OPTN Living Donor Committee Meeting Summary September 13, 2023 Conference Call

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

Introduction

The OPTN Living Donor Committee (the Committee) met in via WebEx teleconference on 09/13/2023 to discuss the following agenda items:

- 1. Public Comment Presentation: Clarification of OPO and Living Donor Recovery Hospital Requirements for Organ Donors with HIV Positive Test Results
- 2. Public Comment Presentation: Recognizing Seasonal and Geographically Endemic Infections in Organ Donors: Considerations during Deceased and Living Donor Evaluation
- 3. Public Comment Updates

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

1. Public Comment Presentation: Clarification of OPO and Living Donor Recovery Hospital Requirements for Organ Donors with HIV Positive Test Results

The OPTN Ad Hoc Disease Transmission Advisory Committee (DTAC) presented their public comment proposal, *Clarification of OPO and Living Donor Recovery Hospital Requirements for Organ Donors with HIV Positive Test Results.*

Summary of Discussion:

The Vice Chair asked for more information on how the system handles situations when there are discrepancies in testing with both positive and negative results. The Chair of DTAC stated that if a deceased donor tested positive but a confirmatory test is negative and the individual is thought not to have HIV, then an organ procurement organization (OPO) is able to send organ offers out as HIV negative. The Chair of DTAC requested feedback on whether there are certain circumstances when this should not occur. The Vice Chair noted that it may be important to consider whether this has an impact on the non-use of organs.

A member agreed that creating guidelines for OPOs is necessary. The member asked what timeframe nucleic acid testing (NAT) should be performed. The Chair of DTAC stated there has not been a definitive answer to when the testing should be conducted due to consideration of multiple variables in the process.

The Chair stated that HIV testing considerations are different for living donation because there is more time in the process compared to deceased donation and feasibility to delay these transplants in most cases.

Another member asked whether there are data and literature on these topics from the general population. The Chair of the DTAC noted that the transplant populations are unique and general population data would not be comparable.

Next steps:

The Committee's feedback will be summarized and submitted to the DTAC for consideration.

2. Public Comment Presentation: Recognizing Seasonal and Geographically Endemic Infections in Organ Donors: Considerations during Deceased and Living Donor Evaluation

The OPTN Ad Hoc Disease Transmission Advisory Committee (DTAC) presented their public comment proposal, *Recognizing Seasonal and Geographically Endemic Infections in Organ Donors: Considerations during Deceased and Living Donor Evaluation.*

Summary of Discussion:

The Chair noted that since travel is more accessible, donors come from all over. The Chair asked whether DTAC has considered universal screening. The Chair of DTAC responded that there are some universal screenings such as toxoplasmosis. The Chair of DTAC added that screening is balanced based on the number of events that occur, the likelihood of positive screening, and the burden on the living donors, transplant programs, OPO.

A member noted support for having more required serology testing within the 28-day timeframe and have more testing occur closer to the donation. The member noted that living donors come from a wide range of locations and also have travelled to a wide range of locations. The member added that climate change is also impacting endemic regions. The Chair of DTAC noted that this proposal is a guidance document that will help transplant programs to develop internal screening and testing processes for living donors who may come from outside their region. The member added that DTAC may consider developing guidance for paired donation as there are additional complexities in those processes.

Next Steps:

The Committee's feedback will be summarized and submitted to the DTAC for consideration.

3. Public Comment Update

Members discussed public comment feedback received to date on their concept paper, Concepts for a Collaborative Approach to Living Donor Data Collection.

Summary of Discussion:

A member stated that feedback from their region was mostly supportive especially in regards to collecting more data about access and barriers to living donation. The member noted that some feedback suggested collecting data earlier than what was proposed in the concept paper. The member stated that additional feedback included concerns about the level of participation in long-term follow-up from living donor candidates and living donors, and suggestions to leverage technology.

The Chair noted feedback from the OPTN Patient Affairs Committee that expressed concern that the added burden would cause transplant programs to perform less living donor evaluations, therefore decreasing living donation.

An SRTR representative noted that living donor candidates and living donors have the option and the right to opt out of follow-up with the Living Donor Collective at any point and that decision would be respected.

The Vice Chair agreed that the community has been supportive of the goals of the project. The Vice Chair stated that there are two areas of concern from community feedback. The Vice Chair said the first of these concerns is the logistics and burden for implementing any version of the conceptualized future state of living donor data collection. The Vice Chair stated that the second concern from the community

is the ability for the Living Donor Collective to perform the long-term follow-up in a meaningful way. The Vice Chair stated that a focus on education may help alleviate some of these concerns.

Another member noted feedback from their region on the variations in definitions for living donor evaluation. The member stated that the Committee may need to accept that there are variations in practice but continue forward in order to start collecting the necessary data. The member added that their region was also interested in showing proof that these concepts will work in practice. The member stated additional feedback expressed concern around funding and ease of data entry.

The Vice Chair stated that the Committee will need to continue to collaborate with OPTN committees as the proposal continues to be developed.

Next Steps:

The Committee will continue to review and discuss public comment feedback.

Upcoming Meetings

• October 3, 2023 (Detroit, MI)

Attendance

• Committee Members

- o Anita Patel
- o Annie Doyle
- o Ashtar Chami
- o Camille Rockett
- o Catherine Huynh
- o Danielle Reuss
- o Dylan Adamson
- o Henkie Tan
- o Karen Ormiston
- o Kelley Hitchman
- o Nahel Elias
- o Nancy Marlin
- o Stevan Gonzalez

• HRSA Representatives

- o Arjun Naik
- o Mesmin Germain
- SRTR Staff
 - o Avery Cook
 - o Caitlyn Nystedt
 - o Krista Lentine

• UNOS Staff

- o Jennifer Wainright
- o Laura Schmitt
- o Meghan McDermott
- o Samantha Weiss
- o Sara Rose Wells
- o Tamika Watkins