

**OPTN/UNOS Patient Affairs Committee**  
**Meeting Summary**  
**January 13, 2016**  
**Conference Call**

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

*Discussions of the full committee on January 13, 2016 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**

None

**Other Significant Items**

**1. 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 then reviewed data to understand how many children may face similar situations. From September 1, 2014 through August 31, 2015, there were 80 first-time waiting list registrations for candidates age 18 at listing, and 60% of these were kidney registrations (N=48). Of those 48 kidney registrations, approximately 40% (19) started dialysis prior to their 18th birthdays.

The Committee discussed several potential solutions to this problem, including education for transplant programs and parents and policy changes. Potential policy changes discussed included:

- Creating an exception pathway for programs to petition for pediatric priority for candidates not registered prior to 18 years old
- Assigning pediatric priority to children who begin dialysis prior to turning 18 years old but registered after turning 18 years old
- Assigning pediatric priority to candidates registered after turning 18 years old who met certain glomerular filtration rate (GFR) requirements prior to turning 18 years old

Members learned that many pediatric exception pathways have been removed from policy, most recently for liver in November 2014. Some members expressed interest in identifying objective criteria indicating end-stage renal disease prior to age 18.

The Committee voted unanimously to continue developing this project idea for submission for POC approval in March. The Committee Chair plans to consult with the Chairs of the Pediatric Transplantation and Kidney Transplantation Committees regarding potential solutions.

## **Upcoming Meetings**

- February 10, 2016
- March 7, 2016