

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

**Darnell Waun, R.N., M.S.N., Chair
Garret Erdle, M.B.A., Vice Chair**

Introduction

The Patient Affairs Committee (PAC) met via Citrix GoToMeeting teleconference on 07/21/2020 to discuss the following agenda items:

1. New Member Orientation
2. Public Health Service (PHS) Guidelines Education/Communications Centers for Disease Control & Prevention (CDC) Call Summary
3. Public Comment Item Preview
4. Cross Committee Work Group Report Out

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

1. New Member Orientation

New committee members were informed of the policy development process, committee structure, committee purpose, and committee member expectations.

2. Public Health Service (PHS) Guidelines Education/Communications Centers for Disease Control & Prevention (CDC) Call Summary

The PAC reviewed the purpose, intention, and changes to PHS Guidelines.

Summary of discussion:

The Chair explained the PHS Guidelines are for donors who have been in a medical or social situation which increased their exposure to human immunodeficiency virus (HIV), hepatitis B virus (HBV), and hepatitis C virus (HCV). The purpose of the post-operative testing is to ensure that recipients, whose donor met the PHS Guidelines for potential exposure, have not contracted a virus.

Changes to the PHS Guidelines clarify and update language based on new research. The PHS Guidelines will be published for the Summer 2020 Public Comment cycle. If adopted and implemented, there is accompanying education materials that will be released.

A member asked if the revisions extended testing to a year and inquired who was responsible for payment. Staff responded that revisions extended liver recipients testing to 11 – 13 months for Hepatitis C. Also, staff responded that the OPTN policy does not delve into payment issues.

Next steps:

PHS Guidelines will be released for Summer 2020 Public Comment in August. PAC will be updated regarding future discussions with the CDC.

3. Public Comment Item Preview

The PAC reviewed Summer 2020 Public Comment proposals, which begins August 4 and ends October 1.

Summary of discussion:

Summer 2020 Public Comment proposals

- Enhancements to the National Liver Review Board (NLRB), part 2
- Modify Data Collection on Vascularized Composite Allografts (VCA) Living Donors
- Programming VCA Allocation into UNet
- Modify Living Donor Policy to Include Living VCA Donors
- Guidance and Policy Clarifications Addressing Adult Heart Allocation Policy
- Guidance on Addressing Use of Pediatric Heart Exceptions
- Update on Continuous Distribution of Lungs Project
- Updated Cohort for Calculation of the Lung Allocation Score (LAS)
- Align OPTN Policy with U.S. Public Health Service Guideline, 2020
- COVID-19 Emergency Policies and Data Collection

A member asked if they should encourage members from their communities to add input during Public Comment period. The chair responded that all input is highly encouraged.

Next steps:

PAC leadership will identify relevant proposals that necessitate patient feedback. Each member will review assigned proposal by August 19.

4. Cross Committee Work Group Report Out

Members reported their collaboration with other committees.

Summary of discussion:

A member, representing PAC on the Facilitating Patient Navigation Workgroup, mentioned that the Workgroup is discussing how to provide all patients with equal information on navigating the factors relevant to successful outcomes for organ transplant. The member continued that the Workgroup intends to analyze ethical principles, such as justice and fairness, for all that would benefit from the scarce resources required for transplantation.

Next steps:

Members on cross committee workgroups will continue report outs during the August meeting.

Upcoming Meetings

- August 18, 2020 (teleconference)
- September 1, 2020 (formerly our in-person meeting, now teleconference)