

**OPTN Living Donor Committee
Meeting Summary
January 11, 2023
Conference Call**

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

Introduction

The Living Donor Committee met via Citrix GoToMeeting teleconference on 01/11/2023 to discuss the following agenda item:

1. Living Donor Data Collection Next Steps

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

1. Living Donor Data Collection Next Steps

The Chair reviewed the OPTN Board of Director's feedback on the Committee's findings and recommendations related to long-term living donor follow-up. The Committee will discuss potential project ideas and hear more from the SRTR regarding their Living Donor Collective.

Summary of discussion:

Potential project idea:

- OPTN policy and data collection revisions to support a national long-term donor candidate registry in partnership with the SRTR Living Donor Collective
 - Collection of living donor candidate data by the OPTN, and then share with SRTR to start the registry
 - Removal of required transplant program reporting of 1 year and 2 year post-donation follow-up, and pass long-term follow-up responsibility to the SRTR

SRTR staff stated that the goal of the potential project is to collaboratively address the call for long-term living donor data collection that has come across transplant community stakeholders. SRTR staff reminded the Committee that the Living Donor Collective is funded by HRSA. SRTR staff stated that feedback from the Task 5 Consensus Conference was supportive of upstream and downstream data collection efforts.

SRTR staff explained that registering living donor candidates may provide information on which ones then proceed to donation which could inform analyses regarding disparities or potential barriers to living donation. SRTR staff added that registering living donor candidates also would allow the Living Donor Collective to follow-up with individuals who do not donate as a non-living donor comparator group.

A member spoke to the many benefits to being a living organ donor that are sometimes overlooked in light of the risks. The member recommended that data related to the benefits could be collected. Other members agreed and suggested that data on elements of impact, such as the benefits, or the reasons behind exclusions for living donor candidates, be collected and examined as part of Living Donor

Collective. A member added that the connecting living donor data to outcomes data for recipients may add additional information on how transplant outcomes impact living donors.

The Vice Chair stated that the one and two year follow-up are already established policy requirements, so it may be beneficial to build on top of that foundation. The Vice Chair wondered whether the OPTN could write policy mandating participation in the SRTR Living Donor Collective. An SRTR representative consented that collaboration with the OPTN on living donor data collection was preferable, and also mentioned their concerns relating to additional burden on transplant centers which members agreed should not be increased. The Vice Chair noted that this project would require extensive collaboration and alignment between the OPTN and SRTR.

Members discussed the potential of removing the 1 and 2 year follow-up mandate that is currently part of OPTN policy. The intent of this removal is to reduce the burden on transplant programs, allow a focus on living donor candidate data collection, and transfer the one and two year follow-up to the Living Donor Collective. Some concerns were expressed about the perception this might present, that the community might raise issue with removing a mandate that is critical to data collection. Another concern was whether registration to the Living Donor Collective could be mandated. A SRTR representative stated that the objective perhaps should not be to mandate registration to the Living Donor Collective, but that the OPTN collects living donor candidate data and then shares that data with the SRTR.

The Vice Chair stated that the community will need to support this proposal. The Vice Chair suggested that removing the one or two year living donor follow-up requirements, while adding living donor candidate data collection requirements may be a necessary tradeoff to receive community support.

A member asked if the Committee has discussed the feasibility of living donors self-reporting the data. SRTR staff stated the Living Donor Collective is interested in exploring opportunities for living donors to self-report data to the registry. The Chair wondered whether some data would be lost if relying on living donors to self-report, such as clinical data. SRTR staff responded that some clinical data would still need to be reported by transplant programs and living donors can self-report quality of life data.

Another member stated that this project idea is a complex topic, and the Committee should take the lead. The Chair agreed. Members agreed it will be important to have early engagement and collaboration with transplant coordinators and transplant administrators.

The Vice Chair considered that the SRTR could provide annual monitoring reports to the Committee to monitor compliance with long-term follow-up of living donors.

A member expressed concern with the messaging of removing the one and two year living donor follow-up OPTN requirements. SRTR staff recommended to message it as transferring the long-term follow-up to the SRTR, not removing the follow-up. The member stated that the messaging should ensure living donors that they will be followed-up with, regardless of who is performing the follow-up. The member emphasized that this potential project is data collection re-alignment, rather than data collection removal. The Vice Chair agreed. Another member added it will be important to consider the solutions which are easiest for the living donors themselves.

The Committee members agreed with the importance and significance of collecting more upstream data. The Committee was also open to sharing and collaborating with the SRTR Living Donor Collective in an effort to support the goal of long-term living donor data.

Next steps:

The Committee will continue discussing the project idea of collecting living donor candidate data.

Upcoming Meetings

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

Attendance

- **Committee Members**
 - Aneesha Shetty
 - Douglas Penrod
 - Dylan Adamson
 - Henkie Tan
 - Hoylan Fernandez
 - Katey Hellickson
 - Laura Butler
 - Nahel Elias
 - Nancy Marlin
 - Mark Payson
 - Mary Beth Stephens
 - Stevan Gonzalez
 - Tyler Baldes
 - Vineeta Kumar
- **HRSA Representatives**
 - Mesmin Germain
 - Jim Bowman
 - Marilyn Levi
 - Vanessa Ariola
- **SRTR Staff**
 - Krista Lentine
 - Caitlyn Nystedt
 - Katie Siegert
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- **UNOS Staff**
 - Carol Covington
 - Cole Fox
 - Jen Wainright
 - Kim Uccellini
 - Krissy Laurie
 - Lauren Motley
 - Lindsey Larkin
 - Meghan McDermott
 - Samantha Weiss
 - Stryker-Ann Vosteen
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