

**OPTN/UNOS Living Donor Committee
Meeting Minutes
August 8, 2018
Conference Call**

**Randolph L. Schaffer, Chair
Heather F. Hunt, Vice Chair**

Introduction

The Living Donor Committee (LDC) met via teleconference on 08/08/2018 to discuss the following agenda items:

1. Patient Affairs Committee (POC) - Proof of Concept
2. Status of Other Living Donor Committee Projects
3. Fall 2018 Public Comment Overview
4. New Project: Pre-POC/ExCom Project Form Review

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

1. Patient Affairs Committee - Proof of Concept

Kim Uccellini (PAC Policy Analyst) and Sara Sampsel (LDC representative to PAC) presented the Proof of Concept pilot.

Data summary:

Major themes from the Public Comment:

- Overall support for the overarching goals
- Agreement that concept may increase broader participation
- Concern how everything would be operationalized and perceived loss of constituent voice in the policy development process.

The Executive Committee (EC) reviewed the comments and had three considerations:

- Move forward as proposed
- Abandon the concept completely
- Test the concept

The EC decided to test the concept with the Patient Affairs Committee (PAC) and the Transplant Coordinators Committee (TCC), who will get the modified version of the proposed restructure. A number of members of the Living Donor Committee will participate on the Patient Affairs Committee.

Four problems were discussed in the concept paper:

- Increasing diversity in perspectives on committees and in the policy development process. Patients and coordinators joining respective committees will act as liaisons between their constituency and the subject committees. Then there would be more opportunity to weigh in on new or proposed policies before, during, and after public comment.
- Increasing connections between the EC and the Committees

- Historically, EC members do not interact with the committees. Proof of concept will expose more EC members to committee work and facilitate dialogue amongst groups.

Proof of concept testing will begin in the fall and will be implemented as follows:

- Patient or coordinator on other committees and BOD will merge with the current roster of members for that committee. Other members of the constituency who identify as having patient perspective, but do not serve in the official capacity on their home committees.
- Additional members will attend and participate in the core committee's current meetings.
- Communication through Basecamp application to manage committee work between monthly conference calls.

The Proof of Concept is intended to break down silos between committees through a larger collaborative, facilitate real-time intra-committee and BOD communication via Basecamp, and amplify constituency voices throughout the policy development process by empowering members to speak on behalf of a larger group of people with common perspectives versus being a lone patient or coordinator on a committee.

The Proof of Concept would not change bylaws, change PAC's or TACC's ability to propose or sponsor projects, or interfere with existing committee work.

The PAC/TCC just completed a baseline survey (results will be reviewed at the upcoming in-person meeting), provide feedback via debrief and Basecamp communication and update at regional meetings; and at conclusion of Proof of Concept, UNOS will provide analysis to the EC and BOD. The EC and BOD will determine the next steps, which could be another iteration of the pilot or public comment. Living Donor Committee is not currently using Basecamp.

Summary of discussion:

PAC meetings typically consistent of an education topic per call since PAC leadership found that how patients were recruited into the system did not lend itself to recruiting folks with in-depth knowledge on what OPTN does, as well as policy work.

The PAC Policy Analyst stated her difficulty with PAC is that the group is very large, 50 members, with around 40 people on a conference call. Therefore, maybe only 5 or so people speak up on the call and tend to be one-directional in the flow of information. It is difficult to see how the dialogue amongst committee members meets the subject of objectives of the committee. PAC leadership struggles with this as well.

The hypothesis of PAC was to connect all patients (including living donors and donor families) who are lone members of a committee. Then policy and project proposals could be discussed earlier in the process to people who are more confident in voicing their opinions. The education helps lend itself to the empowering objective, so patients are confident and knowledgeable enough to speak up. There is a PAC in-person meeting on 8/27/2018. An hour and a half to 2 hours will be set aside for discussing this process.

One Committee member reiterated that part of the entire process is to collect information from people's experiences. The committees get too big so they may not want 20 patients, and instead come up with other hypotheses on how things might work and meet the same goals. Some of that will come out of a periodic survey process moving forward. The baseline survey was just completed, followed by a midpoint survey mid-September, and then endpoint survey in early November. The results will be analyzed and recommendations can be made to the BOD.

