

**OPTN/UNOS Living Donor Committee
Meeting Minutes
February 14, 2018
Conference Call**

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Introduction

The Living Donor Committee met via Citrix GoToTraining teleconference on 2/14/18 to discuss the following agenda items:

1. Concept Paper on Improving the OPTN/UNOS Committee Structure

The following is a summary of the Living Donor Committee's (the Committee) discussions.

1. Concept Paper on Improving the OPTN/UNOS Committee Structure

Summary of discussion:

A UNOS Policy Department manager led a PowerPoint presentation. She explained that the current committee structure is a one-sized fits all approach that limits opportunities for participation and makes it difficult to incorporate diverse perspectives in the policy development process. Goals of the changes under consideration include 1) increased opportunities for participation, 2) increased minority representation, 3) ensuring diversity of perspectives on committees, and 4) strengthening connections between the Board and committees.

There are limited opportunities to participate or increase diversity because most positions on the Committees are filled by leadership and the eleven regional representatives. All committees may not need regional representatives. Similarly, not all committees need the at-large member representation that is currently required by the Bylaws.

Committees are not mandated by National Organ Transplant Act or the Final Rule, however committees add significant value by providing subject matter expertise, advancing diverse perspectives, and helping to garner community buy-in.

The development of this concept paper started with considering what the current committee structure provides to the OPTN. The characteristic of the current committees were categorized into three categories including subjects, perspectives and tasks.

The concept paper is proposing a new committee framework. Under this framework:

- Subject Committees present policy proposals to the Board, and leaders are often identified for Board service
- Expert Councils communicate with Subject Committees through their representatives, and Councils are educated on proposal development
- Representatives from the Board sit on Expert Councils providing:
 - Knowledge sharing
 - A direct link to the Board
 - A more established pipeline for succession planning
 - Leaders often identified for Board service

The presentation included an overview of what tasks and functions would be assigned to subject committees and to expert councils. Next the presentation addressed how the expert councils and subject committees would interact.

As currently envisioned, the expert councils would be comprised of different groups to include leadership, core membership and general members.

The presentation addressed how improvement under each of the goals would be measured. The presentation included the list of proposed subject committee and expert councils.

The Committee was asked to provide feedback regarding:

- What is your opinion of this concept?
- Will the proposed change in OPTN committee structure allow for greater opportunity for participation by the transplant community?
- Will the proposed change in OPTN committee structure strengthen your voice in the policy making process?
- Do the proposed expert councils and subject committees capture all perspectives needed in the policy making process?

After the presentation concluded, Committee members were invited to ask questions or share comments.

A member shared that she agreed with the stated goals in the concept paper but has substantial concern about changing the LDC to become an expert council because it has a history of leading policy development. The past work of the LDC has been a mission driven collaboration between living donors and transplant professionals. Many current living donor policies contain unpopular elements that were deemed necessary but transplant professionals find cumbersome or too proscriptive. Living donor policies might look very different if they had been developed under the proposed committee structure outlined in the concept paper.

Another member spoke about the importance of living donors and transplant professionals working together. Subject committees will silence living donors. Living donors need a strong voice. The goal of the Kidney Committee is to increase transplants, the LDC focuses on living donor advocacy.

Another member stated she did not think the proposed changes would result in the stated goals of increased diversity and greater participation by the transplant community. She questioned if the current structure is broken and if so, is there documentation that there are problems with the current structure. Even if there are problems with the current structure why not address the problems with the current structure.

A UNOS staff member responded that a work group reviewed a lot of data on the current committee structure and identified problems with race and ethnicity and certain groups of stakeholders. The current committee structure is outlined in bylaws and limits flexibility to add subject matter experts to Committee. Under the plan outlined in the concept paper, expert council members would have a seat and a vote on subject committees, and would be positioned to provide early feedback. A committee member suggested that this mechanism already exists in the current committee structure through the use of joint committee work groups.

A living donor serving on the LDC, shared that prior to her donation she intentionally avoided online donor groups because they often provide misinformation, and notes that groups with moderators in place did not prevent misinformation. She commented that donors learn from interaction with transplant professionals and said there is a need to balance the quality and quantity of donor input. She questioned if the workgroup had considered how to manage a large living donor online community and how to control potential misinformation. She commented that if one percent of the living donors who donated an organ in the past decade participated in an on-line group it would result in a group of 600-700 members.

Another living donor serving on the LDC, commented that he was a visual learner and questioned if some type of visual aid could be developed to show an ideal for a new product or policy suggested by a member of an expert council could move through a subject committee and to the Board. He questioned how many people would serve on a core council. UNOS staff responded that it would depend on the number of members who would simultaneously serve on a core council and a subject committee, but should generally be eight to twelve members. He commented on the importance of face-to-face interaction so members know, support and trust each other, and was concerned that expert panels without face-to-face interaction would make it more difficult for new ideals for projects to get traction.

The last member to comment during the meeting wanted to emphasize the importance of face-to-face interaction versus web based environments. He opined that people may be more engaged during in-person meetings and may find it hard to have their voices heard in on-line communities. He suggested that the LDC is already an excellent representation of what the concept paper is proposing. The LDC includes diverse members working together in a productive environment. The LDC is a model for what other committees should be striving to achieve. He suggested that you don't need 100 people to represent a population, and commented that broader engagement does not necessarily provide more meaningful engagement. He commented that one individual can monopolize an in-person meeting and the same will be true of online communities.

As the meeting was concluding members wanted more time to discuss this concept paper and supported using a recurring work group call on the fourth Wednesday of each month for a follow-up meeting. The Committee liaison will send information regarding the meeting.

Next steps:

The Committee will meet by web conference on February 28th. Members will be invited to send questions or comments regarding the white paper for LDC leadership to review prior to this follow-up web conference.

Upcoming Meetings

- February 28, 2018
- March 14, 2018