

**OPTN Transplant Coordinators Committee (TCC)
Meeting Minutes
June 19th, 2019
Conference Call**

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Introduction

The OPTN Transplant Coordinators Committee (TCC) met via Citrix GoTo teleconference on 06/19/2019 to discuss the following agenda items:

1. TCC Learning Series Development
2. Living donor Committee (LDC) project update
3. Member Acknowledgement
4. Open Forum

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

1. TCC Learning Series Development

Members will discuss learning series ideas. Members are encouraged to explain the need and rationale.

Summary of discussion:

- Committee leadership reviewed a list of proposed topics with members for the TCC learning series and members were asked to consider the following questions:
 - What topics have a lack of educational resources?
 - Is there information that currently exists that needs to be update?
 - Why is this an issue for the transplant community?
 - What information would help close that gap?
- Committee members were asked to review these topics offline and send their top four choices to UNOS staff.
- While briefly reviewing this list members proposed TIEDI[®], compassion fatigue and prediction calculator topics as contenders. As well as a series on how the OPTN data services portal can be useful to transplant coordinators.

Next steps:

Committee members will review materials offline and email UNOS staff with their top four topics of interest to discuss on the next committee call.

2. Living Donor Committee (LDC) project update

Update on the LDC guidance on seeking a living donor via social media.

Summary of discussion:

- A brief update was given by UNOS staff:
 - Goal of this project:
 - To provide guidance to transplant teams on counseling candidates about the use of social media to try to identify potential living donors.

- Effective practices for managing an increase in living donor interest during a social media campaign.
 - A representative from TCC is present on the LDC monthly work group calls and will report to the full committee on their progress.
 - Timeline:
 - Public Comment: January 2020
 - OPTN Board Approval: June 2020
- The representative from TCC gave a brief update to the committee on the status of the project and what concerns/topics the project plans on addressing.
- UNOS staff then asked for feedback on this project. The following are members comments on this project:
 - Would like guidance for the donor intake teams on how to handle a large bolus of calls from perspective donors after a social media post/campaign has taken place.
 - What is the transplant programs role in terms of HIPAA regulations if a candidate puts inaccurate information on social media and the programs have donors calling in to donate to that candidate?
 - Guidance for transplant programs on how to keep donor and recipient anonymity (should they chose to be) after donation with social media.
 - How do transplant programs facilitate communications between the donor and recipient? What is their role?
 - Guidance on how to/ or what to communicate to potential donors that call in during a bolus of calls (during a social media campaign) but are not a match for the candidate they are calling in for.
 - A member then asked what the effectiveness of social media is on finding a donor and what do other programs do to educate their candidates. The following are responses from members:
 - Participating in a donor application study at John Hopkins, where it helps candidates make something alike to a Facebook page to help locate a donor.
 - Have a template that has gone thru program leadership and legal on what candidates should or should not put on their social media.
 - Members made a comment that there are many gray areas regarding this and guidance on this would be beneficial. Especially when there may be a discrepancy between candidates, who are not as social media savvy or their stories will not garner as much support as other candidates.
 - Created a workbook for candidates to share their story on social media.

Next steps:

- A representative from TCC will give an update on this project to the full committee on its next call.

3. Member Acknowledgement

The new upcoming Vice Chair will acknowledge outgoing members and announce new members joining on July 1, 2019.

Summary of discussion:

- The new upcoming Vice Chair shared her gratitude for outgoing member's service and welcomed new members to the committee.

4. Open Forum

Staff asked committee members to share any concerns about topics or issues they would like to share with their fellow committee members.

Summary of discussion:

- The current Vice Chair thanked both new and old members and expressed her excitement about working with members and on developing the TCC learning series together.
- A member would like to add to the calls a 10 minute presentation about best practices to share with other members.
- Committee Leadership shared the dates of upcoming regional meetings and reminded members the importance of their attendance.

Upcoming Meeting(s)

- July 17th, 2019 Full Committee Call.
- Fall 2019 Meeting – September 9, 2019 (UNOS, Richmond, VA)