OPTN Living Donor Committee
Meeting Summary
February 12th, 2025
Conference Call

Stevan Gonzales, Chair
Introduction

The OPTN Living Donor Committee met via Cisco WebEx teleconference on 2/12/2025 to discuss the following agenda items:

- Announcements

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

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.

Some members expressed frustration that the collaborative meetings were held but not the regional meetings. Staff explained that the collaborative meetings are UNOS private meetings and the OPTN holds regional meetings.

There are two Living Donor Committee meetings this month and the in-person meeting will be held in Detroit 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).

1. **Prior Living Donor Data Report**

No decisions. The full report and a manuscript will be sent to the Committee.

Summary of Presentation:

Staff presented on data compiled about the status of prior living donors who have been waitlisted for any organs from 1994-2024. Most prior living donors donated a kidney. Prior living donors needing an organ is very rare. The percentage of prior living donors on the waitlist at any point is less than one percent. If these donors are prioritized, it does not impact the waitlist much and increases faith in the system.

Summary of discussion:

This is well timed, if questions about this come up in regional meetings. A member asked about the racial breakdown for this report. This data request does not include this, but there is a UNOS manuscript of risk of ESRD by race. Staff will send this report.

2. Project Check In: Data Collection Project

No decisions.

Summary of Presentation:

The workgroup has been using the last few meetings to create a mockup of Form B, including data elements and options for demographic data, clinical information, and decision data. The group will review the former Living Donor Follow Up (LDF forms) next.

The workgroup timeline was shown. Form B should be ready for full Committee review shortly. The Policy Language Framework will also be reviewed soon.

Summary of discussion:

The Committee came up with Form names at the last in person meeting. The group should come back to this soon to review the full project. Thank you to all who are working on this.

3. Review and Discussion: Definition of a Candidate and Evaluation Start for Data Collection Purposes

Evaluation should be the first point of contact (verbal or in person) but should be revisited after the draft forms are completed.

Summary of Presentation:

The overall purpose of the project was reviewed: to better understand the barriers to living donation and to expand data collection and to understand the long-term outcomes of living donation.

While the definition of a candidate has been determined by the committee, the committee must determine when data collection starts in the evaluation process.

A living donor candidate, as determined by the committee, is someone who is undergoing evaluation, as determined by OPTN policy 14.1-14.4. Currently, each program may have a different way they start evaluation.

The proposed definition of the evaluation start for the purpose of data collection is when the first tests are ordered OR the first appointment with a member of the transplant team or the Independent Living Donor Advocate (ILDA). This aligns to when data collection begins for pre-wait list candidates and is supported by the Data Advisory Committee (DAC).

Summary of discussion:

This is a complex definition due to Centers for Medicare and Medicaid Services (CMS) regulations. It is easier for large centers to follow this. CMS indicates the ILDA must be the first contact with the patient. It is important to keep this definition as specific as possible. Because centers do things differently, some centers may be highly burdened with data collection, depending on their process. Small and large centers must be considered. Does the evaluation start when you talk with someone or poke them?

Another recommended this should be a first full evaluation as a team, to reduce data burden.

There should be a balance between deciding on something that allows centers to adopt it into current processes but not add too much burden. There are many similarities between how data is collected for pre wait list candidates and how the living donor candidate process might work.

Should the start be initiating contact with the individual? This would be a large number. Does UNOS or SRTR collect data on screening or evaluations completed? No, the OPTN does not collect this data. Collection begins with the Living Donor Feedback Form (right before surgery).

Many potential donors speak with an ILDA and then never complete the labs ordered. Many centers do this differently. It would still be too much data to decide if the starting point was at the start of a medical record.

If the goal is to understand the barriers to becoming a donor, we cannot restrict the data to those that physically come to the center. Should it be the point where there is some form of human contact? Many people are screened out for various reasons before they complete an evaluation.

Even if data is collected at initiation and the person does not donate, it will not take long to fill out Form B.

Staff clarified that data would not be collected on people only screened. If evaluation is defined when a program makes contact, is it possible the potential living donor would have had prior testing first? This depends on the program.

If we put aside the burden of collecting data, we want to do this early to understand the barriers best. Let's say it is first verbal contact and then focus on making the forms easier to complete.

Next Steps:

Revisit this topic but consider it after the draft forms are completed. Feedback from the DAC will be helpful, too.

Upcoming Meetings

- 2/26/2025

Attendance

- **Committee Members**
  - Annie Doyle
  - Stevan Gonzalez
  - Trysha Galloway
  - Annesha Shetty
  - Michael Chua
  - Laura Butler
  - Danielle Reuss
  - Anita Patel
  - Elizabeth (Lisa) Thomas
  - Nancy Marlin
  - Macey Levan (Visiting Board Member)
  - Ginger Ireland-Hoffman
  - Milton Mitchell
  - Dylan Adamson
  - Nathan Osbun
- **SRTR Representatives**
  - Katie Siegert
  - Avery Cook
  - Caitlyn Nystedt
- **HRSA Representatives**
  - Allison Hutchings
- **UNOS Staff**
  - Sara Langham
  - Samanthia Weiss
  - Cole Fox
  - Emily Ward
  - Lauren Mooney
  - Sara Rose Wells