

OPTN VCA Transplantation Committee

Meeting Summary

December 11, 2019

Conference Call

Linda Cendales, MD, Chair

Bo Pomahac, MD, Vice Chair

Introduction

The Committee met via teleconference on 12/11/2019 to discuss the following agenda items:

1. Collecting Health Information on Children Born to Uterus Recipients
2. VCA Data Collection
3. Next Steps: Review VCA Committee Project Ideas

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

1. Collecting Health Information on Children Born to Uterus Recipients

- a. No questions or discussion
- b. Vote – lack of quorum, but no objections from the call attendees against moving forward to public comment

2. VCA Data Collection

- a. Sheila – noted her advocacy for the PRI scale and appreciates the question on the validation of this instrument. She acknowledged that lack of validation in the VCA recipient population. This is the same for the other scales.
- b. Vijay – saw others' comments and understands their perspective. Would the appearance of the comment "these are un-validated" be a weakness. He favored grading these tools for their strength noting the premature state of VCA transplantation and the length of time to develop numbers for validation in the VCA population.
- c. Sandi – she supported a comment in the proposal to note there are no validated tools in this area for VCA.
- d. Linda – the field is evaluating the patients using surrogates from other fields (e.g.: immunosuppression experience from transplantation). What needs to be considered is the use of an un-validated tool while other areas of OPTN data collection use validated tools rather than surrogate tools.
- e. Sheila – would be helpful to describe in the proposal how broad the use of the SF 12 and PGI vs SF 36 is in healthcare. Would be helpful to add supporting literature sources in the paper.
- f. Linda - supports the addition of abstracts to describe each of the tools.
- g. Sandi – the actual surveys are most helpful –answer the questions: how long does it take, who is going to administer the tool...people care about time and feasibility.
- h. Vote – lack of quorum, but no objections from the call attendees against moving forward to public comment. Note that the Committee voted at a previous meeting, Nov.15, to approve the data elements.

3. Next Steps: Review VCA Committee Project Ideas

- a. Staff summarized recent new project ideas, as well as two ideas that have some potential to get started. 1) Modify Data Collection for Living VCA Donors (VCA led initiative), and 2) Modifications to OPTN Policy 14 (Consent and Medical Evaluation of Living Donors) to apply to living VCA donors. The latter is led by the OPTN Living Donor Committee. The Chair provided background information for members. Nicole Johnson volunteered to work on the project with the Living Donor Committee. Sheila Jowsey Gregoire will look at the projects and let staff know. The Chair thanked the volunteers and encouraged others to communicate with staff. Staff described the stages of development for projects.
- b. Staff profiled the Membership Requirements for Living VCA Donor programs. The Chair noted there is not an absence of requirements.
- c. VCA fields in organ disposition
 - Johnson- do we not have any data, or is the data “limited”? Staff responded
 - Sandi – Adding VCA organ disposition would address critical gap. Johnson agrees.
- d. Increasing awareness of VCA donation & transplantation
 - The Chair noted that some efforts have taken place in the past.
- e. Other new project ideas shared:
 - None

Upcoming Meeting

- January 8, 2020