

OPTN Living Donor Committee

Meeting Minutes

January 8, 2020

Conference Call

Randy Schaffer, Chair, MD

Heather Hunt, Vice Chair, JD

Introduction

The OPTN Living Donor Committee (the Committee) met by teleconference on January 8, 2020 to discuss the following agenda items:

1. Social Media (SoMe) Guidance Document Update and Vote
2. LDC/VCA Project Overview and Planning
3. Federal Register Notice: Removing Living Donor Disincentives Discussion
4. Cross-Committee Updates
5. Other Updates and Open Forum

1. Social Media (SoMe) Guidance Document Update and Vote

The Committee received an update on the current state of the SoMe paper.

Summary of discussion:

The final draft of the SoMe Guidance Document has completed internal review and has been sent to HRSA and the Policy Oversight Committee (POC) for further review. The Committee voted on the final paper to go to Public Comment.

Vote

Do you support the Living Donor Committee's Social Media Guidance Document going forward to the OPTN Spring 2020 Public Comment period?

Yes – 100%

No- 0%

Next Steps

The SoMe Guidance Document will be reviewed by the POC and the Executive Committee prior to going to Public Comment beginning January 22, 2020. The Chair encouraged Committee members to review the full slate of Spring 2020 Public Comment items and select any that may be of interest to the Committee.

2. LDC/VCA Project Overview and Planning

The Committee reviewed the goals and project plan for the new Living Donor Committee (LDC) and Vascularized Composite Allograft (VCA) Committee projects.

Summary of data:

The Chair summarized past developments of *OPTN Policy 14: Living Donation* and previous committee discussions regarding this project. From September 2017-October 2019, there have been 18 living uterus

donations. To date, uterus recipients have given birth to four children in the U.S. For the past three years, over half of the candidates added to the OPTN VCA waiting list were uterus candidates and uterus is currently the most common VCA transplant. With the growing numbers of VCA uterus transplant, there is an apparent gap in living donor policy to cover living uterine donors and other VCA living donors.

The Living Donor Committee and the VCA Committee are proposing two simultaneous projects:

- Living Donor Committee: Examine OPTN Policy 14: Living Donation and revise as needed.
- VCA Committee: Review current living donor TIEDI® forms and develop a data set for living uterus donors.

The Committee reviewed the proposed project timeline and workgroup members who have expressed interest so far and ideas for other stakeholders to include.

Summary of discussion:

A Committee member asked whether the focus of the project will be on uterine donors only or if the intent is to expand OPTN Policy 14 to cover all VCA donors. The Chair explained this will continue to be an initial discussion item within the LDC/VCA Workgroup.

Next Steps

The Living Donor and VCA workgroups are being finalized and the project forms are in development. The project forms will be approved by the Committee in February to go to the POC for approval.

3. Federal Register Notice: Removing Living Donor Disincentives Discussion

The Committee reviewed the recently released Federal Register Notice on Removing Living Donor Disincentives.

Summary of data:

A Federal Register Notice was posted by the Department of Health and Human Services entitled “Removing Financial Disincentives to Living Organ Donation”. The proposed rulemaking would:

- Expand the scope of reimbursable expenses incurred by living organ donors to include:
 - lost wages
 - child-care expenses
 - elder-care expenses
- Adds these to the OPTN Final Rule as categories of reimbursable incidental non-medical expenses
- Does not expand financial eligibility – HRSA is considering a revision to eligibility guidelines and will publish in a separate Federal Register notice

The notice also asks if there are additional financial barriers to organ donation that should be considered.

Summary of discussion:

Overall, the committee believes this is a positive step toward removing barriers for living donation and would also like to see the expansion of financial eligibility for the National Living Donor Assistance Center (NLDAC) program.

A Committee member questioned the accuracy of the Medicare data on end-stage renal disease (ESRD) expenses included within the notice as they don't seem to take into account maintenance dialysis. The

Committee member also commented that bone marrow donors get mandated paid time off but it is not mandated for all living donors. A HRSA representative clarified that legislation cannot be proposed through a Federal Register Notice and would have to be proposed by the U.S. Congress.

Next Steps

The Committee will draft a response to the notice to be submitted to the Executive Committee for approval. Per the public comment request in the notice, the Committee is considering other financial barriers that should be included and gathering appropriate literature.

4. Cross-Committee Updates

The Vice Chair shared the POC reviewed the items going out for spring public comment.

5. Other Updates and Open Forum

The floor was opened for any remaining comments or questions.

Summary of discussion:

The Chair informed the Committee a manuscript based on the SoMe survey data is being developed over the next few weeks.

Committee members discussed issues their hospitals have recently experienced involving potential living donors who have been declined for donation by the transplant hospital due to their being incarcerated. Some of these programs then experienced significant negative media attention regarding these cases. A committee member asked if there is any guidance or a process in place to offer support to transplant programs who are experiencing similar situations. The Committee and staff was not aware of any guidance currently in place but this will be added to the agenda for the April in-person agenda for further discussion.

Upcoming Meetings

- February 12, 2020 – Teleconference
- March 11, 2020 - Teleconference