

**OPTN Living Donor Committee
Meeting Summary
November 9, 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 11/09//2022 to discuss the following agenda items:

1. Living Donor Data Collection Report

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

1. Living Donor Data Collection Report

The Committee continued discussing living donor data collection and reviewed a draft report.

Summary of discussion:

The Vice Chair suggested the report should clarify the differences between the living kidney and liver donor reporting thresholds per Policy 18.4: Living Donor Data Submission Requirements. A member asked for the reason why living kidney and liver donor reporting thresholds are different. An SRTR representative stated that the consensus, at the time the policy was created, was that complications for living liver donors would occur earlier.

Another member suggested that the report include mention to the potential to collect data on the psychological or emotional benefits of living donation. A member agreed that the potential benefits of living donation should be highlighted in the report.

The Vice Chair suggested the report emphasize the importance of living donor centered outcomes. The Vice Chair stated it is important to hear from living donors what is important to them. Another member agreed. The member added that in addition to understanding what living donors seek to know regarding long-term outcomes, it is important to understand what living donors report as barriers to long-term follow-up and what living donors wish they knew before going into the living donation process. A member suggested adding an additional recommendation to emphasize the importance of engaging a broader population of living donors. The Committee agreed.

A member asked for the percent of living donors who lost insurance due to donation. Staff responded, that data from 2019 shows that the six-month living donor follow-up forms reported eight living kidney donors (0.1 percent) and one living liver donor (0.2 percent) had lost insurance due to donation. Of the eight living kidney donors, six lost health insurance and two lost life insurance. The one living liver donor lost health insurance.

Another member asked whether there has been discussion whether the recipient's insurance should continue to pay for the living donor follow-up appointments. The member explained this may alleviate the major concern of financial coverage for living donor follow-up appointments. An SRTR

representative state the Centers for Medicaid and Medicare Services (CMS) has explicitly disallowed billing living donor follow-up costs to the Organ Acquisition Cost Center (OACC) on the Medicare Cost Report (MCR) or to a recipient's Medicare.¹

Another SRTR representative expressed interest in working closely with the OPTN to address long-term living donor data collection. The SRTR representative noted that both of the efforts are funded by HRSA to serve living donors nationally. A HRSA representative stated that the OPTN and SRTR should ensure that living donor data collection efforts are not repetitive.

Another member asked if the number of living donor candidates registered in the Living Donor Collective is a sufficient number to provide a comparator group. An SRTR representative estimated that currently about ten to fifteen percent of living kidney donor candidates and about twenty-five percent living liver donor candidates that are evaluated are registered in the Living Donor Collective. The SRTR representative stated they are working to continue to increase these numbers.

Next steps:

The suggestions provide by the Committee will be incorporated into the report. The Committee will submit a report to the OPTN Board of Directors for discussion during the December 5, 2022 OPTN Board of Directors meeting.

Upcoming Meetings

- December 14, 2022 (teleconference)
- January 11, 2022 (teleconference)

¹ Centers for Medicare and Medicaid Services. CMS Provider Reimbursement Manual; Chapter 31; Section 3106; page 10. <https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Paper-Based-Manuals-Items/CMS021929>. Accessed 09/07/2022.

Attendance

- **Committee Members**
 - Aneesha Shetty
 - Doug Penrod
 - Dylan Adamson
 - Henkie Tan
 - Hoylan Fernandez
 - Katey Hellickson
 - Mark Payson
 - Mary Beth Stephens
 - Nancy Marlin
 - Stevan Gonzalez
 - Tyler Baldes
 - Vineeta Kumar
- **HRSA Staff**
 - Jim Bowman
 - Marilyn Levi
 - Vanessa Arriola
- **SRTR Staff**
 - Bertram Kasiske
 - Caitlyn Nystedt
 - Katie Siegert
 - Krista Lentine
- **UNOS Staff**
 - Carol Covington
 - Cole Fox
 - Dzhuliyana Handarova
 - Kim Uccellini
 - Lauren Motley
 - Lindsay Larkin
 - Meghan McDermott
 - Sam Weiss
- **Other Attendees**
 - Christopher Woody