

**OPTN Patient Affairs Committee
Meeting Minutes
June 18, 2019
Conference Call**

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

Introduction

The PAC Committee met via Citrix GoTo teleconference on 06/18/2019 to discuss the following agenda items:

1. Liver Litigation Update
2. Constituent Council Debrief

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

1. Liver Litigation Update

UNOS leadership gave a brief update regarding the liver litigation.

Summary of discussion:

During the discussion, a Committee member was concerned that the current liver litigation may impact the kidney and pancreas allocation policies being developed for fall 2019. UNOS staff assured Committee members that the same policy development process is still in place (hypothetically though this could change), and that decisions should be defensible as long as they are sound and in compliance with the OPTN Final Rule. Another Committee member wanted more clarity surrounding the current liver litigation and the 2016 lung litigation. UNOS staff responded that there are very distinct differences between the two legal cases: the lung litigation was whether to use donation service area (DSA) as a unit of distribution, whereas the liver litigation is about the procedure that was used to develop the policies.

One Committee member asked how the Kiser litigation case being heard in the Supreme Court may affect other organ policies. UNOS staff clarified that this case is not about organ allocation; it is about a federal agency having deference or discretion in interpreting their own regulations. However, the Kiser case could have impact on how the U.S. Department of Health and Human Services (HHS) interprets the OPTN Final Rule and regulations.

In continuing the discussion, another committee was concerned that the plaintiffs suing the OPTN might postpone the implementation of the liver allocation because the policies would have to be released for a second public comment cycle. UNOS staff stated that if this occurred, the policy would eventually be approved, though it would take more time. The time to pass the policy may also increase if the Supreme Court decides that HHS does not have the deference to interpret their own regulations, thereby forcing the policy to go through the Advisory Committee on Organ Transplantation (ACOT).

2. Constituent Council Debrief

The PAC Chair discussed the ending of the proof of concept, and how to maintain committee diversity and increase patient engagement on the PAC.

Summary of discussion:

During the discussion, there were two starkly contrasting opinions expressed by Committee members regarding the proof of concept. One Committee member stated that the constituent council just needed more time to mature. This member opined that in their view, the proof of concept should have continued for a while longer. On the other hand, there were several Committee members who stated that they were not actively participating on the constituent council because there was too much going on, especially on Basecamp (BC). For example, one Committee member commented that though using BC was a really good learning experience in the beginning, it soon became overwhelming. Furthermore, once the PAC expanded to include more members, they felt confused as to what their place was on the PAC and if their input actually mattered. In response, this member stated that felt lost and pulled back from engaging on the PAC in response. Another concern was that they didn't know who to contact during the proof of concept, and felt that prior to this, there was more organized and direct communication.

In response to these concerns, a Committee member suggested that the PAC creates a mentor system. This mentoring system would pair new members and those members rolling off the Committee, which might especially help new members whom attend regional meetings for the first time. Other suggestions from the Committee included adding an ad hoc group to the PAC, which would be composed of individuals with expertise in certain areas (such as liver). This might be a way in which to engage those members no longer on the PAC, and may allow them to still have a voice in what is happening on the PAC. Another suggestion was to have those members no longer on the PAC be involved in other Committees or on the Board of Directors (BOD) via an email system. In this way, members can continue to rise onto the BOD. It was noted however that since the BOD is looking to increase their diversity, that the PAC should increase their diversity as well. In response, the PAC Chair stated that they want to ensure new PAC members have the background and education to be on Committees or in Workgroups. Also, the Chair was supportive of continuing to enhance communication between the PAC, other Committees and to the BOD.

Last to be discussed was the future use of BC. The PAC Chair voiced support for retaining the ability to communicate on a platform other than SharePoint, because SharePoint is not good for agile discussions. In the Chair's view, SharePoint is merely a depository for meeting minutes and other Committee materials. UNOS staff replied that they want to be responsive to PAC's needs and suggested thinking about other possible platforms that may be used to facilitate discussion other than BC. Another alternative might be to maintain BC solely for communication, but have all materials posted on SharePoint.

The PAC Chair stated that education, strategy & process improvement, and patient engagement should be the 3 initiatives that the PAC goes forward with.

Next steps:

UNOS staff asked that PAC members suggest new platforms for communication. UNOS staff recommended that PAC members continue to educate patient and donor family members about the UNOS systems and about OPTN processes.

Upcoming Meeting

- August 20, 2019 (in person)

Attendance

- **Committee Members**
 - Randee Bloom
 - Darnell Waun
 - Jeff Graham
 - Mary Beth Callahan
 - Jeff Goldstein
 - Terry Box
 - Bill Tribett (phone)
 - Nancy Metzler
 - Phil Williams
 - Beth Rubinstein
 - Stephanie Little
 - Garrett Erdle
 - Bill Freeman
 - Tara Storch
 - Joseph Hillenburg
 - Bob Goodman
 - Deana Santana
 - Melissa McQueen
 - Kathy Schwab
 - Tim Mose
 - Debi Hammel
 - Hamang Patel
 - Julia Coleman
- **HRSA Representatives**
 - Arjun Naik
 - Marilyn Levi
 - Janet Crawford-Kamuto
 - