

**OPTN/UNOS Patient Affairs Committee
Report to the Board of Directors
December 1-2, 2015
Richmond, Virginia**

**Kristie Lemmon, MBA, Chair
John Fallgren, RN, BS, Vice Chair**

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This report reflects the work of the OPTN/UNOS Patient Affairs Committee from May through November 2015.

Committee Projects

1. Increase Community Participation in Public Comment

Public Comment: N/A

Board Approval: N/A

The UNOS Strategic Plan passed by the Board in June 2015 identifies increasing community participation in UNOS meetings and public comment as an initiative. Working closely with the UNOS Communications Department, the Committee has begun developing an outreach strategy to increase awareness of public comment, especially among patients, donor families, and advocates. The Committee implemented the first of these new outreach efforts during the August 2015 public comment cycle. Committee members disseminated a print-on-demand marketing campaign to transplant hospitals, dialysis centers, and rehabilitation centers. Information about this campaign can be found online at: <http://transplantpro.org/optn-public-comment-opens-august-14-help-us-spread-word/>. The Committee continues work developing a patient outreach directory, which will facilitate direct communication with patients and patient advocates regarding policy development and public comment.

Committee Projects Pending Implementation

None

Implemented Committee Projects

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

Public Comment: [January - March 2015](#)

Board Approval: [June 2015](#)

Implementation Date: September 1, 2015

In June 2015, the Board passed a proposal to clarify the policy language and process for individual waiting time transfer. The proposal also modified policy to include individual waiting time calculations for various transfer scenarios, including transfer between two current registrations and transfer from a removed registration. This proposal was implemented on September 1, 2015.

While developing the proposal last March, the Committee reviewed an analysis of individual waiting time transfers, which showed that 8,954 registrations removed for reasons other than transplant or death from 2010-2013 had a subsequent registration for the same organ at a different program within the year. About 25% (N=2,338) did not have a waiting time transfer. The Committee asked for further analysis to examine this population of candidates that do not request waiting time transfers.

In September 2015, the Committee reviewed the analysis of the 2,338 subsequent registrations without a waiting time transfer. Over 60% (N=1,423) were registered for a kidney transplant. Notably, this cohort of registrations predates the Kidney Allocation System (KAS), under which a candidate begins accruing waiting time after starting dialysis. The majority of patients (47.7%, N=1,115) were removed from the waiting list at the earlier program with a reason of transferred to another center, with other common reasons including patient noncompliance (7.7%, N=179) and unable to contact candidate (7.1%, N=166). Over two-thirds of registrations were on the waiting list at the earlier program for at least 365 days, with an additional 16% waiting from 181-365 days.

The Committee was satisfied that most of these patients were not being adversely impacted by lost waiting time. However, the Committee expressed interest in partnering with the Transplant Coordinators Committee to develop and share best practices in waiting list management. For instance, if a patient is in the process of transferring to another center, the patient's original center should inactivate rather than remove that person while he is being evaluated for transplant at the new center. The Committee also sees a need for additional patient education about the importance of communicating with your transplant team about your plans for transferring care, as well as promptly being evaluated at another transplant center when moving or transitioning from a pediatric to an adult program.

Review of Public Comment Proposals

The Committee reviewed two of the proposals released for public comment from August – October 2015.

3. Proposal to Modify Pediatric Lung Allocation Policy

After a presentation, the Committee voiced unanimous support for the proposal. This proposal makes best use of the small amount of infant donor lungs available and has the potential to decrease waiting list mortality among infant candidates. The Committee sees the potential to replicate for lung recipients the successes seen with ABO-incompatible heart transplants. The Committee supports making the eligibility criteria for ABO-incompatible lung transplant similar to that of OPTN heart policy, citing demonstrated safe and positive outcomes in ABO-incompatible heart transplant despite limited international cases studies of ABO-incompatible lung transplant.

4. Establish Pediatric Training and Experience Requirements in the Bylaws

The majority of the Committee is in favor of this proposal. One Committee member questioned how the proposal would impact training for transplant surgery fellows but was pleased to learn of the ASTS Fellowship Training Committee Chair's involvement in developing the proposal. She also expressed concern for geographic access to care for pediatric patients. One member suggested excluding the primary surgeon from the pediatric requirements.

5. Simultaneous Liver Kidney (SLK) Allocation Policy

After a presentation of the proposal, Committee members expressed appreciation for the Kidney Committee's work on this difficult issue. The Committee believes this policy will improve the overall equity and utility of the allocation system, since kidneys used in SLK transplants are among some of the highest quality and for which pediatric candidates also receive priority.

One member asked about the eventual impact of liver redistricting on this policy. Another member expressed discomfort that this policy allows for OPO discretion and voiced continued support for a comprehensive multi-organ allocation policy that ensures fairness for all candidates.

6. Revising Kidney Paired Donation Pilot Program Priority Points

After a presentation, the Committee unanimously voiced support for this proposal without further comment.

Other Committee Work

7. Brainstorming New Project Ideas

During its September 21, 2015 meeting in Chicago, the Committee broke into small groups to brainstorm new project ideas, keeping in mind the priorities of the OPTN Strategic Plan. After the groups shared their ideas with the full Committee, five themes emerged.

The Committee wants to continue its efforts to improve communication with patients. Members will continue to look for ways to be more accessible to patients in their Regions. Members also discussed establishing a patient portal so patients could have access to their information in UNetSM.

The Committee will continue to contribute patient education resources. Members will conduct periodic reviews of OPTN patient education materials, both to update existing resources and identify unmet needs. Members also expressed interest in promoting peer mentoring programs as an important source of education and support for candidates and recipients.

The Committee wants to expand public education on transplantation and donation. Rather than traditional communications regarding regulation and compliance, this communication would promote awareness among the general public and dispel popular myths.

The Committee is interested in efforts to improve OPO performance, including aligning OPTN and CMS requirements, using standard metrics to monitor performance and improve quality, and sharing best practices.

The Committee also wants to investigate living donor disincentives. Should candidates that received a previous living donor kidney transplant as a child receive additional priority? Could a safety net be developed to protect otherwise eligible living donors who are undocumented or uninsured from costly yet relatively rare complications?

The Committee will work over the next three months to prioritize and further develop these new project ideas in anticipation of submitting a new project for Policy Oversight Committee

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(POC) approval. The Committee will also look for opportunities to partner with other committees on projects of interest to patients.

8. User Experience Workshop

During the most recent in-person meeting in Chicago, Committee members participated in a User Experience Workshop. Led by the UNOS Communications Department, this series of exercises was designed to provide feedback about what information patients need and how to best communicate it. This feedback will be used to create or redesign content online and in print.

In 2016, the Committee will continue to contribute to patient education resources. Members will conduct periodic reviews of OPTN patient education materials, both to update existing resources and identify unmet needs.

Meeting Summaries

The committee held meetings on the following dates:

- May 13, 2015
- July 8, 2015
- August 12, 2015
- September 21, 2015
- October 14, 2015

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