

**OPTN/UNOS Living Donor Committee
Meeting Minutes
February 8, 2017
Conference Call**

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Introduction

The Living Donor Committee met via Citrix GoToTraining teleconference on 02/08/2017 to discuss the following agenda items:

1. Removing Disincentives for Candidates to Consider Living Donation
2. Recently Completed Projects
3. New Projects
4. Previous Project Currently on Hold
5. Potential New Projects

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

1. Removing Disincentives for Candidates to Consider Living Donation

A workgroup has completed work on a preliminary draft of a new transplant candidate brochure to help transplant candidates identify a potential living donor. The brochure is entitled *Help a Living Donor Find You*.

Summary of discussion:

The project includes three files, the new brochure, an Evidence Report, and a file with feedback from reviewers and the response by workgroup. The reviewers included a review by health literacy experts and the current draft is at an eighth grade reading level.

These files have been sent to four committees (Minority Affairs, Patient Affairs, Transplant Coordinators, and Pediatrics) for review and feedback due back by March 17th. The current draft was sent to UNOS Communication for formatting and branding.

There has been some disagreement on certain language used in the brochure (e.g. using the word compatible versus the word match). Committee members were invited to review this preliminary draft to respond with questions or comments via email to the Committee liaison. Committee members were invited to provide feedback on any content that may need to be reconsidered.

Future steps include a Spanish version of the resource. Current draft will be sent to members by email after the meeting.

Next steps:

Committee liaison will collect and collate all feedback regarding the new resource. The work group assigned to this project will review and respond to feedback. Current goal is to have a final version ready for review at the Committee's in-person meeting on March 27, 2017.

2. Recently Completed Projects

Some living donor adverse events must be reported in Tiedi and the Patient Safety System. Committee members asked for updates to these system to notify members that are required to report a living donor adverse event in both systems.

UNOS IT has completed this work. A member commented that she had noticed new warnings in Tiedi and the changes should help members met policy requirements.

3. New Projects

Lay person language version of informed consent policies

During a previous meeting, a Committee member raised concern about the complexity of the current informed consent policy requirement, and commented that many in the general public would not be able to comprehend the policy requirements. In response, Committee members supported the development of a lay person language version of the informed consent policy requirements.

UNOS Communications department is taking the lead on this project and has a deadline for completing the project before the upcoming full committee meeting on March 27, 2017. A member requested an update on the project and to preview a current draft on the March 8, 2017 web conference. This project will include a Spanish version of the resource.

Template for Informed Consent Policy

During recent public comment on proposed modifications to living donor informed consent requirements, the Committee received requests to develop and provide an informed consent policy template to assist members with policy compliance.

UNOS staff has completed a draft informed consent policy template that is undergoing internal review. The draft should be ready for review during the March 8, 2017 web conference.

Revise Brochure entitled *Living Donation, Information you need to know*

UNOS Communications will soon need to reprint this brochure because stock will be depleted. The current supply will be depleted in three months. The Committee liaison was asked to review this brochure and to recommend possible changes before reprinting. Some Committee members reviewed the brochure and recommended revisions. The required revisions are extensive. A project form to address this work was completed, the project does not require Policy Oversight Committee approval because this is an education resource.

During this meeting, Committee members reviewed feedback and proposed revisions for this brochure. Committee members questioned if the brochure should address all categories of living donors or if there should be a separate resource for living liver donors. Several committee members volunteered to work on this project. The Committee agreed to use the recurring web conference on the fourth Wednesday of each month to start work on this project. The brochure with potential revisions identified to date will be emailed to Committee members.

4. Consider Previous Projects Currently on Hold

Proposal to Require the Recipient Center to Report the Status of Living Donor Transplants

In April 2015, the Committee reviewed a request from the Membership and Professional Standards Committee (MPSC) to consider if the intended recipient's hospital should be responsible to report the non-utilization or redirection of a living donor organ after taking recipient of that organ. The Committee did not support changing policy at that time, but did support exploring whether or not the recipient's hospital should be required to report the status of the donated organ back to the living donor recovery center within some specific period of time after receipt of the organ. The Committee did not peruse this project after the emphasis on patient safety projects was changed in the 2015 OPTN/UNOS Strategic Plan. Of note, since 2013 there have been two cases of non-utilized living donor organs and five cases of redirected living donor organ reported to the Improving Patient Safety Portal. There have been no new

reports of failure to report a living donor adverse event because the donor hospital did not receive information on the status of the donor organ within time to report the adverse event as required under policy.

The Committee discussed if this work on this project should resume. A Committee member commented that these have been rare events and might not justify the effort that would be required to propose changes to policy. Options could include a new reporting requirement for the recipient center. It could be helpful for Committee members to review past responses from this Committee to the MPSC regarding this problem.

A staff member from UNOS' Member Quality Department commented that although these may be rare events each event does create considerable work for members, UNOS staff and for the MPSC. The Member Quality department has been invited to propose policy changes for this Committee to consider at a future meeting.

Under Policy 18.6 (Reporting of Living Donor Adverse Events) non utilization must be reported within 72 hours of recovery. One option to consider would involve revising policy to require reporting within three business day versus 72 hours.

Improve Categorization of Living Donor Adverse Events

Current policy requires reporting some events that would be better categorized as "unanticipated" rather than "adverse" events. For example, a living donor organ may be recovered but found to have a cancer that had not be detected during the donor evaluation process and the organ cannot be transplanted because the potential recipient had not consented to receive a higher risk organ. Also, a living donor organ may be recovered but may not be transplanted due to a transportation failure. Living donor deaths may occur within two years of donation due to unrelated medical problems or trauma. These types of events should be reported through the Improving Patient Safety Portal but should not be categorized as "adverse" events.

The Committee supported resuming work on this project.

Guidance on the Use of Social Media by Transplant Candidates, Potential Donors and Transplant Hospitals

The use of social media to match transplant candidates and potential donors is increasing. The Committee is interested in researching this increasing phenomenon and providing guidance for candidates, potential donors and transplant hospitals. Some Committee members reported that their hospital has been overwhelmed with sudden large responses to social media request for living donors.

A committee member questioned if there will be anything for the Committee to address that has not already been addressed in existing resources.

Committee members were reminded to finalize their travel arrangements for the March 27, 2017, meeting in Chicago. A date for fall 2017 meeting was discussed, some members were concerned with possible conflicts with a national liver meeting.

The meeting was adjourned.

Upcoming Meeting

- March, 2017