

Meeting Summary

OPTN Living Donor Committee
Meeting Summary
November 18, 2020
Conference Call

Heather Hunt, JD, Chair Titte Srinivas, MD, Vice Chair

Introduction

The Living Donor Committee (the Committee) met via Citrix GoToMeeting teleconference on 11/18/2020 to discuss the following agenda items:

- 1. National Living Donor Assistance Center Presentation
- 2. New Project Decision

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

1. National Living Donor Assistance Center Presentation

The National Living Donor Assistance Center (NLDAC) presented an update on their program expansion. NLDAC's mission is to reduce financial disincentives to living organ donation.

Summary of discussion:

NLDAC is expanding their program to assist applicants who are lawfully present residents. NLDAC's program expansion will help cover lost wages and child/elder-care expenses, as well as travel expenses. NLDAC is expanding to cover those applicants below 350 percent of the Department of Health and Human Services (HHS) poverty guidelines, which covers about 67 percent of United States households. Additionally, NLDAC is planning to allow non-directed donors to apply without an identified recipient.

A member asked what the average reimbursement is per donor. NLDAC staff responded that the average changes based on applicants who donate and applicants who are evaluated but unable to donate. NLDAC added that they work on an individual basis in order to best address each donor's needs through reimbursement.

Another member asked if the usage report showed a breakdown of applicants that were not approved. NLDAC staff stated those numbers are relatively small but will look further into it for the Committee.

A member stated that transplant programs have difficultly determining whether or not donors will be covered by recipients' insurance, or if they should apply to NLDAC's program. NLDAC staff responded that there are three ways (state programs, insurance company, or organ recipient) that a donor can be covered. NLDAC staff stated that their organization is open to working collaboratively with other programs and continues to work towards not being viewed as a payer of last resort, by the community.

Additionally, the member asked if NLDAC is moving towards lessening restrictions on non-directed donors since there are no additional recipient screening criteria for the non-directed donors. NLDAC staff responded that this change comes from HRSA being responsive to the community, since non-directed donors do not have recipients. NLDAC staff added that non-directed donors will be means tested on their household income, and prioritized in categories one through four.

Next Steps:

NLDAC staff offered to come present to the Committee again once the program expansion is established.

2. New Project Decision

The Committee discussed their top project ideas to decide which projects to pursue.

Summary of discussion:

Evaluating Exclusion Criteria in Living Donor Policy

Based on previous discussions, the Committee agreed to pursue this topic as a project.

Prior Living Donor Priority

The Committee discussed the prospect of adding living vascularized composite allograft (VCA) donors to be included in kidney prior living donor priority policy. The Committee reviewed a data table which showed the number of waiting list registrations for prior living donors by waitlisted organ and donated organ, from 1994 - 2019. Staff explained that within the table there are patients who were listed for multiple organs which is counted as separate registrations. Additionally, within the table there are patients who were listed multiple times for the same organ which is only counted as one registration.

A member stated that the data table highlights the importance of allowing living donors to cross over for prioritization in other organ areas. Other Committee members agreed. The member requested more data regarding the time between donation and listing, the date of donation, total living donations per organ, age, and liver donors' diagnoses at time of listing.

The Chair stated the Committee needs to decide whether their project will address adding living VCA donors to the current list of donors who receive priority points for kidney transplantation or change policy language to include "all living donors". A member stated that this project should address all living donors receiving priority for all organs, not solely kidney priority. Some committee members agreed.

Another member stated they felt conflicted about adding living uterus donors to the prior living donor priority. The member explained that uterus transplant is a life enhancing transplant and not a lifesaving transplant. The member added the deceased donor supply of uteri was thought to be enough to cover the demand of uterus transplants, so adding prior living uterus donors to priority would impact some candidates who had been waiting a long time. Another member responded that data shows the most successful uterus transplants have come from living donors.

A member cautioned the Committee from creating value systems for living donors. Another member agreed and stated the system should reward prior living donors based on reciprocity of the act of giving and not based on the potential future consequences from donating.

Another member asked if it is in the purview of the Committee to address this policy if it is under the kidney policy section. Staff responded that the OPTN Kidney Transplantation Committee will have to be involved in discussions for this project. Staff further added that as the organ specific committees continue to develop continuous distribution projects, there is opportunity for the Committee to bring prior living donor prioritization to those discussions. A member asked for more information on how the current prior living donor priority policy was developed.

The Committee agreed to pursue this topic as a project.

Next steps:

Project forms for each project will be developed. The Committee will review project plans at the next Committee meeting. Once scope and goal are determined, the projects will be taken to the Policy

Oversight Committee (POC) for approval. Based on POC approval, the Committee will build a project timeline, a workgroup roster, and schedule meetings.

Upcoming Meetings

- December 9, 2020 (teleconference)
- January 13, 2020 (teleconference)

Attendance

Committee Members

- Aneesha Shetty
- Angie Nishio Lucar
- Carol Hay
- o Carolyn Light
- Heather Hunt
- Jessica Spiers
- Katey Hellickson
- Mark Payson
- Mary Beth Stephens
- Nahel Elias
- Omar Garriott
- o Pooja Singh
- Randy Schaffer
- o Roberto Hernandez
- Stevan Gonzalez
- o Vineeta Kumar

• HRSA Representatives

- Adriana Martinez
- o Mesmin Germain

SRTR Staff

- o Bertram Kasiske
- Krista Lentine
- Michael Conboy

UNOS Staff

- o Kerrie Masten
- o Leah Slife
- Lindsay Larkin
- o Meghan McDermott
- o Michelle Rabold
- Sarah Booker
- Tina Rhoades

• Other Attendees

- Kimberly Gifford
- o Sidni Booker