OPTN Living Donor Committee
Meeting Minutes
October 28, 2019
Chicago, IL

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Introduction

The OPTN Living Donor Committee (the Committee) met in Chicago on October 28, 2019 to discuss the following agenda items:

1. Committee Charge
2. Policy Oversight Committee Update and Discussion
3. Research Orientation and Living Donor Data Discussion
4. Social Media Project Work Session
5. Vascularized Composite Allograft (VCA) Update
6. Scientific Registry of Transplant Recipients (SRTR) Update

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

1. Committee Charge

The Committee reviewed its charge and voted to pass it.

Summary of discussion:

A member asked why the OPTN does not allow the committee to promote living donation. Another member answered that the committee is permitted to make it easier to donate by improving policy, by helping to remove barriers to donation, and by educating the community; but the committee cannot play a role in any action that might appear to solicit or entice people to become living donors.

All present members voted to pass the Committee's charter with no changes. It reads,

"The Living Donor Committee develops policy and guidance related to the donation and transplantation or organs from living donors to recipients. The goal of the committee's work is to continue to improve the informed choice of prospective living donors, and the safety, protection and follow- up of all living donors."

Vote
Do you approve the OPTN Living Donor Committee charge?
Yes – 100% - 15 members
No – 0%- 0 members

Next Steps:

The Committee's charge will go to the Board for approval in December 2019.

2. Policy Oversight Committee Update and Discussion

A Committee member presented the Policy Oversight Committee's (POC) new role as an OPTN Operating Committee and three selected project themes. These themes are continuous distribution, more efficient donor/recipient matching to increase utilization, and improved equity for multi- organ and single organ candidates.

Summary of discussion:

Members asked how the Committee's projects will fit into the new POC system, as it did not seem as though the themes were geared towards living donation. A member responded that they had been told that a certain portion of projects will be allowed to fall outside of the three policy priority themes.

A member suggested that living donation could play a role in multi- organ transplant (MOT). Other members agreed that guidance on this subject is necessary, as they are currently undefined. Members reported that opportunities for living donation in MOT (particularly combined liver-kidney) are often overlooked due to the safety net, but that they should be explored as a way to expedite MOT access. Members suggested the development of guidance on this subject should include conversing about living donation with families and ensuring organ- specific teams avoid silos in MOT.

Next steps:

The Committee will continue to pursue projects that support the important work of the LDC.

3. Research Orientation and Living Donor Data Discussion

The Committee heard a research orientation presentation and reviewed previously presented living donor short –term outcomes data.

Summary of discussion:

The Committee had a variety of comments. One member reported that living donors needed more education on disability and insurance should something happen to them post- donation. Another member called out the very small chance of death after living donation with a 1 in 10,000 people at 30 days and .025% at 90 days. A member asked how this data was currently being used. This data is being utilized for knowledge on donor safety and follow-up, to examine the living donor population as a whole, and to give programs a quantified standard of comparison.

Next steps:

The Committee will keep a placeholder on future agendas for continued discussion about living donor data.

4. Social Media Project Work Session

The Committee reviewed the Social Media (SoMe) Project survey data. Then, they broke out into three groups to work on their respective sections of the paper. Each group reported out on what content needed to be added to their section. All three groups aimed to reduce redundancy throughout the paper.

Summary of discussion:

Report out:

White Paper group:

- Add an introduction to the survey and state its purpose
- Identify key areas of focus:

  - Access to technology/Ability to use technology
  - Transparency surrounding risks and privacy concerns
- Value in involving the family/network of support early in the process

Administrative Challenges Group:

- Staffing and preparedness for influx of potential donors
- Begin to give guidance early in process
- Educate donors and recipients on realistic expectations
- Development of tools: Automated screening and responses
- Guide programs to develop and use a protocol
- More consistent use of social media- less time consuming when influx does occur

Patient Guidance:

- How to educate patients
- Education on what it’s like to be a living donor
- Setting realistic expectations for donors and recipients
- Autonomy of patients

Next steps:

The committee will work to write a more complete draft over the next two weeks. They will discuss and make edits during their next SoMe Workgroup meeting.

5. Vascularized Composite Allograft (VCA) Update

The Committee reviewed a potential project that would go to the board in December 2020. This project Updates OPTN Policy 14: Living Donation to include living VCA donors, as uterine donation has become increasingly popular over the past five years. The VCA committee presented a project that would run in tandem to update the living donor follow- up (LDF) form.

Summary of discussion:

A member commented that a key question in the modification of Policy 14 would be if the committee should add the language “all living VCA donors” or limit the policy modification to “living uterine donors”. This sparked questions about what uterus-specific information should be required for medical evaluation and informed consent portions of the policy.

Next steps:

A workgroup will be formed for this project in December. A member suggested reaching out to a uterine donor for input. The Committee will also seek input from the VCA and Ethics committees.

6. Scientific Registry of Transplant Recipients (SRTR) Update

The SRTR gave an update on the Living Donor Collective. SRTR explained that their goals for this collective are to maintain contact with living donors, understand factors behind the choice not to donate, and provide data and infrastructure to study risks of donation. The SRTR expressed that a goal for the future is to supplement or replace the current OPTN living donor follow-up procedure. They sought feedback on this data collection from the Committee.

Summary of discussion:

Members questioned if SRTR would be able to collect and follow individuals that ultimately decided not to donate or those who were screened off of being a donor.

Members agreed that should the SRTR take over living donor follow-up duties, they should be sure to share this data with respective programs. A member expressed that this sharing of information would be important so programs would stay informed about the health of their donors.

A member asked if donors are aware of what the SRTR does and questioned if donors would be willing to give out their health information to the SRTR over the program where they donated. This member added that it could be difficult for the SRTR to obtain this data due to a lack of relationship with donors. The Committee also encouraged the SRTR to solicit feedback from patients on this method of follow-up data collection.

<u>Next steps:</u>

The SRTR will take the Committee’s feedback into consideration throughout this project.

Upcoming Meeting(s)

- November 13, 2019 (teleconference)
- December 11, 2019 (teleconference)