

**OPTN/UNOS Patient Affairs Committee**  
**Meeting Summary**  
**August 15, 2016**  
**Chicago, IL**

**Kristie Lemmon, MBA, Chair**  
**Darnell Waun, MSN, RN, Vice Chair**

*Discussions of the full committee on August 15, 2016 are summarized below. All committee meeting summaries are available at <https://optn.transplant.hrsa.gov>.*

### **Committee Projects**

#### **1. What Every Parent Needs to Know**

There are limited resources currently available tailored to the specific needs and concerns of parents of pediatric transplant candidates. A workgroup comprised of members from the Patient Affairs Committee (Committee) and the Transplant Coordinators Committee, in addition to external experts, will develop a companion brochure to *What Every Patient Needs to Know*, one of UNOS' most popular resources. The workgroup Chair informed the Committee that they are currently refining the problem statement and plan on generating a list of potential topics on their next call.

#### **2. Effective Practices in Peer Mentoring**

Studies show that peer support is effective for patients with chronic illnesses, including kidney disease and in long-term dialysis therapy. Peer support has also been shown to be effective for patients with a variety of other health conditions, including in the transplant setting. Although some transplant centers and transplant organizations offer peer mentoring programs, many do not. A Subcommittee is exploring sharing best practices in peer mentoring programs for transplant centers in an effort to improve patient outcomes. The Subcommittee is currently working on refining the problem and identifying robust peer mentoring programs in the transplant or related (kidney disease) setting.

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

#### **3. Modifications to Informed Consent Requirements for Potential Living Donors**

The Living Donor Committee presented their proposal to clarify existing informed consent requirements and to add other new requirements. The Committee supported the following proposed changes:

- Informing female potential living donors of risk of preeclampsia or gestational hypertension may be increased in pregnancies after donation
- Informing potential living donors that transplant hospitals determine candidacy for transplantation based on existing hospital specific guidelines or practices and clinical judgment.

The Committee found the following proposed policy language confusing:

- Informing potential living donors that the recovery hospital can disclose to the living donor certain information about candidates only with permission of the candidate, including:

- The reasons for a transplant candidate's increased likelihood of adverse outcomes
- Personal health information collected during the transplant candidate's evaluation, which is confidential and protected under privacy law
- Any transplant candidate may have an increased likelihood of adverse outcomes (including but not limited to graft failure, complications, and mortality) that:
  - Exceed local or national averages
  - Do not necessarily prohibit transplantation
  - Are not disclosed to the living donor

In light of technical challenges during the meeting that prevented effective dialogue between the Committee and the presenter, the Committee requested to hear the presentation again at their next committee meeting.

#### **4. Liver Redistricting**

The Liver and Intestine Committee presented their proposal to modify current regional boundaries to better match organ supply with demand, ensuring more equitable access for those in need of liver transplant regardless of their place of residence or listing. The Committee had the following questions:

- What is the anticipated impact of this proposal with simultaneous liver kidney allocation?
- What is the proposed effects of the proposal on median waiting times?
- What is the anticipated effect of this proposal on access to pediatric patients?
- What does the Liver Committee anticipate will happen with discard rates, if organs are being transported further distances?

In light of technical challenges during the meeting that prevented effective dialogue between the Committee and the presenter, the Committee requested to hear the presentation again at their next committee meeting.

#### **5. Modifications to the Adult Heart Allocation System**

The Thoracic Organ Transplantation Committee presented the second round of changes proposed for the modification to the adult heart allocation system. One Committee member emphasized that communicating to and educating patients on the new statuses would be crucial. This member inquired whether the Thoracic Committee would explore a heart allocation score in the future. Another member asked for clarification on how patients would be transitioned to their new status. The Thoracic Committee representative answered both of these questions.

In light of technical challenges during the meeting that prevented effective dialogue between the Committee and the presenter, the Committee requested to hear the presentation again at their next committee meeting.

### **Other Significant Items**

#### **6. Orientation**

As part of the orientation process, UNOS Research staff and the Scientific Registry for Transplant Recipients (SRTR) presented overviews of their capabilities and expertise in

supporting OPTN/UNOS Committees. The new Committee Vice Chair also provided an update from the most recent Policy Oversight Committee (POC) call, during which the POC recommended 15 proposals be released for public comment.

## **7. OPTN/UNOS Patient Services**

UNOS staff provided an overview of the Patient Services hotline, a service provided in accordance with the OPTN contract. The OPTN Contractor must communicate and share resources with OPTN members, transplant patients, living donors, donor families and the general public. In addition, the Contractor must support callers with English as a second language. UNOS staff also shared data on volume and types of calls fielded in 2015.

## **8. Pediatric priority exceptions for candidates registered after turning 18 years old**

At their May meeting, the Committee requested data to monitor the frequency of first-time registrations of transplant candidates who were either referred or evaluated for transplant prior to their 18th birthdays, but not registered on the waiting list until after turning 18 years old. UNOS staff presented requested data to the Committee. Although the population of affected patients was small, the Committee was still concerned about their access and outcomes, and recommended that pediatric problems be framed in potential patient years, and not simple numbers. Some members still felt strongly about a policy solution; others were satisfied with including information in *What Every Parent Needs to Know*. Educating community nephrologists and adult dialysis centers was also discussed, but the Committee acknowledged that because those groups were not members, it was beyond the OPTN's purview to engage with them.

However, as part of the OPTN strategic goal of improving waitlisted patient, living donor and transplant recipient outcomes, there is an objective to develop and distribute educational materials to assist primary care providers on best practices for partnering with the transplant center in the ongoing care of transplant recipients. In light of this, the Committee was interested in having a representative from the Kidney and/or the Pediatric Committee(s) attend a future Committee meeting and explain pediatric priority points. In addition, the Committee would like to understand the exception system generally (all organs).

## **9. New Project Ideas Discussion**

In the time remaining, the Committee discussed new potential project ideas:

- Improving Patient Notification of Waiting List Status/Educating patients on the waitlist
- Improving OPO performance
- Standardizing listing practices among transplant centers/evaluation of pre-transplant evaluations
- Insurance barriers to accessing transplant
- Improving OPO outreach and education in donor hospitals
- Increasing efforts to expand the number of kidney chains/kidney paired donation
- Creating a national donor registry
- Promoting donation via social media to increase donor registrations in younger populations

- Improving pediatric access to the waiting list by addressing social barriers
- Improving rates of living donation to pediatric candidates
- Risk aversion to transplanting complicated pediatric transplant candidates
- Reducing risk aversion to utilizing marginal organs

**Upcoming Meeting**

- September 6, 2016