

OPTN/UNOS Patient Affairs Committee
Meeting Summary
March 7, 2016
Richmond, Virginia

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

Discussions of the full committee on March 7, 2016 are summarized below. All committee meeting summaries are available at <http://optn.transplant.hrsa.gov/>.

Committee Projects

None

Review of Public Comment Proposals

1. Proposal to Modify the Adult Heart Allocation System

With this proposal, the OPTN/UNOS Patient Affairs Committee (PAC) appreciates the Thoracic Committee's efforts to reduce waitlist mortality and increase access to transplant for the most urgent candidates through better stratification and broader geographic sharing. After a presentation, PAC members had an opportunity to ask the Chair several questions about the proposed changes.

They wanted to understand why the Committee had not chosen to pursue a heart allocation score similar to that for liver or lungs. The Chair explained that additional data collection, as proposed, is necessary in order to develop an accurate score. Since the proposal seeks to increase transplant rates in the sickest candidates, PAC wanted to understand the impact on post-transplant survival rates. One member suggested that the Committee consider creating an expected post-transplant survival (EPTS) score, as is currently done in kidney allocation. The Chair explained that modeling does not indicate a negative impact on two year post-transplant survival rates under the proposed changes, despite not creating such a candidate risk model. In addition to a heart allocation score, this may be something the Committee considers in future changes to heart allocation.

One member asked how many heart transplants currently take place under exception and whether this proposal will have any impact on that. PAC will be interested to see if the Committee chooses to pursue a national heart board, similar to that for lungs and the one that is currently being proposed for liver.

Finally, while PAC realizes this is an organizational challenge beyond this proposal, it is eager for the OPTN to clarify multi-organ allocation policy to ensure that multi-organ candidates are receiving an appropriate level of priority in allocation.

2. National Liver Review Board

The OPTN/UNOS Patient Affairs Committee (PAC) supports the Liver Committee's effort to reduce geographic variation in exception practices and improve equity in access to transplant for all liver candidates through a national liver review board. PAC supports creating specialty boards, which allow for reviewers with appropriate policy and clinical expertise to evaluate requests. PAC also supports the improvements to the overall

efficiency of the system, especially automating the standardized exceptions, so that the peer review process is reserved for those cases that require expert review.

While supportive of the structure and operations proposed thus far, PAC is eager to review the next phase of development of this proposal. Revisions to current exception policy must be fair to both exception and non-exception candidates and adequately account for geographic differences in average MELD at transplant.

Other Significant Items

3. Imminent Death Donation

The Ethics Committee requested that PAC review a draft report on the ethical considerations and policy issues that might need to be addressed for imminent death donation (IDD) to be considered as an option for organ donation. The Ethics Committee requested that PAC provide formal comments either in support of the report or outlining any specific questions, concerns, or suggestions regarding this analysis. The Ethics Committee plans to include feedback from PAC and other Committees in a final comprehensive report to the Board of Directors.

After a presentation and intensive discussion, consensus was that IDD is not an acceptable practice, is unlikely to increase organs for transplantation, and risks decreasing donation rates, especially among racial and ethnic minorities, by eroding public trust. The Committee understands that there are families who advocate for this as an option, but the risk to public trust in the organ donation system outweighs the potential increase in the number of transplants through IDD. The Committee voted that discussion may continue at the Committee or Board level, although PAC is unlikely to support an IDD policy proposal.

4. Recruiting and Preparing Patients and Patient Advocates to Serve on OPTN Committees

Members participated in small group discussion to answer the following questions:

- How can patients learn about the opportunity to serve on OPTN/UNOS Committees?
- How should patient representatives be chosen to serve on OPTN/UNOS Committees? What relationship should PAC have with them?
- What have you learned during your experience serving on PAC that you wish you had known at the beginning of your term?

Having brainstormed several recruitment strategies, the Committee will choose which they believe will be most effective and work with the UNOS Policy, Regional Administration, and Communications Departments to implement them.

Members will also reach out to current patient representatives on OPTN Committees to introduce themselves and offer PAC as a resource. Going forward, they will continue to discuss ideas that originated in these small group discussions, such as recommended service on PAC before serving on other OPTN Committees, expanded orientation for new patient representatives, including a voluntary mentorship program, and support for OPTN Chairs in making the best use of their patient representatives.

5. Involving Patient Community Stakeholders in Policy Development

Members discussed how the OPTN can better engage patients in:

- Identifying and prioritizing transplant community needs
- Developing policy to address those needs.

One idea that will soon be implemented is to notify the public when a new project receives approval from both the Policy Oversight Committee (POC) and the Executive Committee. Committee members agreed that there is an opportunity for PAC to engage with other Committees early in their policy development process. Committee members will review the list of new projects to identify projects where PAC could collaborate.

Upcoming Meetings

- April 13, 2016
- May 11, 2016
- June 8, 2016