

OPTN/UNOS Patient Affairs Committee
Meeting Summary
November 18, 2015
Conference Call

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

Discussions of the full committee on November 18, 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. Increase Community Participation in Public Comment

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. Several members volunteered to develop a survey to collect contact information for patient advocates, which the Committee hopes to distribute to OPTN members as well as to members of their own professional and personal networks.

Other Significant Items

2. Brainstorming New Project Ideas

Keeping in mind the priorities of the OPTN Strategic Plan, the Committee brainstormed new project ideas during its September in-person meeting. The Committee further developed several of these ideas during its November conference call, including:

- Establishing a patient portal so patients can have access to certain information in UNetSM
- Creating new educational materials for two identified special populations: potential living donors and parents of pediatric candidates
- Expanding public education on transplantation and donation to promote awareness among the general public and dispel popular myths.

3. Examining the Special Population of Candidates Adding to the Waiting List for the First Time at 18 Years Old

In response to a concern raised through the Patient Services line, the Committee discussed situations where transplant candidates with chronic disease are either referred or evaluated prior to their 18th birthdays, but not registered on the waiting list until after turning 18 years old. In these instances, the candidate does not have pediatric priority for organ allocation. The Committee has requested a data analysis to better estimate the scope of this problem. After reviewing the analysis next month, the Committee will consider whether educational materials should be created to ensure patients are waitlisted in time, and also whether policy should be changed to allow patients in this situation to retain pediatric priority.

Upcoming Meetings

- January 13, 2016