

OPTN/UNOS Patient Affairs Committee
Meeting Summary
March 30, 2015
Chicago, Illinois

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

Discussions of the full committee on March 30, 2015 are summarized below and will be reflected in the committee's next report to the OPTN/UNOS Board of Directors. Meeting summaries and reports to the Board are available at <http://optn.transplant.hrsa.gov/>.

Committee Projects

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

The Patient Affairs Committee (hereafter, the Committee) reviewed public comment for its "Proposal to Clarify Policy Language and Process for Individual Wait Time Transfer," which overall was favorable. All of the OPTN/UNOS Regions approved of this proposal as part of the non-discussion agenda. The Committee did receive questions regarding how the new Kidney Allocation System (KAS) impacts individual waiting time transfers, specifically for those candidates who started accruing waiting time when they began dialysis. Under KAS, a multiply-listed candidate will have the same amount of waiting time at both transplant programs if the candidate began accruing time at the date of dialysis. While it is not necessary in this instance to transfer waiting time, the new transplant program may still submit a Wait Time Transfer Form to exchange the registration dates for the programs such that the earlier registration date is associated with the candidate's preferred program. The registration date will be used as a tiebreaker to ensure that the preferred program receives offers for that candidate before other centers where the candidate is also registered.

The Minority Affairs Committee expressed concern that the proposed policy disadvantages some patients by defining gap time as ineligible for transfer. Gap time is the interval between consecutive registrations when a candidate is not registered at either program. The Patient Affairs Committee reviewed data to understand how many patients experience gap time. The Committee found that, of the 8,954 registrations that registered for the same organ at another program, after having been removed from the waiting list for reasons other than transplantation or death from 2010 to 2013, 73.9% (6,616) transferred waiting time from the earlier registration. Of these, 99.1% (6,554) were registered at the new program before being removed from the earlier program, and therefore did not experience gap time. After reviewing the evidence, the Committee decided not to modify the proposed policy in regards to gap time. The Committee plans to share the results of this analysis with the Minority Affairs Committee and anticipates working with both the Minority Affairs and Transplant Coordinators Committees to educate about best practices in waiting list management, including preventing gap time when possible.

The Committee requested additional demographics on the 26.1% of registrations (N=2,338) that did not have a waiting time transfer, including the average amount of time of the earlier registration. When the Committee reviews this data at its next in-person meeting, it will determine whether further investigation into transfer process is necessary to ensure that patients are being offered the opportunity to transfer waiting time.

After a final language review, the Committee will vote to send the proposal to the Board in April. No substantive post-public comment modifications will be made.

Other Significant Items

2. Strategic Planning

The Committee reviewed the proposed OPTN 2015-2018 Strategic Plan. The Chair discussed the importance of considering the Strategic Plan when developing new projects. The Committee then reviewed a list of potential projects, expressing interest in further developing two for the Policy Oversight Committee's consideration later this year. They include: (1) a project to improve participation in public comment, especially among patients, patient advocates, and the general public, through the use of social media and (2) a project to research peer mentoring programs for transplant candidates.

3. Representative Patient Perspective on OPTN Subcommittees and Working Groups

A Committee member shared his experience over the past six months serving as a non-voting patient representative on the Heart Subcommittee. The Subcommittee has been working on revisions to the adult heart allocation system. He said that he believes it's important for others from the Patient Affairs Committee to serve on subcommittees and working groups so they can contribute early in the policy development process.

The Committee discussed resources that would be helpful to patient representatives to effectively participate in organ-specific committee projects, especially regarding allocation. Committee members appreciated a presentation from the SRTR Representative earlier in the day that provided information about allocation modeling. Committee members that are not transplant professionals also may need clinical or other background information relevant to the project prior to serving on the subcommittee or working group. Several members expressed interest in the opportunity to serve as patient representatives on subcommittees and working groups in the future.

4. Liver Redistricting Update

The Liver and Intestinal Organ Transplantation Committee Liaison presented an overview of current liver allocation policy. The SRTR Representative also presented and received feedback from the Patient Affairs Committee on a tool the SRTR is developing that will allow candidates to explore waiting list outcomes by geographic area and a variety of patient variables (blood type, age, MELD score). The Chair of the Liver Committee then presented on the progress of liver redistricting and provided information about the upcoming forum in Chicago.

5. Kidney Allocation System (KAS) Update

The Kidney Transplantation Committee Liaison presented preliminary monitoring data on the new kidney allocation system, which was implemented in December. The Committee asked questions about consent and eligibility requirements for A₂ and A₂B to B compatible transplantation. Another member asked about cost assessments regarding the increasing number of non-local recipients. While this is not an unexpected change, the Liaison shared that the Kidney Committee continues to partner with the OPO Committee regarding post-implementation logistics, especially cross matching. The Committee expressed interest in helping with continued education efforts regarding KAS as additional needs may become apparent post-implementation.

6. Length of Committee Terms

At the request of the POC, the Vice Chair asked the Committee to provide its recommendation on extending the length of terms for all OPTN Committees to three years. It expressed support for continued three year terms for Patient Affairs Committee members, which is especially advantageous to patient representatives. They deferred to the other committees regarding whether members wish to extend their service terms but cautioned that broad representation is very important, especially with the increasing pace of projects. If terms are extended to three years, the OPTN needs to consider other ways to maintain broad representation.

Upcoming Meetings

- May 13, 2015, conference call
- June 10, 2015, conference call
- July 8, 2015, conference call