

OPTN Vascularized Composite Allograft Transplantation Committee

Meeting Summary

January 24, 2024

Conference Call

Sandra Amaral, MD, MHS, Chair
Vijay Gorantla, MD, PhD, Vice Chair

Introduction

The OPTN Vascularized Composite Allograft (VCA) Transplantation Committee (Committee) met via Webex teleconference on 01/24/2024 to discuss the following agenda items:

1. Donation and Allocation of VCA Organs in Clinical Practice: Candidate Side
2. Expeditious task force update
3. Potential Project Ideas: Brainstorming Session
4. Open Forum

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

1. Donation and Allocation of VCA Organs in Clinical Practice: Candidate Side

Current data collection in the OPTN Computer System allows for candidate registration, acceptance, and removal at the body part level for covered VCAs. The Committee considered whether current data collection for candidate registration, acceptance, and removal reflects clinical practice for the following covered VCAs:

- External male genitalia
 - Selection options: Penis, scrotum
- Head and neck
 - Selection options: Face, larynx, scalp, trachea, vascularized parathyroid gland, vascularized thyroid
- Other genitourinary (GU)
 - Selection options: External and internal female genitalia (other than uterus, cervix, vagina), internal male genitalia, urinary bladder

Summary of discussion:

Decision #1: Head and Neck – The Committee decided to display selection options as follows: face; larynx; scalp; trachea; vascularized parathyroid gland; vascularized thyroid.

Decision #2: Other GU – The Committee decided to display selection options as follows: external and internal female genitalia (other than uterus, cervix, vagina); internal male genitalia; urinary bladder.

The Committee recommended the selection options for candidate registration, acceptance, and removal remain at the body part level for head & neck and other GU. A member said the Head and Neck specialist at their organization confirmed there are instances in which only the face is transplanted, so selection at the body part level is necessary. A member who specializes in other GU transplantation VCA confirmed there were no changes needed to the selection options for other GU. There were no external

male genitalia subject matter experts on the conference call, however, a subject matter expert followed up with OPTN contractor staff via email.

Next steps:

The Committee will discuss questions to improve the functionality of the OPTN Computer System and will begin working on the Donor Side of Donation and Allocation of VCA Organs in Clinical Practice.

2. Expeditious task force update

The [Expeditious task force](#) was established by the OPTN Board of Directors in September 2023 to study and make recommendations to improve the efficiency of the OPTN. The Committee received an overview of the task force and their work to date.

Summary of discussion:

There was no further discussion about the Expeditious task force.

Next steps:

The Committee will continue to receive updates about the work of the Expeditious task force.

3. Potential Project Ideas: Brainstorming Session

The Committee continued previous discussions surrounding potential project ideas. They considered the following potential projects:

- Project to address the barriers to creating and expanding VCA programs
- Project that leverages the Limb Loss and Preservation Registry
- Project to capture the voice of donor families and recipients (and recipient families)

Summary of discussion:

Although third-party payment and clinical standards of care are out of scope, the Committee discussed whether these factors could be considered barriers to equitable access to VCA transplantation. The Chair prompted Committee members to consider project ideas that involve indirect ways to identify and address inequitable access to VCA transplantation. Suggestions included data collection for potential candidate demographics or to capture candidates that were referred to a VCA transplant program but were not registered to the waitlist or did not receive transplant. A representative from the Health Resources and Services Administration (HRSA) noted that guidance and white papers are two ways the OPTN has indirectly addressed issues related to access and equity in the past.

A member suggested a project involving the [Limb Loss and Preservation Registry](#) (LLP Registry) to increase awareness about the possibility of VCA transplantation through patient education. The LLP Registry aggregates data from hospitals and prosthetic & orthotic providers to measure quality outcomes for patients with a limb loss or limb difference and encourages self-management of care. A member advised that there may be an opportunity to leverage the LLP Registry's network of stakeholders to promote VCA transplantation as an option for patients who may have not otherwise considered it.

The Committee discussed pursuing a project to increase awareness of quality-of-life improvements associated with VCA transplantation. A member specializing in uterus transplantation noted that most OPTN metrics measure quantity, rather than quality of life improvements. The member discussed the importance of capturing the recipient voice to promote VCA transplantation as a viable and greatly beneficial option for eligible patients. A member emphasized that VCA recipients and their support

persons are uniquely positioned to comment on the immense benefits of undergoing a life-improving surgery. In addition to personal testimonies, visualization of cosmetic and functional improvements, particularly in face and hand transplants, is key in helping potential candidates and the current VCA community to appreciate these benefits, which was noted by a member. The Committee may consider ways to leverage available technology to provide such visualization.

The Committee discussed the development of tools to measure quality of life before and after transplantation. A member commented that work in this area has focused on defining pathology, not on transplantation. Another member mentioned that quality-of-life studies related to upper limb transplants may soon be published which would help to identify quality outcomes that are most important to patients. The difficulty of validating patient-reported outcomes when sample sizes are small was noted.

Next steps:

The Committee will continue to discuss potential project ideas at their upcoming meeting on March 4, 2024.

4. Open Forum

There were no open forum speakers.

Upcoming Meeting

- March 4, 2024 at 8:30 AM CT (Houston, TX)

Attendance

- **Committee Members**
 - Sandra Amaral
 - Brian Berthiaume
 - Alexa Blood
 - Vijay Gorantla
 - Christina Kaufman
 - Todd Levy
 - Paige Porrett
 - Elliott Richards
 - Charlie Thomas
 - Gerald Scott Winder
 - Donald Rickelman
 - Anji Wall
- **HRSA Representatives**
 - Jim Bowman
- **UNOS Staff**
 - Kayla Balfour
 - Kelley Poff
 - Kaitlin Swanner
 - Kristina Hogan
 - Susan Tlusty
 - Leah Nunez
 - Jesse Howell
 - Asma Ali
 - Avery Cook