

**OPTN Living Donor Committee  
Meeting Summary  
July 13, 2022  
Conference Call**

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

## **Introduction**

The OPTN Living Donor Committee (the Committee) met in via Citrix GoTo Meeting teleconference on 07/13/2022 to discuss the following agenda items:

1. Introduction to OPTN Living Donor Data Collection
2. Living Donor Data Collection Discussion
3. New Committee Member Orientation

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

### **1. Introduction to OPTN Living Donor Data Collection**

The Committee received an introduction to OPTN living donor data collection.

#### Summary of discussion:

The Chair expressed interest in reviewing center-level compliance data for living donor registration (LDR) and living donor follow-up (LDF) forms' data submission.

The ex-officio requested that a report be shared with the Committee.

A member asked for information regarding the OPTN Membership and Professional Standards Committee's role in transplant programs non-compliance with LDR and LDF data submission thresholds. Staff will follow-up with more information regarding this process. The member questioned whether the 80 percent threshold for living kidney donor follow-up data submission, as required by OPTN Policy 18.5.A, is achievable. SRTR staff shared an article that showed an increase trend in meeting the thresholds placed in OPTN policy.<sup>1</sup>

A member asked whether LDR and LDF analyses have been done for living liver donors as they have been for living kidney donors. It was noted that most published literature focuses on living kidney donation, and research regarding living liver donation follow-up may not be as updated.

### **2. Living Donor Data Collection Discussion**

The Committee discussed potential timeframes of living donor data collection.

#### Summary of discussion:

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<sup>1</sup> Henderson ML, Thomas AG, Shaffer A, Massie AB, Luo X, Holscher CM, Purnell TS, Lentine KL, Segev DL. The National Landscape of Living Kidney Donor Follow-Up in the United States. Am J Transplant. 2017 Dec;17(12):3131-3140. doi: 10.1111/ajt.14356. Epub 2017 Jun 30. PMID: 28510355; PMCID: PMC5690895.

A member suggested reviewing international living donor follow-up rates, timeframes for data collection, and best practices. SRTR staff responded they have researched information regarding international living donor follow-up and will share their summary with the Committee. SRTR staff noted that transplant programs with public insurance that pay for the follow-up are able to achieve higher rates of follow-up over time. The Chair stated that insurance coverage is an important factor.

The Chair added that the interaction between data collection systems and electronic medical records (EMRs) is another important factor. The Chair explained that ensuring an EMR at a living donor's physician's office connects with the transplant program's EMR would make it easier to collect data.

SRTR staff outlined the structure that Switzerland has for living donor follow-up. SRTR staff highlighted that this system is one of the best for living donor follow-up, and yet achieves 65 percent follow-up rates around ten years post-donation. SRTR staff noted the University of Minnesota program, which has about 90 percent follow-up rates beyond ten years. This is found to be achievable due to project grants as it is a resource intensive program.

A member noted that the Veterans Affairs (VA) system has 100 percent follow-up at six months, one-year, and two-year due to the VA paying for the follow-up.

Another member suggested reviewing Canadian data regarding living liver donation and follow-up as a comparison. The member explained that a transplant program in Toronto performs the most living liver transplant surgeries in North America and understanding their protocols for follow-up may be beneficial.

A member emphasized that medical professionals need to consider what is the necessary information to provide a potential living donor about their risk in donating in order to sign an informed consent form that is meaningful. The Chair stated that current information provided to potential living donors is limited to surgical safety and short-term outcomes. The Chair advocated that lifetime risk should be the necessary amount of information. The Chair stated that after determining the necessary amount of information, then the barriers to overcome and resources needed should be identified to achieve that. The Vice Chair agreed and stated it may be beneficial to speak with transplant programs and living donors to understand what they perceive to be barriers. The Vice Chair stated that the project must balance collection of meaningful data with simplicity.

Another member shared an article that reviews prior living donors perspective's on potential barriers to post donation.<sup>2</sup> A member noted that it may be important to ask how to incentivize living donors to follow-up in addition to understanding the barriers. Another member noted that despite pre-donation education, many living donors do not perceive the need for follow-up. A member noted that emphasis and effort regarding living donor follow-up may itself increase rates of follow-up.

Another member suggested the Committee consider how to extend long-term data collection on living donors post-donation, while removing the burden off of transplant programs after two-years. A member suggested understanding how living donors seek to be followed long-term

### **3. New Committee Member Orientation**

New members were oriented to the ongoing work of the Committee and the structure of the OPTN.

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<sup>2</sup> Orandi BJ, Reed RD, Qu H, Owens G, Brooks S, Killian AC, Kumar V, Sheikh SS, Cannon RM, Anderson DJ, Lewis CE, Locke JE. Donor-reported barriers to living kidney donor follow-up. *Clin Transplant*. 2022 May;36(5):e14621. doi: 10.1111/ctr.14621. Epub 2022 Feb 27. PMID: 35184328; PMCID: PMC9098679.

**Upcoming Meetings**

- August 10, 2022 (teleconference)
- September 14, 2022 (teleconference)

## Attendance

- **Committee Members**
  - Alexandra Shingina
  - Aneesha Shetty
  - Camille Rockett
  - Doug Penrod
  - Dylan Adamson
  - Heather Hunt
  - Henkie Tan
  - Hoylan Fernandez
  - Erik Lum
  - Heather Hunt
  - Henkie Tan
  - Katey Hellickson
  - Mary Beth Stephens
  - Nahel Elias
  - Nancy Marlin
  - Stevan Gonzalez
  - Tyler Baldes
  - Vineeta Kumar
  - Yee Lee Cheah
  - Christopher Woody
- **HRSA Staff**
  - Jim Bowman
  - Vanessa Arriola
- **SRTR Staff**
  - Bert Kasiske
  - Katie Siegert
  - Krista Lentine
- **UNOS Staff**
  - Carol Covington
  - Cole Fox
  - Jennifer Wainright
  - Kim Uccellini
  - Lauren Motley
  - Lindsay Larkin
  - Meghan McDermott
  - Sam Weiss