

OPTN Vascularized Composite Allograft (VCA) Transplantation Committee Meeting Minutes May 8, 2019 Conference Call

Linda Cendales, M.D., Chair Bohdan Pomahac, M.D., Vice Chair

Introduction

The Vascularized Composite Allograft (VCA) Transplantation Committee met via Citrix GoTo teleconference on 05/08/2019 to discuss the following agenda items:

1. Project Discussion-Update to VCA Transplant Outcomes Data Collection

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

1. Project Discussion-Update to VCA Transplant Outcomes Data Collection

The Committee will review the:

- list of proposed data points developed during the in-person meeting to ensure it is ready for wider sharing.
- Base line data set collected on all VCA transplants to ensure 1) relevancy, and 2) applicability for developing VCA transplants.

Data summary:

- A. Work Plan for the development of this project.
 - a. Review any corrections/modifications
 - b. Outreach to VCA transplant community
 - Contacting OPTN approved VCA transplant programs and asking for feedback.
 - c. Bring the feedback back to the Data Subcommittee
 - d. Engage with stakeholder OPTN committees
- B. Project Timeline
 - a. May/June 2019: Engage VCA community for feedback
 - b. August/ September 2019: Engage with other OPTN committees
 - c. October 2019: Committee Vote
 - d. January 2020: Go out for Public Comment
 - e. June 2020: OPTN Board of Directors
- C. Recent Work
 - At the VCA committee in-person meeting earlier this year, members broke into breakout groups by VCA type and discussed potential improvements to the TRR (Transplant Recipient Registration) and TRF (Transplant Recipient Follow up)
 - b. A matrix of all the proposed changes was circulated and reviewed.

Summary of discussion:

The Committee reviewed all data fields in the VCA TRR form. Members were asked to keep in mind 1) What should be collected on all VCA transplants regardless of type 2) Review the content in the forms and what changes are needed 3) Will these data fields work for future VCA types.

Below are what sections members proposed changing:

- Patient Hospitalization/life support
- Tolerance induction technique
- Number of pre-transplant pregnancies
- Malignancies
- Risk Factors
- Pre/post-transplant labs
- SF-36 Score
- Cognitive and Motor development
- Carroll Test score

In conclusion, the committee decided that the VCA Transplant Outcomes Subcommittee would review the TRF form.

Next steps:

- UNOS Staff will
 - Create a summary of all the proposed changes and will contact VCA Program Directors and other key stakeholders for their feedback.
 - Schedule calls with subcommittee members and other key stakeholders from the VCA community.

Upcoming Meeting

• June 12th, 2019 Committee call

Attendance

• Committee Members

- o Timothy Pruett
- Lawrence Levin
- Linda Cendales
- Danielle Niedfeldt
- Sandra Amaral
- o Bohdan Pomahac
- Shelia Jowsey
- Linda Irwin
- Matthew Scott

HRSA Representatives

- o Jim Bowman
- o Marilyn Levi
- Shannon Dunne

UNOS Staff

- o Sakshi Thassu
- o Chris Wholley
- Hannah Byford
- o Paula Dehetre
- Jen Wainright
- o Leah Slife