

**OPTN/UNOS Patient Affairs Committee
Meeting Summary
May 11, 2016
Conference Call**

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

Discussions of the full committee on May 11, 2016 are summarized below. All committee meeting summaries are available at <https://optn.transplant.hrsa.gov>.

Committee Projects

1. Pediatric Priority for Kidney Candidates Registered after Turning 18 Years Old

The Patient Affairs Committee (Committee) continued its discussions regarding potential situations where transplant candidates who experienced chronic disease were either referred or evaluated prior to their 18th birthdays, but not registered on the waiting list until after turning 18 years old. The Committee acknowledged the potential barriers to pursuing a policy solution at this time and felt that developing education for parents and transplant centers, in collaboration with other Committees, may address the issue.

However, they requested data to monitor the frequency of these first-time registrations and possible evidence of chronic disease prior to age 18. These data will be analyzed and presented to the Committee every six months.

Other Significant Items

2. 2015-2018 OPTN Strategic Goal Review and Project Prioritization

The Committee reviewed the 2015-2018 OPTN Strategic Plan and the current alignment of all active projects. UNOS staff noted that Strategic Goals 2 and 4 continue to be over allocated with projects, and Goals 1 and 3 under allocated. The Committee then reviewed their portfolio of project ideas and prioritized two:

- Peer Mentoring of Transplant Candidates and Recipients (Goal 3)
- What Every Parent Needs to Know (Goal 2, Goal 3)

They also discussed initiatives that would further engage and improve PAC as a committee. The Committee will form workgroups for each project.

Upcoming Meetings

- June, 2016
- July, 2016
- August, 2016