

OPTN Living Donor Committee

Meeting Summary

February 26th, 2025

Conference Call

Stevan Gonzales, Chair

Introduction

The OPTN Living Donor Committee met via Cisco WebEx teleconference on 2/26/2025 to discuss the following agenda items:

- Announcements
- Public Comment Presentation: Barriers Related to the Evaluation and Follow-Up of International Living Donors
- Data Collection Project: Project update and continue discussion to determine start of data collection

The following is a summary of the Subcommittee's discussions:

1. Announcements

Remaining regional meetings will be virtual only and any postponed meetings will be rescheduled to be held before March 19, end of winter public comment. Please check the optn website for update to date dates and agendas.

There are two Living Donor Committee meetings this month and the in-person meeting will be held virtually instead on April 23rd.

Public Comment ends March 19th. The Committee asks for any comments to be included in the Committee comments for the Continuous Distribution Update Papers (Kidney and Pancreas).

2. Public Comment Presentation: Barriers Related to the Evaluation and Follow-Up of International Living Donors

Staff will draft and submit a Committee comment.

Summary of Presentation:

A Ad Hoc International Relations Committee member provided an overview of the guidance proposal, focused on the challenges and strategies for evaluating and following up on international living donors, with an emphasis on data collection and standardization. [The slides and proposal can be found on the OPTN website.](#)

Summary of discussion:

A Living Donor Committee member served on the workgroup and emphasized that the proposal thoroughly considered all issues and barriers and this is meant as guidance, not policy. A member commented that his institution avoids incentivizing potential living donors by helping to secure a visa. A member commented that while securing a visa is the biggest barrier, the center can provide education. A member asked how many international candidates come through centers and what is the burden on

coordinators. There should be a special team designated to assist these candidates. Also, most of the international donors are non citizens, but living in the United States.

3. Data Collection Project: Project update and continue discussion to determine start of data collection

The Committee decided the start of data collection will be when the potential living donor has the first in person appointment with the transplant team.

Summary of Presentation:

The Vice Chair provided a brief data collection project update. The workgroup will finish the Form B draft, which included information about potential donors that did not go on to donate, by the next meeting. It will be brought to the full committee for review. The additional existing forms will be reviewed after Form B. The workgroup have has productive conversations about what data should be collected for all organs versus only a kidney or a liver, for example

The Chair reviewed points to consider as the Committee decides when data collection should start. It should be supported by the Data Advisory Committee, be uniform, require minimal change to unique center protocol, reasonable data entry burden, be supported by SRTR, receive likely community support during Public Comment, and be easy to monitor.

The Committee previously considered the start point of data collection to be:

- A. Either the first test ordered or the first appointment with a member of the living donor team or the Independent Living Donor Advocate (ILDA)
- B. First initiation of contact with a member of the living donor team or the Independent Living Donor Advocate (ILDA) – virtual or in person

The proposed new start point for the Committee to consider is first in person appointment with a member of the transplant team. This is support by leadership and the SRTR. A visual showing how considerations are balanced was provided for the Committee to view. It is important to decide today when collection will start. It can be shared during Public Comment and changed, if necessary.

Summary of Discussion:

A member commented that this is clear and helpful it is supported by SRTR and supports this proposed start to be the first in person appointment. This is also aligned with what triggers data collection for candidates in the pre wait list project.

One member commented that selecting option B would better capture barriers but he would prefer first in person appointment with due to burden. Another member commented that sometimes labs are ordered even before an in person appointment. Will the data be as valuable due to variation in level of tests among programs? This is one negative aspect, but there is so much variation in how programs evaluate potential living donors. This could just be a question in public comment: at what point are patients being seen for evaluation? Centers would likely agree to this and the collection could potentially be expanded. Long term, this can be adjusted. The first in person appoint option provides enough data for a comparator group. There can be subsequent projects coming from this one.

A member expressed concerns that barriers to donation will not be thoroughly captured at the first in person point and is too late. Psychosocial reasons for not donating are typically uncovered before in person appointment. The member still supports the in person choice, but has concerns. The Committee can seek feedback during public comment.

Committee consensus is that the trigger for data collection on potential living donors is the first in person appointment.

Next steps:

The workgroup and committee will continue to work through the data collection project decisions.

Upcoming Meetings:

- 3/12/2025
- 4/23/2025

Attendance

- **Committee Members**
 - Annie Doyle
 - Stevan Gonzalez
 - Trysha Galloway
 - Tiffany Caza
 - Annesha Shetty
 - Michael Chua
 - Laura Butler
 - Danielle Reuss
 - Nathan Osbun
 - Nancy Marlin
 - Nahel Elias
 - Dylan Adamson
 - Frankie McGinnis
 - Nathan Osbun
 - Trysha Galloway
- **SRTR Representatives**
 - Katie Siegert
 - Caitlyn Nystedt
- **HRSA Representatives**
 - Arjun Naik
- **UNOS Staff**
 - Sara Langham
 - Samantha Weiss
 - Cole Fox
 - Emily Ward
 - Lauren Mooney
 - Sara Rose Wells
 - Tamika Watkins
- **Other**
 - Cythnia Forland, Presenter