

**OPTN Living Donor Committee  
Meeting Summary  
March 3, 2023  
Chicago, IL**

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

## **Introduction**

The Living Donor Committee (the Committee) met in Chicago, IL on 03/03/2023 to discuss the following agenda items:

1. Welcome and Announcements
2. OPTN Policy Oversight Committee Update
3. Policy Development and OMB Processes
4. Project Idea Prioritization
5. Living Donor Death Verification
6. Public Comment Presentation: OPTN Kidney Paired Donation (KPD) Blood Type Policy Alignments and Donor Re-Evaluation Efficiency Requirements
7. Public Comment Presentation: Update on Continuous Distribution of Livers and Intestines

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

### **1. Welcome and Announcements**

The Chair welcomed Committee members and requested any volunteers to join a workgroup that the Ad Hoc International Relations Committee is starting for a new project.

### **2. OPTN Policy Oversight Committee Update**

The Vice-Chair provided an update about the OPTN Policy Oversight Committee (POC) and next steps the Committee will need to take on introducing any future projects to the POC.

#### Summary of discussion:

The Committee discussed their potential project about collecting data on living donor candidates, as well as the current Workgroup project on living donor data collection. The Vice Chair suggested continually evaluating prior Committee-sponsored projects in order to monitor the impact. Additionally, the members discussed what metrics could to be monitored for their data collection project.

### **3. Policy Development and OMB Processes**

The Committee reviewed the OPTN policy development process and the Office of Management and Budget (OMB) process.

#### Summary of discussion:

. Members discussed the recent review of the Living Donor Feedback form, and noted that it is the least burdensome of the OPTN living donor data collection instruments. One member brought up the concern of the length of the process, but was assured that it is necessary for transparency and ensuring due process for all projects.

#### 4. Project Idea Prioritization

The Committee members divided into groups and discussed project prioritization. The objective was to identify a project area of focus for the Committee to move forward with.

Previously identified project ideas:

- Address gender disparity in living donors
- Social determinants of health and living donation
- Improve primary care physician knowledge of living donation and post-donation care (journal article/one-pager)
- Education on race-neutral estimated glomerular function (eGFR) and impact for prior living donors
- Paper recommending NLDAC removes recipient income as eligibility requirement for living donor lost wages reimbursement
- Body mass index (BMI)/obesity and living donation – impact on outcomes; resources to improve health/nutrition prior to donation
- Collect living donor candidate and donation decision data
- Review of Policy 14.4: Medical Evaluation Requirements for Living Donors

##### Summary of discussion:

A representative for SRTR provided clarification on NLDAC and the legislation that surrounds federal funding for living donors. Members wondered if the rulings could be altered so that there is more living donor specific assistance available. A representative for HRSA clarified that the way the law was initially structured was to make it easier for transplant candidates to find a living donor and be able to cover expenses them without it being unethical.

One member opined that disparities still exist with this system, and sometimes if a transplant candidate makes too much money, then the living donor will not be able to get funding through the program.

Another member asked whether it would be possible for living donor programs to collaborate on a larger scale and share best practices on how to run a successful living donor transplant program.

Committee members discussed the other project ideas, coming to consensus on a few different topics that could be bundled together into larger projects. Members discussed certain topics that could be addressed more quickly such as developing more education for primary care physicians to have about living donors. That education could include information on eGFR. The Committee acknowledged that there may be opportunity to incorporate some of these ideas into American Society of Transplant's (AST's) living donor toolkit.

Another idea that members spoke about was changing OPTN Policy 14.4 to include more methods of measuring a living donor's kidney function, such as iohexol testing.

One member brought up another priority that came up during their group discussion which was the gender disparity that exists in living donation, as more women are living donors than men. Members agreed that this along with other equity issues would be projects that the Committee should take up. Another member brought up the concern that members of the LDBTQ+ community are often underrepresented in the data and experience disparities at a higher rate than other members of the transplant community.

Members discussed the project to collect living donor candidate data and the intricacies of it. One member brought up the necessity of timing, as when the data is collected was is an equally important

part of the process. The Committee considered the involvement of SRTR's Living Donor Collective. A member spoke to how critical living donor candidate and donation decision data would be for the safety of living donors both short and long term. Members agreed that it would be difficult to collect data while not adding extra burden, and that transplant programs all have different methods of collecting the data, even if they all need to collect the same data, as the use different dashboards or electronic medical record (EMR) systems.

Committee members agreed that it would be a significantly large project and that a concept paper would be the best method to ascertain the communities' sentiments on this shift in data collection and how to best support the living donor community. The Committee agreed that gathering information on potential living donors would be a good starting point, and discussed at what point in the evaluation process data on the living donor candidates would be collected. Additionally, the representative from SRTR stated that with respect to long-term follow up, the SRTR could take that on while the OPTN would collect living donor candidate and donation decision data.

The Chair recommended collaborating with the OPTN Transplant Administrators Committee and the OPTN Transplant Coordinators Committee, and the OPTN Patient Affairs Committee as there are many differing opinions and positions to be heard.

