

OPTN Living Donor Committee Meeting Summary July 8, 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 07/08/2020 to discuss the following agenda items:

- 1. Public Comment Update
- 2. New Project Review and Discussion
- 3. Committee Orientation

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

1. Public Comment Update

The Committee received an update on the upcoming Public Comment period.

Summary of discussion:

The Social Media Paper was removed from the Public Comment slate. The Social Media Paper will be repurposed into a UNOS education resource to allow it to have the highest level of visibility and impact.

Modify Living Donor Policy to Include Living Vascularized Composite Allografts (VCA) Donors will go out to Public Comment in August. The proposal is drafted and under final review.

Regional Meetings are now virtual, and the dates have remained the same.

Next steps:

Staff will follow up with Regional Representatives on regional meeting presentations.

2. New Project Review and Discussion

The Committee continued discussion on new project ideas.

Summary of discussion:

New potential project ideas:

- Evaluate Exclusion Criteria in Living Donor Policy
- Living Donation in Multi-Organ Transplant
- Disparity in Access to Living Donation

Tabled project ideas:

- Use of Living Donation for other types of Liver Disease
 - Documented as a project idea to revisit at a later date
- Optimization of Living Donor Follow-up (LDF) form

o Revisit after Committee receives presentation on updated data process

A member asked about the concerns and arguments raised regarding absolute contraindications to living donation. Another member responded that in regards to malignancy, a program specifically asked about a potential donor who had low grade prostate carcinoma. The program requested information on the ability to utilize this donor and the possible implications that could occur if they continued with the transplant. Additionally, the program wished to know if the exclusionary criteria is relevant to all malignancies. The member explained a second query came from another program requesting diabetes to be removed as an absolute contraindication from policy. The program argued that this policy change would potentially open access to large numbers of living donors.

Another member stated the importance of periodic evaluation of criteria as well as interest in comparing the United States' exclusion criteria to other countries' policies. A member stated that research needs to be examined to understand if removing certain exclusion criteria would be in the best interest of the patient. Another member agreed and mentioned that age should be considered as well.

A member stated the Committee should consider the necessity of disclosing living donor information to a patient and the possible violations of Health Insurance Portability and Accountability Act (HIPPA). Another member responded that there is language in current policy that provides guidance to programs and donors about what information will and will not be shared.

A member asked if staff could find when the current policy was implemented and what evidence the Committee cited for their decision making. Staff responded that that information will be researched. The Chair asked staff to give the Committee an overview on the processes and timeline of developing potential project ideas. Staff responded that depending on the project the Committee chooses, the next steps would include developing a problem statement and proposed solution. Additionally, the Committee will gather literature for review and submit a formal data request to the research team.

In regards to the living donation in multi-organ transplant project idea, a member stated the Committee should research the frequency and barriers of multi-organ transplantation. Another member asked if multi-organ transplant is performed in living donors or only deceased donors. A member responded that policy does not prohibit a patient from receiving multiple living donor organ transplants. Additionally, there is no language prohibiting a living donor to donate multiple organs at the same time. The member continued to explain that while there are no prohibitions in policy, they are not aware of either instances being performed. A member stated that multi-organ transplants is increasing, but living donation in multi-organ transplant is likely an underutilized resource. The member suggested developing education materials for providers and patients. Another member stated that the Committee should analyze how this project could potentially fit into the broader OPTN project of multi-organ transplant allocation prioritization.

The Chair requested that the Committee continue to think of concrete ideas that would impact disparities in access to living donation and to consider it a central theme to ongoing project work.

Next steps:

The Committee will continue discussion on project ideas. Staff from Data Governance will present on the new data update process during the August meeting.

3. Committee Orientation

New committee members were informed of the policy development process, committee structure, committee purpose, and committee member expectations.

Upcoming Meeting

- August 12, 2020 (teleconference)
- September 9, 2020 (teleconference)