

**OPTN/UNOS Patient Affairs Committee
Report to the Board of Directors
June 23-24, 2014
Richmond, Virginia**

**Laura Ellsworth, Chair
Kristie Lemmon, Vice Chair**

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This report reflects the work of the OPTN/UNOS Patient Affairs Committee between November 20, 2013 and April 1, 2014.

Action Items

None

Committee Projects

1. Clarify Policy Language and Process for Individual Wait Time Transfer

Public Comment: Fall 2015 (estimated)

Board Consideration: June 2016 (estimated)

The Committee believes that policies related to waiting time transfers are unclear, and that refinements to policies may facilitate certain waiting time transfers. Staff are reviewing the last 500 wait time transfer requests in an effort to identify patterns or problems with wait time transfer requests and resolutions that might help to answer the following questions:

- Do the issues raised regarding the current waiting time transfer process warrant changes in policy; or
- Can these issues best be addressed by formal procedural guidance?

The Committee voted to pursue modifications to current policies to clarify the process for waiting time transfer.

2. Update to Patient Materials Encouraging Safety-related Caution in the Use of Social Media

Public Comment: n/a

Board Approval: n/a

The Committee surveyed the transplant community to identify existing resources for addressing the use of social media by transplant candidates. The Committee also completed a comprehensive literature review and reviewed available articles on social media in transplantation.

The Committee worked closely with UNOS Communications staff to identify venues through which to communicate with the transplant community regarding the safe use of social media. The Committee wanted to convey two points:

- The importance of practicing safety when using social media or other public outlets to solicit donors or to seek information; and
- The importance of early and regular communication with the transplant team.

The Committee is developing and collecting resources for patients and transplant professionals related to the safe use of social media in transplantation. These resources include:

- Related OPTN Policy references
- Sample educational resources on the use of social media in transplantation
- Sample policy language for programs interested in developing policy or position statements
- Related journal articles

3. Pediatric to Adult Care Transition Project

Public Comment: n/a

Board Approval: n/a

The Committee is working to update resources on early preparation for transition from pediatric to adult care. The Committee provided feedback on the types of materials that it believes will be helpful. Staff will present ideas to the Pediatric Transition Subcommittee in May 2014. The Committee is developing language on Pediatric Transition for the upcoming rewrite of *What Every Patient Needs to Know*.

4. Develop Policy to Address Safety Concerns Related to Large Volume Waitlist Transfers

The Committee developed language for a patient-focused *Frequently Asked Questions* document. This document will be included as part of an online toolkit for transplant programs. For additional information on this project please see the **Operations and Safety Committee's Report to the Board**.

5. The Patients Guide to Referral to Kidney Transplantation

The Committee is supporting the Minority Affairs Committee in the Patients Guide to Referral to Kidney Transplantation Project. For more information see the **Minority Affairs Committee's Report to the Board**.

6. Patient Brochures for Pancreas and Islet Allocation

The Committee is supporting the Pancreas Committee in developing a Pancreas Allocation brochure. For more information see the **Pancreas Committee's Report to the Board** and the **Minutes from the March 12, 2014 Pancreas Committee's meeting**.

Committee Projects Pending Implementation

7. None

Implemented Committee Projects

8. None

Review of Public Comment Proposals

The Committee reviewed 10 of the 17 proposals released for public comment from March – June, 2014.

9. Proposal to Modify Existing or Establish New Requirements for the Psychosocial and Medical Evaluation of all Living Donors (Living Donor Committee)

After some discussion, the Committee concluded that the proposal is a positive move for the transplant community. The Committee supported establishing overall changes to the requirements for psychosocial and medical evaluation for living donors. The Committee discussion focused more the substitution of the term living donor for the previous language "potential living donor."

The Committee recognized the potential for transplant programs to be cited during site surveys for failure to complete an entire evaluation on a potential living donor who was ruled out early in the evaluation process, while operating under the potential living donor policy language. The language change is not particularly significant to persons who hope to be living donors. The Committee felt continuation of the word "potential" and any resulting citations during a site survey could create an administrative hardship for transplant programs, thereby discouraging some programs for doing living donor transplant. Any decrease in living donor programs creates a hardship for patients.

The Committee was also concerned that Living Donor Social Workers were not included in the Joint Societies Workgroup. This was felt to be an issue since social workers are key members of the living donor team, and often serve as the Living Donor Advocates at their programs. The Committee voted unanimously to support this proposal (19 in favor, 0 against, 0 abstentions)–.

10. Proposal to Modify Existing or Establish New Requirements for the Informed Consent of all Living Donors (Living Donor Committee)

The Committee raised a concern regarding the lack of social work representation in the Joint Societies Workgroup. The Committee discussed the following issues with this proposal:

- The value and importance of requiring that "Risk of Mortality" for both the transplant hospital and nationally be provided to the patient in the informed consent process
- The psychological impact of including mortality data in consent for living donor candidates
- The value of including a general consent, that is then broken down by organ

The Committee felt it was important to review the proposal again before voting. This proposal was held over until the May 1, 2014, meeting for a final vote.

11. Reporting of Aborted Living Donor Organ Recovery Procedures (Living Donor Committee)

The Committee voted unanimously to support this proposal with minimal discussion (19 in favor, 0 against, 0 abstentions).

Other Committee Work

12. The Greatest Gifts Project

The Committee collaborated with UNOS Communications staff to promote a series of *Letters to the Editor* for newspapers in their local areas. Each writer wrote about transplant as the gift they were most thankful for during the Thanksgiving holiday season. Writers included recipients, living donors, donor families, and transplant professionals.

The core of each letter was the personal story of the writer. Each letter also emphasized the following points:

- The role of patients and families in developing transplant policy
- The sense of satisfaction that "paying-it-forward" by serving on the Patient Affairs Committee provides for the writer

The Committee submitted 10 letters to local newspapers across the country. Greatest Gifts letters were actually posted in the following newspapers:

- Topeka Capital-Journal – Living Donor Story
- Kansas City Star – Heart Recipient
- Cleveland Plain Dealer – Liver Transplant Social Worker

Meeting Summaries

The Committee held meetings on the following dates:

- February 6, 2014
- March 24, 2014

Meetings summaries for this Committee are available on the OPTN website at:
<http://optn.transplant.hrsa.gov/members/committeesDetail.asp?ID=14>