The Committee agreed to combine certain project ideas as detailed below:

- Improve primary care physician knowledge of living donation and post-donation care (journal article/one-pager)
  - Education on race-neutral estimated glomerular function (eGFR) and impact for prior living donors
- Paper recommending NLDAC removes recipient income as eligibility requirement for living donor lost wages reimbursement
- Collect living donor candidate and donation decision data
  - Body mass index (BMI)/obesity and living donation – impact on outcomes; resources to improve health/nutrition prior to donation
  - Address gender disparity in living donors
  - Social determinants of health and living donation
- Review of Policy 14.4: Medical Evaluation Requirements for Living Donors

The Chair recommended developing workgroups or subcommittees to write one-pagers or journal articles on post-living donation primary care physician conversations and education. The Committee decided to reach out to AST and assist the organization with updating their living donor toolkits for both living donors and primary care physicians.

Members discussed how to address Policy 14.4 and the best way to update it. They agreed that it would not be a small project as it would require more data requests and more research in order to ensure policy aligns with current research regarding medical evaluations for living donors. Additionally, the Committee decided that it would be better done collaboratively with the Kidney Committee and as they are working on continuous distribution then this project might have to wait.

The Committee agreed to move forward to sponsor a project for the OPTN to collect living donor candidate and donation decision data. The Committee acknowledged that this is an effort that the community has long asked for. The Committee agreed that this is necessary data to collect to inform knowledge on living donor safety. A member asked how this project would overlap with the existing project to review the OPTN living donor data collection forms. Staff recommended that the concept paper could address both topics as a first step in order to engage the community; if the community

indicates support, there is opportunity to combine the two projects. The Committee discussed and agreed on collaborating with the SRTR on this project to collect living donor candidate and donation decision data as they have the ability to perform long-term follow-up.

Next steps:

The Committee will submit the project for POC approval. Pending POC approval, the Committee will begin drafting a concept paper detailing current and future efforts regarding living donor data collection.

**5. Living Donor Death Verification**

The Committee received a presentation about updates to the living donor death verification process and data collection.

Summary of discussion:

Members discussed how to get more granular data related to living donor mortality rate for each specific organ, as they feel this information would be beneficial for the transplant community. Staff informed the Committee that to get that sort of granularity they would need to put in a data request.

**6. Public Comment Presentation: OPTN Kidney Paired Donation (KPD) Blood Type Policy Alignments and Donor Re-Evaluation Efficiency Requirements**

The Committee received a presentation from the OPTN Kidney Transplantation Committee on their proposal out for public comment.

Summary of discussion:

One member asked whether the notice would be sent only to active or inactive patients. The presenter for the OPTN Kidney Transplantation Committee stated that currently only active patients receive notification, but they should consider adding inactive candidates to the notification list as well. The Chair recommended adding Hepatitis-B virus and Hepatitis-C virus as additional infectious disease retesting exceptions for living donors that have previously tested positive for these diseases. Additionally, the Committee advised that re-evaluation deadline of a donor be based on the initial evaluation date, and not the date they first became active on the waitlist. Members agreed that a 90-day timeframe is sufficient between notification and potential ineligibility of a donor for a re-evaluation to occur. Additionally, members believed an implementation period of a year in which donor eligibility will not be impacted would be necessary.

**7. Public Comment Presentation: Update on Continuous Distribution of Livers and Intestines**

The Committee heard a presentation from the OPTN Liver and Intestinal Organ Transplantation Committee about the update on continuous distribution.

Summary of discussion:

Members discussed the importance of prior living donors priority on the waiting list, as it is important living donor candidates feel secure in their donation that should they ever need an organ of their own, they would be taken care of. One member emphasized that not only is it for the living donor candidates' peace of mind but also for the families.

**Upcoming Meetings**

- April 12, 2023 (teleconference)
- May 10, 2023 (teleconference)

## Attendance

- **Committee Members**
  - Nahel Elias
  - Stevan Gonzalez
  - Vineeta Kumar
  - Aneesha Shetty
  - Mary Beth Stephens
  - Alexandra Shingina
  - Henkie Tan
  - Tyler Baldes
  - Laura Butler
  - Dylan Adamson
  - Hoylan Fernandez
  - Nancy Marlin
  - Katey Hellickson
  - Mark Payson
- **HRSA Representatives**
  - Adriana Martinez
  - Arjun Naik
  - Mesmin Germain
- **SRTR Staff**
  - Krista Lentine
- **UNOS Staff**
  - Anne Zehner
  - Jennifer Wainright
  - Carson Yost
  - Kayla Temple
  - Kim Uccellini
  - Krissy Laurie
  - Laura Schmitt
  - Lindsey Larkin
  - Matthew Cafarella
  - Meghan McDermott
  - Ruthanne Leishman
  - Samantha Weiss
  - Sara Langham
  - Stryker-Ann Vosteen
  - Taylor Livelli
  - Tina Rhodes
- **Other Attendees**
  - Christopher Woody (in person)
  - James Trotter (virtual)
  - Marian Charlton (virtual)