OPTN Living Donor Committee
Meeting Summary
May 14th, 2025
Conference Call

Stevan Gonzales, Chair
Introduction

The OPTN Living Donor Committee met via Cisco WebEx teleconference on 5/14/2025 to discuss the following agenda items:

- Announcements
- Data Collection Project:
  - Discussion/Review
  - Committee Vote
  - Discuss Public Comment Feedback Questions

- Meeting Wrap up and Next Steps

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

1. Announcements

- Public Comment Period: Scheduled to begin in August 2025.
- Meeting Schedule: Staff confirmed that future meetings would follow the same cadence, with updated Outlook invites.
- Recognition: A member was congratulated for being elected as Region 1 Councillor, a significant leadership role within the transplant community.

2. Data Collection Project

The Chair reviewed the Committee's proposal to enhance data collection for living donors, particularly focusing on long-term outcomes and barriers to donation. The proposal has undergone extensive development and was now at a critical juncture, requiring committee approval to move forward to public comment.

Summary of Discussion:

Feedback from the Data Advisory Committee (DAC)

The Chair shared recent feedback from DAC, which raised concerns about:

- **Manual Data Entry Burden**: Less than 50% of the proposed data fields were in discrete format in the propose Living Donor Non-Donation Form, likely increasing the workload for transplant centers.

- **Recommendation to Reduce Fields**: DAC suggested minimizing the number of data elements and focusing on batch collection where possible.

However, the committee emphasized that reducing data elements too drastically would compromise the proposal's dual goals:

1. Understanding barriers to living donation.

2. Establishing long-term outcomes through robust data collection.

The Chair explained that removing data from the donation decision phase would hinder the ability to analyze barriers, while reducing baseline data would weaken the comparator group needed for long-term outcome analysis.

Clarifying the Proposal's Purpose

Several members stressed the importance of clear communication. It was noted that previous public comments questioned whether the data collection effort was worth the burden. The Committee agreed that educational outreach would be essential to convey the proposal's value.

A member raised concerns about public trust in health data, especially in the current political climate. She emphasized the need for transparency about how data would be used and protected.

Scientific Registry of Transplant Recipients (SRTR) staff reassured the Committee that the data collection falls under public health authority protections and that SRTR has robust opt-out mechanisms and data security protocols. They noted that very few participants had opted out during the pilot phase.

Discuss DAC Endorsement

Although DAC did not endorse the proposal, the committee decided to proceed. At their last meeting, the workgroup altered and removed some data elements from the new form and decided to keep minimize changes to existing forms.

The workgroup Chair explained that DAC's requested changes would require removing either the clinical or donation decision components—both of which are essential. She emphasized that the project is not just about data but about addressing a long-standing gap in donor follow-up.

A member advocated for valuing the donor's perspective. She questioned whether the burden on donors was being equally considered and suggested incorporating patient experiences into the proposal to strengthen its impact.

Discussion on Two-Year Follow-Up Transition

The Committee revisited the proposal to transition the two-year follow-up responsibility from OPTN to SRTR. The Chair clarified that this change pertains only to data collection—not to the clinical follow-up of donors, which remains the responsibility of transplant centers.

Staff presented data comparing follow-up rates:

- **SRTR (Voluntary)**: 68% follow-up at one year for donors; 44.6% for non-donors.

- **OPTN (Required)**: 68–74% follow-up at one year.

The committee concluded that SRTR's voluntary follow-up rates were comparable to OPTN's required rates, supporting the transition.

SRTR staff emphasized the value of having a comparator group of non-donors for long-term outcome studies, even with partial follow-up.

Two final proposal items were discussed:

- **Terminology Update**: Replacing "fat" with "steatosis" for consistency with policy language.

- **Cardiac Abnormalities**: A suggestion to expand this category was tabled for future consideration due to its potential impact on multiple forms. There are no proposed changes to existing forms for this phase, but existing forms can be changed in the second phase.

3. **Committee Vote on Living Donor Data Collection Project, 1495:**

Summary of Discussion:

A Committee member made a motion to vote, and the motion was seconded. A quorum (a least 10) was present, even though some members left the meeting.

> Committee Vote to send the Living Donor Data Collection project 1495 to the Policy Oversight Committee for Public Comment, Summer 2025: 11-YES, 0-NO, 0-Abstain.

4. **Public Comment Feedback Questions**

Staff will email the draft public comment feedback questions to the Committee since there was not enough time to discuss this at the meeting. Leadership will consider the questions to be added to the public comment proposal.

5. **Meeting Wrap Up**

Upcoming Meetings:

- 6/11/2025

Attendance

- **Committee Members**
  - Stevan Gonzalez
  - Trysha Galloway
  - Tiffany Caza
  - Annesha Shetty
  - Michael Chua
  - Laura Butler
  - Nathan Osbun
  - Nancy Marlin
  - Trysha Galloway
  - Annie Doyle
  - Danielle Reuss
  - Nahel Elias
  - Dylan Adamson
  - Milton Mitchell
  - Alexandra Shingina
  - Ginger Ireland-Hoffman

- **SRTR Representatives**
  - Krista Lentine
  - Katie Siegert
  - Jon Snyder
  - Caitlyn Nystedt

- **HRSA Representatives**
  - N/A
- **UNOS Staff**
  - Emily Ward
  - Lauren Mooney
  - Lindsay Larkin
  - Laura Schmitt
  - Cole Fox
  - Jesse Howell