviewed for relevancy, accuracy, redundancy, and burden. The Vice Chair also mentioned that 12-months makes sense for having the donor transfer follow-up over to the SRTR, and that retaining the 12-month follow-up allows for an overlap of when living donors will be enrolled in the Living Donor Collective program but also have OPTN follow-up.

A member agreed with option two, stating that in their experience, at 12-months living donors typically feel that the hospital is still involved with their care. A member explained that it may be easier for the living donor to complete follow-up using the survey format.

The Vice Chair asked the Committee to think about the difference between options two and three. The Chair agreed that the forms will be revisited and reviewed for improvements anyway, so option two may make more sense. The Chair explained that during this review, collaboration with the SRTR will be important to determine the appropriate timeframes for collection of specific data elements, such as quality of life questions, to maintain continuity of the forms. A representative from the SRTR explained that there could be overlap in the data collected by the Living Donor Collective and the OPTN, and that the SRTR is making progress on updating and expanding their program through a steering committee.

The Committee reached consensus to proceed with the second option to remove the 24-month follow-up and retain follow-up at 12-months, but review the data collection to ensure that the elements collected as a part of follow-up are efficient, collecting the right type of information, and serving the larger project goals. The Vice Chair explained that this affords flexibility as well, because the SRTR could build upon survey data collection, and the OPTN could focus on the necessary information for follow-up at 12-months.

3. Report to the Board of Directors on Enhancing Living Donation

The Committee discussed their effort to develop a report to the OPTN Board of Directors on enhancing living donation, including the seven draft recommendations.

Presentation Summary:

In December, the President of the OPTN Board of Directors requested a new committee effort to brainstorm out of the box ideas to promote efficiency and enhance living donation.

The Committee completed brainstorming via a form and through discussion at the in-person meeting. The OPTN Board of Directors will then discuss the report, hold conversations about prioritizing work, and possibly create a “Taskforce approach” to address some of the concerns. The OPTN President recognized that this is outside the Committee’s stated charge, but an important topic for the OPTN to consider/think about. For right now, the Committee is only expected to deliver the report, then will hear back about any next steps, if applicable.

The results of brainstorming were compiled into seven draft recommendations:

- Expand OPTN data collection on living donation and collaborate with other entities for data collection
- Develop and promote best practices for key components of the living donation process
- Leverage technology and embrace innovation within the living donation process
- Reduce barriers to becoming a living donor
- Increase awareness about living donation among the general public
- Reduce disincentives for creating and maintaining living donor programs at transplant centers
- Improve and expand upon paired exchange opportunities and investigate other ways to expand the donor pool

A survey will be sent to members to gather additional information about how the Committee wishes to prioritize these recommendations according to feasibility, complexity, urgency, impact, and scope. The Committee will receive a draft report before the May meeting and discuss to finalize it.

Summary of Discussion:

The Chair explained that the first recommendation is clearly applicable to the Committee’s project and that it will be important to emphasize this in the report. The Vice Chair agreed, stating that enhancing the safety, protection, and follow-up of living donors in accordance with the Committee’s charge is clearly the aim of the Committee’s current project, so it makes sense to clearly explain this to the Board and how the project will, in turn, enhance living donation.

The Chair mentioned that different screening tools may pose an opportunity to work together to help living donors proceed with donation. A member recalled hearing a presentation about transparency to transplant candidates and stated that this may be connected to those ideas. This member advocated for including some bold aims (similar to the OPTN Expedient Taskforce) in the report, and the Chair responded that while this is a good idea, it may be outside the scope of the Committee at this time.

A member explained that improving equity in the living donation process should certainly be included in the report, including bias in screening tools and among clinicians. Another member explained that financial barriers are a big disincentive to living donors and explained that the National Kidney Foundation has a program to recognize employers who give paid leave for living donors, and that this may be an interesting avenue to explore to increase awareness and encourage showing support of living donors.

The Vice Chair agreed and stated that the Living Donor Collective will help in identifying barriers, though in that case the barriers will be after the living donor candidate is seen for some part of evaluation. The Vice Chair explained that understanding all barriers, even before this point, will be important. A member explained that single-day evaluation is a great way to reduce barriers.

An attendee stated that the burden of education about transplantation largely lies in the transplant community, and that this is not the best use of resources. Finding ways to educate through internal medicine providers, primary care offices, and at the level of the transplant candidate, would be important to explore. Another member agreed, and mentioned that education should begin at the level of the nephrologist, and focus more on family and friends moving forward to explore living donation as an option.

Next Steps:

Members will fill out the survey and staff will compile the draft report ahead of the May meeting.

Upcoming Meetings

- May 8, 2024 (teleconference)

Attendance

- **Committee Members**
 - Nahel Elias
 - Stevan Gonzalez
 - Henkie Tan
 - Tiffany Caza
 - Tyler Baldes
 - Hoylan Fernandez
 - Dylan Adamson
 - Nancy Marlin
 - Ashtar Chami
 - Anita Patel
 - Camille Rockett
 - Danielle Reuss
- **HRSA Representatives**
 - Mesmin Germain
- **SRTR Staff**
 - Katie Siegert
 - Caitlyn Nystedt
 - Krista Lentine
- **UNOS Staff**
 - Kieran McMahon
 - Meghan McDermott
 - Samantha Weiss
 - Jen Wainwright
 - Cole Fox
 - Sara Rose Wells
 - Laura Schmitt
- **Other Attendees**
 - Aneesha Shetty
 - Nathan Osbun
 - Milton Mitchell