

**OPTN Living Donor Committee
Meeting Summary
April 12, 2023
Conference Call**

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

Introduction

The OPTN Living Donor Committee (the Committee) met via Citrix GoToMeeting teleconference on 04/12/2023 to discuss the following agenda items:

1. Presentation and discussion: Patient Safety Reporting Project, OPTN Membership & Professional Standards Committee (MPSC)
2. Presentation: Prior Living Donor Priority in Organ Allocation
3. Update: Living Donor Data Collection Projects

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

1. Presentation and discussion: Patient Safety Reporting Project, OPTN Membership & Professional Standards Committee (MPSC)

The Chair of the MPSC presented on the Patient Safety Reporting project to the Committee. The MPSC requested specific feedback on whether modifications to table 18-4 in *OPTN Policy 18.5 Reporting of Living Donor Events* need to be made. Additionally, they requested feedback on any timing changes deemed necessary by the Committee.

Summary of discussion:

The Vice Chair affirmed that some of the items in table 18-4 overlap with data elements on the Living Donor Feedback form and the Living Donor Follow-Up Form, opining that perhaps the project to update those forms could also align with the Committee's granular review of OPTN living donor data collection project since the objectives are similar. Staff highlighted that the patient safety portal is a notification tool and not a data collection tool, therefore some items would overlap with data collection forms.

A member suggested that any time a prior living donor is waitlisted for a small bowel, pancreas or lung, that it should be included as an event. The Vice Chair assented and advised that questions remain organ non-specific as they do not want to exclude any type of living donor event in the reporting process.

Another member asked whether primary non-function of an organ should be added to table 18-4. Staff noted that such an event on the recipient side is reported as immediate graft failure or death, and would appear during a review of the program, if that program has been flagged for such a review. It was recommended that perhaps reporting of the event in the patient safety portal could trigger such a flagging for review. Members agreed this is important information to be captured, but that it is outside the scope of the Committee to determine.

The Committee was asked how the proposal should define a "near miss" or what compromises a "near miss,". The Vice Chair offered their view that if a mistake is caught after the initial verification, as most transplant programs require two before organ placement, then that would constitute a near miss.

A member opined that events related to the organ donated might not always qualify for reporting in the patient safety portal as a living donor event, but they should still be reported via data collection instruments.

Next steps:

The MPSC proposal is slated for the Summer 2023 public comment cycle, during which time the Committee can provide more feedback.

2. Presentation: Prior Living Donor Priority in Organ Allocation

Staff presented information on a previous discussion the Committee had concerning prior living donor priority in organ allocation. The Committee previously provided the following recommendations for prior living donor priority:

- Prior living donors should receive priority if they are listed for transplant
- All prior living donors should receive priority regardless of organ donated
- Prior living donors should not be subject to time restrictions
- Prior living donors should not be valued different based on the organ donated

Additionally, the Committee reviewed how the OPTN Lung Transplantation Committee incorporated prior living donor priority into the new continuous distribution allocation.

Summary of discussion:

Members expressed concerns that the graphics, on the OPTN website, used to show how a composite allocation score would function in a continuous distribution framework appear to indicate that a prior living donor may not have enough priority on the wait list. Staff confirmed that the graphic is a hypothetical and not a fully accurate depiction of what a composite allocation score would look like under continuous distribution.

A member suggested that the new system reflect what transplant programs have told living donors regarding their priority if they should ever need an organ. This member also highlighted that because it is only a small fraction of the prior living donor population that may need a transplant in the future, policy should err on the side of prioritizing the prior living donor, as it could have a large impact on one's decision to be a living donor. Another member recommended acquiring modeling data on the anticipated delay of a prior living donor receiving an organ once listed in the new system versus the current system.

Next steps:

The Committee will continue to engage in the development of continuous distribution across the different organ types.

3. Update: Living Donor Data Collection Projects

The Committee's two projects were recently approved by the OPTN Policy Oversight Committee – *Collect Living Donor Candidate and Donation Decision Data* and *Granular Review of OPTN Living Donor Data Collection*. The Committee also presented these projects to the OPTN Data Advisory Committee for feedback and endorsement. Both presentations were well received, and the feedback received thus far included aligning definitions with other data collection efforts, staying aware of the potential for increased data burden, and to establish strong key metrics for evaluating the proposal in the future.

Next steps:

The Committee will schedule additional meetings to accommodate the accelerated timeline for submitting a concept paper on these two projects.

Upcoming Meeting

- May 10, 2023
- May 17, 2023
- May 24, 2023
- June 14, 2023

Attendance

- **Committee Members**
 - Aneesha Shetty
 - Dylan Adamson
 - Henkie Tan
 - Hoylan Fernandez
 - Katey Hellickson
 - Mary-Beth Stephens
 - Nancy Marlin
 - Alexandra Shingina
 - Stevan Gonzalez
 - Tyler Baldes
 - Vineeta Kumar
 - Laura Butler
 - Camille Rockett
- **HRSA Representatives**
 - Adriana Martinez
 - Arjun Naik
 - Jim Bowman
 - Mesmin Germain
- **SRTR Staff**
 - Krista Lentine
 - Caitlyn Nystedt
- **UNOS Staff**
 - Kaitlin Swanner
 - Kim Uccellini
 - Laura Schmitt
 - Meghan McDermott
 - Rachel Hippchen
 - Rebecca Brookman
 - Ruthanne Leishmann
 - Samantha Weiss
 - Sara Langham
 - Strkyer-Ann Vosteen