

# Meeting Summary

# OPTN Living Donor Committee Meeting Summary May 12, 2021 Conference Call

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

#### Introduction

The Living Donor Committee (the Committee) met via Citrix GoTo Meeting teleconference on 05/12/2021 to discuss the following agenda items:

- 1. Prior Living Donor Priority Discussion
- 2. Voting Item: Living Donor Vascularized Composite Allograft (VCA) Language Review

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

#### 1. Prior Living Donor Priority Discussion

The Committee continued their discussion regarding prior living donor priority.

#### Summary of discussion:

Rationale for prior living donor priority:

- Medical rationale
  - Intrinsic risk of donation
  - Still unknown risk associated with donation
  - Prior living donor need for transplant has historically been very low
- Ethical rationale
  - o Sends message to the public that the system values living donors
  - o Offers support and assurance for the donor and the donor's family
  - Societal value of reciprocity

Drafted recommendations:

- Prior living donors should receive priority if they are listed for transplant
- Prior living donors should receive priority for any organ needed
- Prior living donor priority should not have a time restriction
- Prior living donors should not be valued differently based on type of donation

A representative from the OPTN Vascularized Composite Allograft (VCA) Committee joined the meeting to aid in prior living donor priority regarding living VCA donors. The representative stated that while the field is small now, it will grow exponentially. The representative stated support for including living VCA donors in prior living donor priority because they believe in promoting living donation. The representative added that they understood the difficulty of comparing a VCA to a non-VCA transplant.

The VCA Committee representative stated that the decision to be a living donor for non-VCA organs is made in consideration of their health more than a living VCA donor. The representative explained that

living VCA donors do not have to consider the loss of function in their donation because the VCA organ (i.e. uterus) has already served its purpose to the donor.

A member stated that when current prior living donor policy was developed, the Committee did not base access to future kidney transplant upon the type of donation, the motivation, nor the risk to organ specific function for the living donor. The member also stated that the Committee has discussed the inherent risk of procedure to bilateral ureteral injuries, and more specifically, the possibility of a living uterus donor developing obstruction related chronic renal disease resulting in the need for a transplant in the future. The VCA Committee representative responded that there is risk in the uterus donation procedure, and there have been two instances of re-implantation of the ureters. The representative added that there have been no effects on the kidney function of living uterus donors, but it is unknown how the risks will change as the field develops. The member responded that these discussions are about providing foundational protections for living donors.

Another member highlighted the differences between living kidney donation and living uterus donation. The member expressed concerns of prioritizing a prior living VCA donor over a patient who may potentially die on the waitlist, given the limited amount of organs available. A member responded that the Committee advocates for the living donor community. The member added that the Committee will provide their prior living donor priority recommendation to the organ-specific committees, who will then determine where prior living donors belong within their continuous distribution system.

A member stated their support for prior living donor priority for all living donors because it is the right action for the Committee to support. The member added that the Committee should trust the organ specific committees to factor this recommendation into their allocation systems.

The Chair stated support for including living VCA donors in their prior living donor priority recommendations. The Chair explained the reasoning for support is based on the small number of living VCA donations, the charge of the Committee to protect all living donors, trust of medical professionals' assessment of donors, and the ability to revisit this decision annually to review facts and data.

Another member stated that the Committee should trust the judgement and integrity of transplant programs to properly evaluate patients to ensure priority for all living donors is not misused. The member added that simple, straight forward, and transparent recommendations are better, and the Committee must maintain focus on the best interest of living donors. The member agreed with future monitoring of these recommendations.

A member asked about the evaluation processes for living VCA donors. The VCA Committee representative stated that there were no VCA-specific regulations in the beginning, but their program followed the same evaluation processes that are utilized for living liver donors. The representative stated that specific attention is paid to the motivation to donate, as most of the donations are altruistic. The representative added that their program only accepts a living uterus donor that has taken precautions towards sterilization to show they are finished with their own family formation, and these precautions must have occurred before they come forward to be evaluated as a living uterus donor.

Another member stated that the Committee should not value prior living donors differently based on type of donation. A member stated that as the VCA field evolves, their opinion may change but they prefer to trust the system to enforce a policy that is fair and equitable.

The Committee voted on the four recommendations with the caveat that the Committee will revisit recommendations annually and/or as the VCA field evolves. The majority of members voted in support of all four recommendations. One member did not support the fourth recommendation, *prior living* 

*donors should not be valued differently based on type of donation,* because they did not agree with including living VCA donors. The member voted in support of the other three recommendations.

## Next steps:

A memo detailing these recommendations will be drafted and sent to the Committee for review. Upon review, the memo will be sent to the organ specific committees.

## 2. Voting Item: Living Donor Vascularized Composite Allograft (VCA) Language Review

The Committee reviewed the updated language for their proposal, *Modify Living Donation Policy to Include Living VCA Donors*.

## Summary of discussion:

The living donor VCA proposal was delayed due to concerns about language in the updated definition of VCA. The proposal was removed from the December 7, 2020 OPTN Board of Directors meeting agenda to ensure proposed language would be in alignment with the VCA Committee's language clarification. The VCA Committee finalized their proposed changes and living donor policy language has been updated to match.

VCA Committee proposed changes:

- Relocate the list of covered body parts in policy so that it does not appear to either narrow or expand the definition of VCA as defined in the Final Rule.
- Modify the list of covered body parts to be exclusive.
- Updated all policies specific to VCA to more clearly identify the body parts covered by those policies. Living donor policy language updated to match the updated VCA language.

## VOTE

Does the Living Donor Committee support sending the proposed language to the OPTN Board of Directors at their June 2021 meeting?

The Committee unanimously supported sending the proposed policy language to the OPTN Board of Directors for the June 2021 meeting.

### **Upcoming Meetings**

- June 9, 2021 (teleconference)
- July 14, 2021 (teleconference)

#### Attendance

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### • Committee Members

- Angie Nishio Lucar
- Carol Hay
- o Carolyn Light
- Heather Hunt
- Jessica Spiers
- Katey Hellickson
- Mark Payson
- Nahel Elias
- Randy Schaffer
- Roberto Hernandez
- Stevan Gonzalez
- **HRSA Representatives** 
  - Arjun Naik
  - Jim Bowman
  - o Marilyn Levi
  - Michael Conboy
  - o Raelene Skerda
  - o Vanessa Arriola
- SRTR Staff
  - o Bert Kasiske
  - o Krista Lentine
- UNOS Staff
  - Kaitlin Swanner
  - o Leah Slife
  - Lindsay Larkin
  - Matthew Prentice
  - Meghan McDermott
  - Nicole Benjamin
  - Sarah Booker
  - Tina Rhoades
- Other Attendees
  - o Liza Johannesson