

OPTN Vascular Composite Allograft Transplantation Committee

Meeting Summary

October 14, 2020

Conference Call

Bohdan Pomahac, MD, Chair
Sandra Amaral, MD, Vice Chair

Introduction

The OPTN Vascular Composite Allograft Transplantation Committee (the Committee) met via Citrix GoToMeeting teleconference on 10/14/2020 to discuss the following agenda items:

1. Review public comment feedback
2. Review top project ideas
3. Membership requirements for genitourinary programs
4. Increase awareness of VCA donation & transplantation

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

1. Review public comment feedback

The Committee reviewed public comment feedback for their proposals *Programming VCA Allocation in UNetSM* and *Modify Data Collection on Living VCA Donors*.

Summary of discussion:

The Committee discussed feedback on the *Modify Data Collection on Living VCA Donors* proposal.

American Society of Transplantation (AST): Collect more granular data for disease testing

A member asked about the implications of submitting equivocal vs unknown as a response to infectious diseases on the Living Donor Registration (LDR). UNOS staff shared that the help documentation for the Living Donor Registration (LDR) provides the following guidance for indicating equivocal results: "For an equivocal (or indeterminate) result that changes to either positive or negative, change the result to the newer more specific value even though it may be a different test date. For a result that was originally equivocal (or indeterminate) or remains equivocal (or indeterminate) after repeated testing, record as "UNK/cannot disclose"."

AST: Collect data on syphilis screening for uterus donors

OPTN policy requires syphilis screening for living donors and requires the screening to be documented in the living donor's medical record. A member asked about a scenario in which a patient tested positive for syphilis at the time of medical evaluation. She asked if the patient would be treated and if so, would it be acceptable to enter the negative test result after treatment. A member responded that her program would offer treatment and continue consideration of this potential living donor. Since uterus transplant programs would treat the donor and enter the negative test result produced after treatment, members did not think it would be helpful for these data on syphilis screening to be reported to the OPTN.

AST: Collect "anesthetic complications" under "intraoperative complications" for all VCA living donors

A member reported that all other living donors, except for lung, do not collect this data. A member pointed out that guidance on which complications fall under these rather generic categories may be helpful for the program staff who must complete this form. Members thought that information on anesthetic complications may be more relevant for lungs than for VCA but agreed it is always far more useful to have more detailed information on complications. Accordingly, the Committee recommended including “anesthetic complications” under “intraoperative complications” on the LDR for all VCA living donors.

AST: Collection on “post- operative complications during the initial hospitalization” in addition to “complications requiring intervention”

Initially, the Committee proposed collecting data on “complications requiring intervention” for uterus and for other VCA following living donation, as currently collected for living kidney donors. During public comment, AST recommended collecting data on “post-operative complications during the initial hospitalization,” as currently collected for living lung donors. The Committee recommended broadening the data element on the LDR to “post- operative complications” to include both those during hospitalization and those that require intervention. Members also recommended keeping “complications since donation” as is on the Living Donor Follow-up (LDF).

AST & Ethics: Collect new onset psychological symptoms for all VCA living donors

Members agreed psychological symptoms data should be collected on the LDF, but added that guidance should be clear on and how and what to collect. The Vice Chair said that a member of the Living Donor Committee (LDC) supported this data collection for all VCA living donors, and suggested that the LDC consider adding this data collection for all living donors as part of a future project. The Chair noted that this data collection would apply to any future VCA living donor that is not genitourinary, and such transplants are not being performed currently. Members discussed the best way to collect high-quality data on psychological symptoms. A member suggested that patients could self-report using a questionnaire such as the SF-36, but other members voiced concern about data accuracy and use issues. The committee discussed the benefits of collecting this data in a similar fashion as registries, such as providing continuity for safety and research. UNOS staff clarified that major changes to this proposal in terms of how data on new onset psychological symptoms are collected are not feasible at this time, but could be an opportunity for additional development in the future. After hearing this, the committee decided that data on new onset psychological symptoms should be collected for all living donors.

Comment: Add data collection regarding changes in gender self-identification

The Committee recommended adding “change in body image” as an option under “New onset of psychological symptoms.” The Committee chose the phrase “change in body image” over “gender dysphoria” because members noted that gender dysphoria may be an existing, ongoing condition for a living donor, but that it would not develop as a new-onset psychological symptom as a result of VCA donation.

Next steps:

The Committee will complete the review of public comment feedback by email in order to be prepared to finalize the proposal by October 26, 2020.

2. Review top project ideas

Summary of discussion:

The Committee did not have time to address this agenda item.

Next steps:

The Committee will address this agenda item at their next meeting.

3. Membership requirements for genitourinary programs

Summary of discussion:

The Committee did not have time to address this agenda item.

Next steps:

The Committee will address this agenda item at their next meeting.

4. Increase awareness of VCA donation & transplantation

Summary of discussion:

The Committee did not have time to address this agenda item.

Next steps:

The Committee will address this agenda item at their next meeting.

Upcoming Meetings

- October 26, 2020 (Virtual “In- Person”)
- November 18, 2020 (Teleconference)

Attendance

- **Committee Members**
 - Sandra Amaral
 - Bruce Gelb
 - Darla Granger
 - Lawrence Gottlieb
 - Liza Johannesson
 - Nicole Johnson
 - Debbie McRann
 - Gary Morgan
 - Bohdan Pomahac
 - Debra Priebe
 - Simon Talbot
 - Stefan Tillius
 - Mark Wakefield
 - Linda Cendales
- **HRSA Representatives**
 - Jim Bowman
 - Marilyn Levi
- **SRTR Staff**
 - Bryn Thompson
- **UNOS Staff**
 - Kristine Althaus
 - Sally Aungier
 - Kelley Poff
 - Tina Rhoades
 - Sharon Shepherd
 - Leah Slife
 - Kaitlin Swanner
 - Susan Tlusty
 - Roger Vacovsky
 - Jen Wainright
 - Karen Williams