

**OPTN Patient Affairs Committee
Meeting Summary
April 21, 2020
Conference Call**

**Darnell Waun, MSN, Chair
Garrett Erdle, MBA, Vice Chair**

Introduction

The Patient Affairs Committee (PAC) met via teleconference on 04/21/2020 to discuss the following agenda items:

1. COVID-19 Update
2. Public Comment Update
3. PHS Increased Risk Patient Fact Sheet Review
4. HRSA Request for Public Comment on living donor reimbursement guidelines through National Living Donor Assistance Center Update

The following is a summary of the Committee's discussions.

1. COVID-19 Update

The Committee received a COVID-19 update. The Committee was informed of the OPTN response to COVID-19 including:

- OPTN monitoring practices
- Emergency policy actions
- UNetsm system changes
- OPTN operations changes
- Transplant metrics
- Resources available to patients

Committee members discussed how COVID-19 is effecting them and their hospitals.

2. Public Comment Update

The Committee received a brief update on public comment items of interest.

- The Minority Affairs Committee's *Data Collection to Assess Socioeconomic Status and Access to Transplant* proposal has been placed back in the "evidence gathering" stage of policy development.
- The Kidney Committee have not yet finalized updates to the *Addressing Medically Urgent Candidates in New Kidney Allocation Policy* proposal.

The Committee Chair commented the proposal review team leads could provide more feedback to the respective committees if more input is needed.

3. PHS Increased Risk Patient Fact Sheet Review

The Committee was informed the Centers for Disease Control and Prevention (CDC) have reached out to the OPTN for input on their draft update to the patient fact sheet on PHS Increased Risk Guidelines.

Committee members commented the document does not make it clear whether the donors have already tested negative for the outlined diseases. A committee member commented reducing the testing timeframe to seven days could be a burden on living donors. Another committee member recommended adding language that suggests patients should discuss risk factors and strategies for patient safety with their doctor as a patient cannot make an informed decision if they do not know the risk factors. The Committee also suggested reordering the document so the most important items appear first.

Next Steps

Committee members were asked to independently review the document and send feedback on any additional recommendations.

4. HRSA Request for Public Comment on living donor reimbursement guidelines through National Living Donor Assistance Center Update

The Committee was updated on a Federal Register Notice posted by the Department of Health and Human Services entitled “Reimbursement of Travel and Subsistence Expenses toward Living Organ Donation Program Eligibility Guidelines”. The proposed rulemaking would:

- Increase household income eligibility threshold to 350 percent (currently, the threshold is 300 percent) for living organ donors and organ recipients
- Clarify the use of the existing preference categories in relation to the proposed income eligibility threshold. The Proposal is for the Program to accept applications primarily from preference category 1. However, the Program may accept applications from each subsequent category as funds become available.
- Amend the qualifying expenses section of the eligibility guidelines to allow the Program to reimburse eligible non-directed donors for qualifying expenses

Committee leadership along with the Living Donor Committee drafted a response to include:

- Support increasing household eligibility threshold. However, the change from 300% to 350% is too modest. Endorse ACOT’s recommendation to increase threshold to 500% of federal poverty limit
- Believe there should be less emphasis on the recipient’s income when determining a donor’s eligibility
- There should be special consideration for donors and recipients relying on the same household income (ex. spouse to spouse) and donors serving as the recipient’s caregiver
- Support expanding eligibility to non-directed donors

The Executive Committee approved the response and will be sent on behalf of the OPTN. The letter will be sent to the full committee once it is finalized.

Upcoming Meeting

- May 19, 2020 – Teleconference