

OPTN Living Donor Committee

Meeting Summary

May 8, 2024

Teleconference

Nahel Elias, MD, Chair

Stevan Gonzalez, MD, Vice-Chair

Introduction

The Living Donor Committee (the Committee) met via Webex Teleconference to discuss the following agenda items:

1. Welcome and Announcements
2. Discuss Report to the OPTN Board of Directors on Enhancing Living Donation

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

1. Welcome and Announcements

The Chair welcomed Committee members to the call. Staff reminded members of the special public comment period open for *Establish Code of Conduct and Whistleblower Protection Bylaws* proposal.

2. Discuss Report to the Board of Directors on Enhancing Living Donation

The Committee provided feedback on the draft Report to the OPTN Board of Directors on Enhancing Living Donation.

Presentation Summary:

In December, the President of the OPTN Board of Directors requested a new committee effort to brainstorm out of the box ideas to promote efficiency and enhance living donation.

The Committee completed brainstorming via a form and through discussion at the in-person meeting. The OPTN Board of Directors will then discuss the report, hold conversations about prioritizing work, and possibly create a "Taskforce approach" to address some of the concerns. The OPTN President recognized that this is outside the Committee's stated charge, but an important topic for the OPTN to consider/think about. For right now, the Committee is only expected to deliver the report, then will hear back about any next steps, if applicable.

The results of brainstorming were compiled into seven draft recommendations, with the Committee worked to prioritize according to scope, feasibility, and impact. The results of the survey are reflected in the draft:

1. Reduce systematic barriers to becoming a living donor
2. Expand OPTN data collection on living donation and collaborate with other entities for data collection to increase public trust and promote living donor safety
3. Develop and promote best practices for key components of the living donation process
4. Improve and expand upon paired donation opportunities and investigate other ways to expand the living donor pool
5. Increase awareness about living donation among the general public
6. Leverage technology and embrace innovation within the living donation process

7. Reduce disincentives for creating and maintaining a living donation program at transplant centers

Committee members were asked for their feedback on the draft report so that it can be finalized and shared with the Board.

Summary of Discussion:

The Vice Chair stated that the draft was a great culmination of the Committee's discussions, and that tying the recommendations into the work that the Committee is doing now is very important. The Committee's project, *Update and Improve Efficiency in Living Donor Data Collection*, fits in well with the goal of enhancing living donation. The Vice Chair continued that while enhancing living donation may be outside the Committee's charge, a lot of the components in the report address aspects of protecting living donors and reducing barriers. A member stated that it is difficult to think about the impact of these recommendations without considering the recipients, and provided feedback that perhaps in the introduction section, the benefits of living donation and overarching impacts on the system should be explained.

The Chair discussed the impact of the Committee's third recommendation in helping identify pitfalls and shortcomings of the living donor process, particularly the evaluation process, to promote equity and transparency. The Chair also emphasized how important expanding data collection is and how it is described in multiple places in the report. The Vice Chair agreed, stating that the first two recommendations underscore the goal and need for the Committee's existing project. The Vice Chair asked how the Committee could incorporate the need for additional understanding on the impact on living donor candidates who do not go on to donate into the report. The Chair emphasized the need for transparency in center acceptance criteria, and noted that having long-term follow-up with an appropriate comparator group will aid this goal. The Vice Chair stated that this ties into recommendation three. An attendee noted that the Committee's emphasis on financial barriers is timely and represents huge barriers facing the community. A member asked about specific testing practices among centers and noted that testing can be a double-edged sword. Some information provided by the testing can yield helpful information about risks and outcomes, but some information may discourage patients or providers. Members discussed how their centers approach testing, including some of the nuances with testing for the APOL1 gene. The Chair noted that OPTN policy will never dictate clinical care, and an attendee commented that the Committee can do a lot with promoting transparency surrounding testing practices. The Vice Chair suggested including a clearer link to transparency in the best practices section in the report.

A member suggested including more information about what is currently known about living donor outcomes as context for understanding the Committee's recommendations. The Vice Chair agreed, noting that the Committee has done a lot of work to understand this prior data already, and stated that this could belong in Recommendation 2. A member asked about the discussion of the National Living Donor Assistance Center (NLDAC) and noted that the report did not state where additional funding would come from. The Chair responded that this was a good question and that the scope of the report does not necessarily include providing solutions, just suggestions for ways to enhance the system. The Chair added that it would be worthwhile to include the cost savings for living donor transplant versus keeping a patient on dialysis as context for the recommendations to expand federal assistance programs, understanding the relationship between the government and dialysis administration.

The Chair suggested including more specific references to evaluation tools used by centers as an area for technological improvement, as the OPTN could develop tools in this area to help programs. A member agreed, stating that they had just spoken to a patient that had expressed frustration with the National

Kidney Registry (NKR) evaluation tool, and that an alternative would be a good idea to explore. The Chair agreed, stating that centers can use tools such as Breeze, but that these can often be expensive and hard to use.

A member stated that the report should recommend a platform that lists each center with their specific acceptance criteria, and staff responded that this is included in Recommendation 6. A member stated that in multiple places in the report, it is alluded that a taskforce approach would be a good way to address the Committee's recommendations. This member asked if the report should take a stronger stance and request that the Board create a taskforce on enhancing living donation. Several members agreed with this suggestion. The Vice Chair stated that the report highlights the need to address multiple issues facing living donation and wondered how the report might be shared more widely. Staff noted that the report will be published on the OPTN website. An attendee asked if the OPTN had a social media presence, and noted that people may not think to look on the OPTN website, so finding alternate ways to get the report out to the public may be a good idea. Staff responded that the Committee can work with Communications to develop a plan to get the report out to the public.

Next Steps:

Members can send any additional feedback on the draft to staff via email. The finalized report will be presented to the Board of Directors in June.

Upcoming Meetings

- June 12, 2024 (teleconference)

Attendance

- **Committee Members**
 - Nahel Elias
 - Stevan Gonzalez
 - Henkie Tan
 - Tiffany Caza
 - Tyler Baldes
 - Dylan Adamson
 - Nancy Marlin
 - Ashtar Chami
 - Anita Patel
 - Camille Rockett
 - Alexandra Shingina
 - Kelley Hitchman
 - Laura Butler
- **HRSA Representatives**
 - Mesmin Germain
 - Arjun Naik
- **SRTR Staff**
 - Katie Siegert
 - Krista Lentine
- **UNOS Staff**
 - Kieran McMahon
 - Meghan McDermott
 - Samantha Weiss
 - Sara Langham
 - Kimberly Uccellini
- **Other Attendees**
 - Aneesha Shetty
 - Michael Chua