Meeting Summary

OPTN Ad Hoc International Relations Committee
Management of International Living Donors in the U.S
Meeting Summary
August 27, 2024
Conference Call

Peter Stock, MD, Chair Cynthia Forland, Ph.D., Vice Chair

Introduction

The Management of International Living Donors in the U.S Subcommittee (the Subcommittee) met via WebEx teleconference on 08/27/2024 to discuss the following agenda items:

- 1. Review & Confirm: Content of guidance document subsections
- 2. Review: Plan for guidance document development & expectations

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

Review & Confirm: Content of guidance document subsections

The Subcommittee reviewed the barriers to evaluating international living donors as identified below and confirmed the content for those barriers. The subcommittee also discussed collaboration efforts to work within their groups to develop the guidance document. The goal of the guidance document is to provide transplant programs with common practices for more effectively and efficiently evaluating international living donors in the U.S.

The 5 barriers that will be outlined in the guidance document include:

- Communications barriers
- Logistics barriers
- Risk of exploitation, inducement, and coercion barriers
- Post-donation donor follow-up barriers
- Legal barriers

The project is slated for January 2025 public comment cycle

Communication Barriers

This section of the guidance document will focus on the following components related to the barrier:

- Methods of communication
 - o Better understanding of how centers make initial contact with the potential donor
 - Better understanding of how donation materials are sent to the potential donor
 - o Better understanding of obtaining and translating medical records
 - How donor materials are provided to non-English and non-Spanish speakers
- Cultural communication considerations

- Better understanding of the discernment of non-verbal cues of coercion when evaluating a potential international donor
- Determine who does the consent for donation and determine the risk of coercion.

Logistics barriers

This section of the guidance document will focus on the following components related to the barrier:

- Assessment of donor screening and evaluation
 - o Better understanding when the center brings the donor for an in-person evaluation
 - Center's ability to help potential living donors obtain a visa
 - Better understanding of who covers the cost of the international living donors travel to the transplant center, lodging, and return home.
 - Donor complications post-donation determining how this is paid for.
 - o Determine how donor lab reports are obtained

Risk of exploitation, inducement, and coercion barriers

This section of the guidance document will focus on the following components related to the barrier:

- Defining exploitation, coercion, and inducement
- Assessment of motivation for donation
 - Assessment of the recipient and potential donor relationship
- Ways to achieve bidirectional cultural competencies to evaluate the donor
 - o Assessment to ensure potential donor understands the donation process and impact

Post-donation donor follow-up barriers

This section of the guidance document will focus on the following components related to the barrier:

- Follow-up care post-donation
 - o Better understanding follow-up rate between NCR and NCNR
 - Better understanding of how donors get labs drawn, how it's paid for, and how the center retrieves lab results post-donation
 - Better understanding of post-donation complications

Legal barriers

This section of the guidance document will focus on the following components related to the barrier:

- Better understanding of how centers are categorizing non-U. S citizens/residents (NCR) and non-U.S citizens/non-U.S residents (NCNR)
- Better understanding of how center's ability to accept transplant donor candidates based on legal status
- Better understanding of donors' access to insurance based on the legal status of the recipient
- Better understanding of additional barriers to donation for NCR and NCNR
- Better understanding of donors' insurance and access to care post-donation once they have returned to their home country.

Summary of discussion:

This was not an agenda item that required a decision.

The Chair stated that after the guidance document is developed, it could potentially be published in a journal. He also noted that the guidance document should include recommendations or a summary of common practices to address the barriers. Staff clarified that transplant programs were surveyed to better understand the barriers faced when evaluating an international living donor. The common practices will be based on the results of the transplant programs.

Regarding the legal barrier, a member stated that not only is it essential to consider the donors' access to insurance based on the recipient's legal status, but it's also essential to consider the donor's insurance coverage post-donation follow-up and access to care once they return to their home country. He noted that the recipient's insurance will no longer cover the donor post-donation. The Chair agreed and explained that when the donor is being worked up for a transplant, the recipient's insurance pays the donor's workgroup.

Regarding the communication barrier, a member noted that it maybe important to include information in the guidance document about the consent for donation and who determines if there is risk of coercion. He explained that this topic may overlap with another section; however, it is crucial to consider this as a communication barrier.

Regarding the logistics barrier, a member added that it should be considered how the cost is covered if the donor experiences post-donation complications and needs to return to the U.S. for care. He also inquired how long the donor stays in the U.S. after surgery before returning to their home country. A member shared that in his experience, the donors typically stay for a week. A member also added that it's important to include how donor lab reports are obtained.

Next steps:

The Subcommittee will begin working within their groups to develop their section of the guidance document.

Upcoming Meeting

September 24, 2024

Attendance

• Subcommittee Members

- o Angele Lacks
- o Ashtar Chami
- o Cynthia Forland
- o George Bayliss
- o Julie Spear
- o Abby Ruiz
- o Peter Stock
- o Taryn Shappell

• HRSA Representatives

- o Jim Bowman
- o Marilyn Levi
- o Penni McMahan

• SRTR Staff

o Avery Cook

UNOS Staff

- o Tamika Watkins
- o Brendon Cummiskey
- o Cole Fox
- o Laura Schmit

• Other Attendees