

**OPTN Living Donor Committee
Meeting Summary
December 14, 2022
Conference Call**

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

Introduction

The OPTN Living Donor Committee (the Committee) met via Citrix GoTo Meeting teleconference on 12/14/2022 to discuss the following agenda items:

1. Report to OPTN Board of Directors Debrief

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

1. Living Donor Data Collection Report

The Committee debriefed on the OPTN Board of Directors December 5, 2022 discussion of the Committee's report.

Summary of discussion:

Feedback and discussion points from the December 5, 2022 OPTN Board of Directors meeting regarding the Committee's report on long-term living donor follow-up:

- General support for the findings and recommendations
- Shared experiences with Living Donor Collective participation
- Questions about how to streamline living donor data entry and reduce overlap
- Financial concerns and impact on living donors
- "burden" may be an incorrect term when speaking to living donor lives
- Resources to support living donors in long-term follow-up efforts
- Suggestion to change NOTA
- Living donors shared experiences with insurance issues post-donation

A member suggested that the Committee could utilize language that is solution focused instead of language focused on "burden". The member explained that language could emphasize a call to find and allocate resources which support long-term living donor follow-up. The Chair agreed that it is important to acknowledge the challenges as well as provide solutions to the identified challenges.

Another member noted that "burden" may have a negative connotation due to solutions often being mandates from regulatory bodies. The member explained that identifying solutions in a collaborate manner alongside living donors to improve the safety for the next generation of living donors is a better approach. A member suggested "ongoing engagement" or "ongoing interaction" as a more positive terminology to utilize. Another member suggested terminology such as "time and resource intensive efforts".

A member stated that long-term living donor data collection will require allocation of resources that currently do not exist in order to do justice to the mission of long-term living donor safety. Another

member suggested that ongoing relationships and engagement with living donors that extend beyond two years is also necessary to support the mission of long-term living donor safety.

The Chair stated that allocation of resources are necessary to support living donors in their follow-up as well as for the entity that is performing the long-term follow-up.

An SRTR representative suggested the Committee consider how the OPTN and SRTR can work together to support long-term living donor data collection. The SRTR representative suggested the Committee could consider developing a project to collect data on potential living donors. The SRTR representative stated that the OPTN could mandate data collection on potential living donors, which would help support the SRTR's Living Donor Collective to perform long-term data collection on living donors. The SRTR representative stated that the Committee could consider removing the 12 and 24 month mandatory living donor follow-up to streamline efforts and reduce data collection burden.

The SRTR representative noted that the Task 5 consensus conference highlighted the importance of upstream and downstream information. The SRTR representative requested the Committee consider how to work together to develop solutions and partnerships.

Next steps:

The Committee will discuss potential projects ideas to address long-term living donor follow-up.

Upcoming Meetings

- February 8, 2023 (teleconference)
- March 3, 2023 (Chicago, IL)

Attendance

- **Committee Members**
 - Alexandria Shingina
 - Doug Penrod
 - Dylan Adamson
 - Henkie Tan
 - Laura Butler
 - Mary Beth Stephens
 - Nancy Marlin
 - Stevan Gonzalez
 - Tyler Baldes
 - Vineeta Kumar
- **HRSA Staff**
 - Arjun Naik
 - Mesmin Germain
 - Vanessa Arriola
- **SRTR Staff**
 - Bertram Kasiske
 - Katie Siegert
 - Krista Lentine
- **UNOS Staff**
 - Carol Covington
 - Cole Fox
 - Jen Wainright
 - Kim Uccellini
 - Lauren Motley
 - Lindsay Larkin
 - Meghan McDermott
 - Sam Weiss
 - Stryker-Ann Vosteen
- **Other Attendees**
 - Christopher Woody