

**OPTN VCA Committee
Meeting Minutes
August 14, 2019
Conference Call
Linda Cendales, MD, Chair
Bo Pomahac, MD, Vice Chair**

Introduction

The VCA Committee met via teleconference on 08/14/2019 to discuss the following agenda items:

1. Data Advisory Committee presents public comment proposal: Modify Data Submission Policies
2. Update on Living Donor VCA Project
3. Discuss Project re: Transplant Outcomes (TRR & TRF forms)

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

Welcome was provided by the Chair.

1. Data Advisory Committee presents public comment proposal: Modify Data Submission Policies

DAC public comment proposal presentation by Chair Sandy Feng. The proposal calls for revising Policy 18.1 to extend and clarifying submission deadlines for data in TIEDI, data lock elements, and creation of a data quality dashboard. A PowerPoint slide presentation accompanied the discussion. After a question and answer period, a vote was taken on the proposal.

Voice vote: unanimous in support (14)

2. Update on Living Donor VCA Project

The Chair indicated that VCA will collaborate w/ the Living Donor Committee on revisions to Policy 14 and will lead a project to modify the living donor form for data collection.

3. Discuss Project re: Transplant Outcomes (Sub) Committee's discussions

Bo Pomahac, Chair of this subcommittee, introduced the topic on continued work of revising the data collection instruments (TRR/TRF) for VCA. The committee was asked for additional feedback and given a deadline of 9/6 to email any further comments. Data definitions continue to be identified for any new data element added to the forms. The committee will present the proposed revisions to the OPTN DAC on 9/16. Vice Chair, DAC, Rachel Patzer, listened in on the call to gain insights on the details anticipated at the DAC meeting.

VCA member, Sheila Jowsey-Gregoire presented 3 options (SF 12, SF 36 and Patient Generated Index) for data collection for patients' quality of life following VCA transplantation. Some discussion took place regarding which forms are validated and the burden of time to complete each form. The committee will need to make a final recommendation prior to the DAC meeting.

4. Other:

Staff did announce that HRSA has indicated informal approval (not yet in writing) for data collection on the children born of those patients who have undergone a uterine transplant. The committee must deliberate on to what age of the child should data be collected and what elements of data should be collected.

Upcoming Meeting(s)

- September 11, 2019
- October 9, 2019
- November 15, 2019 (Richmond)