

**OPTN/UNOS Patient Affairs Committee**  
**Meeting Summary**  
**July 10, 2014**  
**Conference Call**

**Kristie Lemmon, Chair**  
**John Fallgren, Vice Chair**

*Discussions of the full committee on July 10, 2014 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. Project to clarify the language for Individual Wait Time Transfer Subcommittee Update**

The Committee received an update on this project. The Subcommittee includes patients, transplant professionals and UNOS Staff. Recent Subcommittee work has focused on developing an outline of the process for transfer of Wait Time. Members of the Subcommittee have spent time in the Organ Center observing the Organ Center Process.

The Subcommittee used the Committee's statement that '*Waiting Time represents hope to patients*' as a guiding lens for reviewing the wait time transfer process. The Subcommittee felt that the current Organ Center process for transferring waiting time supports the needs of transplant programs, staff and patients.

The Subcommittee identified the following as areas that should be addressed in future policy language:

- Responsibility for initiating and following the process fall to the patient
- Responsibilities for the transfer of wait time have not been outlined in process
- Patient notification of status is not required in the policy

It was further determined that there are aspects of Wait Time Transfer that the transplant community should be educated about in greater detail. These include:

- Time at Status: for certain allocations, wait time is transferred at status or time at urgency, and not as a cumulative block of time
  - e.g. a liver candidate has 200 days total time, but has 175 days at a MELD of 15 and 25 days at a MELD of 30. During a wait time transfer that 200 days of time is transferred as days at a particular MELD score, and not as a total block of calendar days.
- Qualifying Date Changes: for some allocations, the date that the patient met qualifying criteria could change depending on the documentation provided during a wait time transfer
- Gap Time: The time elapsed between a removed registration and a new registration, during which a candidate is not on the waiting list at all

The Committee asked questions to clarify the current process for wait time transfer. At the end of the discussion, the Committee agreed to accept the Subcommittee recommendations as follows:

- Establish consensus regarding the acceptable process for waiting time transfer
- Clarify current language to reflect current practice
- Develop resources to educate the transplant community on any clarifications in policy language
- Develop educational resources to clarify concepts that impact wait time transfer

### **Committee Projects Pending Implementation**

**2. None**

### **Implemented Committee Projects**

**3. None**

### **Review of Public Comment Proposals**

**4. None**

### **Other Significant Items**

**5. Liver Redesign Concept Document**

The Committee received a presentation on the current Liver Redesign Concept Document that is out for public review from Dr. David Mulligan, Chair of the Liver Transplantation Committee. The current system is based on the model for end-stage liver disease (MELD) and pediatric end-stage liver disease (PELD) scores since 2002. It prioritizes candidates based on the risk of death while awaiting liver transplantation. The current system faces many challenges. Despite improvements in liver allocation and distribution, waitlist mortality remains high for patients with higher MELD scores. Significant disparity exists between OPOs and regions with regard to mean MELD at transplant and waitlist mortality. The current situation led the Liver Committee to raise this question “how can we redirect livers to those most in need?”

After a review of existing geographic disparities, waiting list outcome probabilities, variations in death rates and in organs procured by DSA, the Liver Committee began to consider other options for liver distribution. In November 2012m the OPTN Board resolved the following:

- The existing geographic disparity in allocation of organs for transplant is unacceptably high
- The Board directs the organ-specific committees to define the measurement of fairness and any constraints for each organ system.
- The Board requests that optimized systems utilizing overlapping v. non-overlapping geographic boundaries be compared

The Liver Committee considered multiple options. After reviewing statistical modeling, the Committee determined to develop and present the concept of geographic redistricting which would include the following:

- The number of districts should be at least 4 and no more than 8;
- The minimum number of transplant centers per district is 6;
- The maximum median travel time between DSAs placed in the same district is 3 hours; and
- The number of waitlist deaths under redistricting must not be statistically significantly higher than in the current system.
- The districts should be contiguous

In response to questions from the Committee, Dr. Mulligan stressed that these are concepts for discussion within the community. At this point these are not policies for implementation. Thus, there is no current timeline for implementation. Dr. Mulligan did outline the current timeline for the review and discussion of the concept document.

The Committee asked for clarification on the impact of sharing in multi-organ transplants. Share 35 has resulted in an increase of offers for multi-organ transplant. One would assume the same would occur. The Committee raised questions about the potential for increased travel time in a new system. The proposed plan would establish a maximum 3-hour travel time requirement. There was also wide discussion regarding the potential pushback from low MELD regions and the potential for disadvantaging low-income, minority and other vulnerable populations. The modeling did not show a statistically significant decrease in organ offers to minority populations or other vulnerable populations. Both Dr. Mulligan and the committee agree that there is much discussion among so-called low-Meld regions regarding geographic redistricting. The Liver Committee encourages this continued open discussion at the upcoming Liver Town Hall Meeting in August, 2014.

The Committee focused on the importance of engaging the transplant community and the general public in the discussions around redistricting. The Committee committed to sharing links to the Town Hall Meeting and any other information on redistricting via social media.

The Committee was also invited to review the Liver Concept Document from a plain language perspective. Michelle Brown, Minority Donor Family, Joseph Hillenburg, Father of Pediatric heart recipient, Peggy Stewart, Liver Social Worker and Kristie Lemmon, Living Kidney Donor Mom and PAC Chair, agreed to review the Liver Concept Document for readability and legibility.

## **6. Updated OPTN Website Preview**

The Committee received a preview of the updated OPTN website. One of the goals of the update is to increase accessibility and usability for patients and the general public. The Committee was very positive regarding the layout of the new public comment page, which allows all comments to be viewed by the reader. The Committee agreed to review the site in greater depth and provide feedback to UNOS Communications.

**Upcoming Meeting(s)**

- August 7, 2014 Conference Call
- October 20, 2014 – Face-to-face Meeting in Chicago