OPTN/UNOS Living Donor Committee Meeting Summary November 9, 2016 Web Conference

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Discussions of the full committee on November 9, 2016 are summarized below. All committee meeting summaries are available at https://optn.transplant.hrsa.gov.

Committee Projects

1. Modifications to Informed Consent Requirements for Potential Living Donors

This proposal was sent for public comment and the Committee supported sending the proposal for Board consideration. The proposal will be reviewed by a subcommittee of the Board on November 18, 2016. Committee leadership is contacting some members of the Board regarding this proposal. UNOS Instructional Innovations is finalizing work on a new electronic learning module on living donor follow-up which will be available to the transplant community on November 22, 2016.

2. Disincentives for Candidates to Consider Living Donation

Committee members discussed the status of this project. A member questioned if the companion resource to the brochure should be considered a "white paper" which would require public comment. The companion will need to be updated frequently, and might best be described as a descriptive appendix rather than a white paper. It could be problematic if the companion resource requires public comment each time it is updated.

The brochure is an educational resource and will not require public comment. The brochure has been sent to subject matter experts for review and will be evaluated by a health literacy program. UNOS Communications will review and edit the brochure to reflect UNOS branding. The Committee plans to ask other committees to review the brochure and provide feedback.

Other Significant Items

3. Review Policy 18 (Data Submission Requirements)

The Committee is considering a review of Policy 18 (Data Submission Requirements). Some members are concerned that this project could result in pressure to lower the current required thresholds for living donor follow-up.

4. Lay person version of informed consent policy and templates

The Committee supports a new project to develop a lay person version of the existing living donor informed consent policy. The project could include the development of templates for informed consent policy.

5. Add warnings to Living Donor Follow-up form

UNOS IT has been consulted regarding the possibility of adding warnings to the Tiedi system to alert users when a Living Donor Follow-up form is missing information that is required for the form to be considered complete under Policy 18.5 (Data Submission

Requirements). At this point, IT is evaluating the level of programming that could be required.

6. Providing priority points for prior living donors

UNOS IT and the Organ Center have been consulted regarding how best to identify former living donors who are now candidates for transplant but who may not have received priority points.

Upcoming Meeting

• December 14, 2016