One Committee member asked if the LDC members would be providing their own voices if there was an issue or if they would come back to the Committee. LDC members would bring to the

PAC what LDC is working on, any questions for the PAC, provide feedback to PAC or get feedback from PAC, present what PAC can help LDC with through collaboration, etc. PAC in turn would go through the LDC members like liaisons if they have questions for LDC. For example, with the maintenance dialysis project LDC is working on, Sarah Sampsel would present the project to PAC (not the Committee Chair), PAC will provide feedback, and Sarah will bring it back to the LDC to discuss at a full committee call. The intent is to get feedback from the constituencies earlier in the process, thereby preventing delays, and for PAC to know if the feedback was incorporated in some way.

2. Status of other Living Donor Committee Projects

Data summary:

Current projects in the pipeline are informed consent and medical evaluation for living VCA donation, self-assessment tool on the Transplant Living Website, and guidance on the use of social media.

LDC is about to go to POC with the clarifications on reporting maintenance dialysis, so it is important to start forward thinking about at least one of the projects and get early preliminary work started. POC is currently wrapped up in the geography changes, so the idea is to present to the VCA Committee December 2018/January 2019.

Summary of discussion:

Regarding the self-assessment tool and guidance on the use social media feedback from Committee members was requested. Management has been steering away from social media for now, given feedback from policy leadership that it might not be the best time to work on it, and therefore leaning towards the self-assessment tool. The Vice Chair stated both projects have been moving along offline and at the last in-person meeting. The self-assessment tool has received strong support from inside UNOS, which could be helpful since it will need IT support in the future. Committee members agreed with leaning towards the self-assessment tool because it seems to fill a gap of internal support, as well as it provides a well thought-out resource for patients. Also from the standpoint of transplant social work, the self-assessment tool could be given to potential recipients to direct people that may be interested in finding out more about living donation.

One Committee member was interested in the social media project from the standpoint of transplant administrator because of the implication for transplant hospitals and patients. Another Committee member was concerned about the self-assessment tool based on variability across centers and whether it would get pushback from certain centers that disagree with certain things on certain live donors. The tool would need to be more evidence-based and agreed upon across centers. The Chair, though not on this conference call, has also talked about the system based in California that he is pleased with.

The Committee could discuss creation of two subcommittees, one working on both and then one fleshing out the questions, on a future conference call.

Next Steps:

Justin Moore will look up the tool that is being used in California and send it to the rest of the Committee. He will also get feedback from policy leadership once again on specific concerns on the social media project, so it could be reworked if necessary. Committee members will email Mr. Moore with the subcommittee they would be interested in working with.

3. Fall 2018 Public Comment Overview

Data Summary:

Proposals up for public comment include:

- Changes to islet bylaws (Pancreas)
- Frameworks for organ distribution (Ad Hoc Geography)
- Change to hospital-based OPO voting privileges (MPSC)
- Pancrease program functional inactivity (Pancreas)
- Pediatric transition and transfer guidance document (Pediatric)
- Addressing HLA typing errors (Histocompatibility)

Individuals Committee members are encouraged to respond to public comment. If it is of interest to the entire Committee, leadership for the other committee or policy analysts for that committee will present to LDC on one or all of the proposals. The Ad Hoc Geography Committee is planning on presenting the framework for organ distribution at the 9/12/2018 conference call.

Next steps:

An email was sent out to Committee members with links to the proposals. Everyone can review those in more detail and bring any questions to the next September conference call.

4. New Project: Pre-POC/ExCom Project Form Review

Data Summary:

Leadership has worked hard on getting the maintenance dialysis project form. This project was brought about due to questions regarding the language. Does "maintenance dialysis" mean chronic dialysis? Does it mean acute dialysis? The project was designed to bring clarity to the language by eliminating "maintenance dialysis" and changing the form. TIEDI follow-up forms in the Patient Safety Portal clarify things so people know what to report and what is required.

In follow-up to the last monthly Committee call, maintenance dialysis is regular dialysis that is required for a person with end-stage renal disease. Terms such as "native organ failure" will be eliminated. The Vice Chair will present the project to POC at their next meeting on 8/28/2018.

The document will be sent off Friday so POC members will have early review and will be able to provide comment. LDC will receive comment 5-7 days before POC meeting to prepare responses to their questions. If the project is approved, the Committee will move into the evidence-gathering phase through the fall, using the September conference call to begin writing the proposal. Further discussion will also take place at in-person meeting in October. After public comment, EC will review the proposal. Then public comment will take place January 2019.

Next steps:

The Committee members will review the project and if there are any questions, those would be helpful for preparation for the upcoming POC meeting.

Upcoming Meetings

- September Conference Call
- In Person Meeting, Monday, October 15, 2018, 8 a.m. to 3 p.m.