

**OPTN/UNOS Living Donor Committee
Meeting Minutes
June 14, 2017
Conference Call**

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

Introduction

The Living Donor Committee met via Citrix GoToTraining teleconference on 06/14/2017 to discuss the following agenda items:

1. Candidate Brochure
2. Completed Projects
3. Pre Public Comment Review of Ethics Committee White Papers
4. Current Projects

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

1. Candidate Brochure

A workgroup finished the development of a new transplant candidate brochure to help transplant candidates identify a potential living donor. The brochure is entitled How to Find a Living Donor Make your Transplant Happen.

Summary of discussion:

UNOS Communications has completed design work on this new brochure. Committee members reviewed a draft of the brochure. Members were pleased to see a mock-up of this new brochure. Members were asked to review the brochure and to send any suggestions for necessary edits. Committee members will review the suggested edits during the June 28th work group call.

Next steps:

The Committee will prepare a list of necessary edits for the brochure for UNOS Communications. This resource could be promoted at upcoming regional meetings.

2. Completed Projects

Plain language English and Spanish versions of the living donor informed consent policy are now available through the OPTN web site.

A template for living donor informed consent policy is now available through the OPTN web site.

3. Pre Public Comment Review of Ethics Committee White Papers

Living Organ Donation by Persons with Certain Fatal Disease who Meet the Criteria to be Living Organ Donors

Summary of discussion:

Committee members reviewed and discussed this white paper in development by the Ethics Committee. In general, Committee members commented that the recommendations in the white paper seem too strong. The Committee liaison explained that the Ethics Committee has been instructed to develop a future white paper so the OPTN/UNOS Board could act on the white

paper, hence the need for recommendations that could be addressed or acted upon by the OPTN/UNOS Board.

Living Donor Committee members commented that public input should be necessary before making recommendations. Members suggested changing the recommendations as follows: If living donation by person with certain fatal diseases is supported in public comment, then the OPTN should consider if individuals with certain fatal disease should be considered for living donation. If this concept is supported by the OPTN, the OPTN should determine how to address the issue which could include determining which policies for living donor informed consent, psychosocial and medical evaluation and follow-up should be necessary for or appropriate for individuals with certain fatal diseases who wish to be living organ donors. The OPTN should take steps to remove disincentives and undue scrutiny of transplant hospitals which undertake the recovery of organs from individuals with certain fatal diseases who wish to be living organ donors.

Committee members opined that the white paper should be sent for public comment.

Next steps:

Comments regarding this white paper will be provided to the Ethics Committee. The Living Donor Committee will reconsider this paper if it is sent for public comment.

Financial Incentives for Living Organ Donation

Summary of discussion:

Committee members reviewed and discussed this white paper in development by the Ethics Committee. Committee members commented that this is an important topic and the white paper should be sent for public comment. However, there was a strong consensus that a trial of financial incentives would be premature and it is not the appropriate next step to increase the number of organs available for transplant. Members opined that there are so many financial disincentives that exist for living donors that need to be resolved first. More work should be done, including empirical research and policy development, to address disincentives as a first step before moving forward with pilot studies to address financial incentives.

A member commented that the way the paper is framed it could give the impression that the problems with disincentives for living donation have been solved.

A member commented that there are more disincentives for living liver donors because their recovery is longer.

A member commented that the disincentives for living donors aren't limited to financial disincentives.

A member commented that it could be important for the Ethics Committee to consider if there is an ethical obligation to remove disincentives before considering an ethical analysis of financial incentives.

Next steps:

Comments regarding this white paper will be provided to the Ethics Committee. The Living Donor Committee will reconsider this paper if it is sent for public comment.

4. Current Projects

Summary of discussion:

Revise Living Donation Brochure

Work continues on this project. The lead author will distribute the current draft of the resource for comment.

Improve Categorization of Living Donor Adverse Events

The Committee liaison is drafting a mini-brief for consideration by the Executive Committee of the Board to address this problem.

Lay person versions of psychosocial and medical evaluation policies

Work on this project will begin after the start of the next committee cycle

The Committee Chair acknowledged and thanked members who were attending their last meeting because their term of service will end on June 30th.

Upcoming Meeting

- To be determined

The meeting was adjourned.