

OPTN Patient Affairs Committee Meeting Minutes July 16, 2019 Conference Call

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

Introduction

The Patient Affairs (PAC) Committee met via Citrix GoTo teleconference on 07/16/2019 to discuss the following agenda items:

- 1. Committee Orientation
- 2. Education Topic: Public Comment Primer
- 3. Public Comment Team Review Process

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

1. Committee Orientation

UNOS staff presented an overview of the PAC, including Committee responsibilities, expectations and the OPTN policy development process.

Summary of discussion:

There were no questions or discussion from Committee members.

Next Steps:

UNOS staff will work to ensure all PAC members have access to Sharepoint and Basecamp prior to the fall 209 public comment cycle.

2. Education Topic: Pubic Comment Primer

UNOS staff presented an overview of the public comment cycle and the processes involved when reviewing public comment proposals.

Summary of discussion:

One Committee member emphasized the need for PAC members to be vocal and express their opinions as members of the patient community. UNOS staff agreed, and encouraged Committee members to amplify their voice by sharing and encouraging other patient stakeholders to contribute during the public comment cycle.

Next steps:

UNOS staff will continue to educate PAC members about the public comment cycle and processes.

3. Public Comment Team Review Process

UNOS staff presented an overview of the public comment process and how the PAC members will engage with each other during the public comment cycle to formulate responses to each respective proposal. This included discussion about accessing resources on Basecamp, the formation of teams to review public comment proposals, and team expectations.

Summary of discussion:

UNOS staff encouraged PAC members to review their respective proposals they were assigned, but to also review other public comment proposals.

One Committee member commented that during the Spring 2019 cycle there were specific deadlines set for when teams needed to submit their feedback. UNOS staff are currently in the process of scheduling a meeting with the PAC team leads in order to give more specific directions, and to provide a more robust timeline for feedback submission.

Next steps:

UNOS staff and PAC leadership will work to ensure all PAC member have access to Basecamp. UNOS staff will send out a meeting invite for the PAC team leads prior to the fall 2019 public comment cycle, along with national webinar registration information.

Upcoming Meeting

• August 20th (in-person)

Attendance

• Committee Members

- Earl Lovell
- Molly McCarthy
- Darnell Waun
- o Julie Siegel
- Garrett Erdle
- Stephanie Little
- o Beth Rubinstein
- Amit Khimji
- o Phil Williams
- o Marvin Lim
- James Sharrock
- o Diego Acero
- Christopher Yanakos
- HRSA Representatives
 - o Melanie Deal
 - o Janet Kuramato-Crawford
- SRTR Staff
 - o Kaite Audette
- UNOS Staff
 - Chris Wholley
 - o Hannah Byford