

OPTN Living Donor Committee

Meeting Summary

June 12, 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. Update and Improve Efficiency in Living Donor Data Collection Project: Overview and Next Steps
3. 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 the Committee of upcoming meeting dates. The Committee also heard an update on the work of the Expeditious Taskforce, which is focusing on the areas of efficiency, growth, and use and utilization. Members who are rolling off of the Committee were recognized.

The Vice-Chair and Chair discussed the community feedback of how this Taskforce did not include living donation, which in part, sparked the ask for the Enhancing Living Donation Report.

2. Update and Improve Efficiency in Living Donor Data Collection Project: Overview and Next Steps

The Committee heard a brief project overview ahead of when the project goes up for approval and discussed the most important aspects to emphasize throughout this process.

Presentation Summary:

A high-level overview of the project goals, scope, and plan were presented, along with information about the project approval process. The Vice-Chair emphasized the importance of how this project has been developed, including the step of taking time to develop a concept paper and working closely with the Scientific Registry for Transplant Recipients (SRTR). Staff went through what the Committee has already decided and the remaining decision points. The Vice-Chair underscored the need for taking the time to get this project right, as it requires new OPTN data collection.

Because this project is comprehensive, it has a relatively large resource estimate attached to it, which may mean additional scrutiny at the Policy Oversight Committee and Executive Committee levels.

Summary of Discussion:

A member volunteered to join the data workgroup. The Vice-Chair noted that these steps are important checks and balances and create a strong project, and that it is important to have everyone understand the project details and impact. A representative from the Health and Human Services Administration (HHS) asked about the timeline for revision of data elements once they are implemented, as typically

the OMB-approved forms are only approved for a couple years at a time. Another HRSA representative stated that the Committee should consider a periodic review of the forms as a future, cyclical effort in order to ensure that the forms are updated according to medical practice. The Vice-Chair agreed, stating that perhaps the OPTN should consider formalizing a periodic review process of policy and data elements across OPTN data collection. An attendee stated that in terms of efficient resource use for programming in the system, the Committee should propose updating all the data elements at once, then consider periodic updates to these as a future enhancement. The Vice-Chair underscored the high impact of this project, noting that the Committee has frequently run into problems making data-backed decisions because the data did not exist, and that this project would help address this problem. A member stated that living donor candidates deserve to know more about their future health outcomes.

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

The Committee discussed the finalized Report to the OPTN Board of Directors on Enhancing Living Donation ahead of it being presented to the Board.

Presentation Summary:

The Committee's finalized Report to the Board of Directors included seven recommendations:

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 what to emphasize when this is being presented to the Board.

Summary of Discussion:

The Vice-Chair explained that the goals of enhancing living donation are only supported by understanding barriers and collecting data, which harkens back to the Committee's project.

Next Steps:

An update will be sent out to the Committee following the project approval process and the Board Meeting with an update. A member asked that at the Board meeting, it will be important to discuss how a Taskforce approach will be proposed and implemented. This member argued that the Committee should build upon the success of Expeditious.

Upcoming Meetings

- July 10, 2024 (teleconference)

Attendance

- **Committee Members**
 - Nahel Elias
 - Stevan Gonzalez
 - Tiffany Caza
 - Tyler Baldes
 - Dylan Adamson
 - Nancy Marlin
 - Ashtar Chami
 - Danielle Reuss
 - Anita Patel
 - Camille Rockett
 - Alexandra Shingina
- **HRSA Representatives**
 - Mesmin Germain
 - Narwaz Shawir
- **SRTR Staff**
 - Katie Siegert
 - Krista Lentine
 - Avery Cook
- **UNOS Staff**
 - Kieran McMahon
 - Meghan McDermott
 - Samantha Weiss
 - Sara Langham
 - Sara Rose Wells
 - Jen Wainwright
- **Other Attendees**
 - Aneesha Shetty
 - Michael Chua
 - Milton Mitchell
 - Nathan Osbun