

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

**Krista Lentine, MD, PhD, Chair
Randolph Schaffer, MD, Vice Chair**

Introduction

The Living Donor Committee met via Citrix GoToTraining teleconference on 03/08/2017 to discuss the following agenda items:

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

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

1. Removing Disincentives for Candidates to Consider Living Donation

A workgroup has completed 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 health literacy experts and the current draft is written at an eighth grade reading level.

Members of four committees (Minority Affairs, Patient Affairs, Transplant Coordinators, and Pediatrics) reviewed this resource and have provided feedback. A previous draft was sent to UNOS Communication for formatting and branding.

Next steps:

The work group leading the development of this resource will review all feedback and prepare an updated version for review during the March 27th meeting.

Future steps include a Spanish version of the resource.

2. Current Projects

Lay person language version of informed consent policies

During a previous meeting, Committee members discussed the complexity of the current informed consent policy requirements, 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.

Summary of discussion:

A representative from UNOS Communications joined the meeting to discuss the status of the plain language version of the informed consent requirements. This new resource will align with the new and revised living donor informed consent requirements set to take effect on June 1, 2017. The current living donor informed consent policies are requirements for transplant

hospitals. This new resource will be a resource for potential living organ donors and explain the informed consent requirements from the perspective of a potential living organ donor. The new resource will include definitions of some elements of informed consent policy requirements. Committee members were asked to review the resource and to send any questions or comments to the Living Donor Committee liaison. This project will include a Spanish version of the resource. A member recommended that it will important that this resource cannot be misconstrued to be living donor informed consent policy requirements.

Next steps:

An updated version of the resource will be posted for review prior to the March 27, 2017 meeting.

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 has been approved by UNOS' Member Quality and Legal Departments.

Next steps:

This resource will be reviewed during the March 27. 2017 meeting.

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.

Summary of Discussion

During a previous 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.

Next steps:

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Infectious Disease Verification to Enhance Patient Safety

This Operations and Safety Committee is leading a work group to develop this new resource. The Living Donor Committee is represented on this workgroup. At this time, the Operations and Safety Committee is seeking pre public comment feedback on this resource.

Next steps:

Committee members were asked to review and provide individual feedback concerning the resource and specifically the proposed policy language.

3. Potential New Projects

Update for Full Committee Meeting – Monday, March 27th

At this time all Living Donor Committee members have finalized travel arrangements to attend this meeting. Most members will arrive early enough to attend the optional dinner on Sunday evening. Members were reminded that they should arrive for the meeting with a least one new committee project form completed. The proposed projects do not need to be limited to work for the Living Donor Committee. Members were invited to propose project ideas regardless of which element of the strategic plan would apply. Meeting materials will continue to be updated and posted on the SharePoint site until the start of the meeting.

4. Consider Previous Projects Currently on Hold

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 to the Improving Patient Safety Portal but should not be categorized as “adverse” events.

The Committee Chair made a data request to determine the frequency of each type of adverse event that must be reported via the Improving Patient Safety Portal.

The meeting was adjourned.

Upcoming Meeting

- April, 2017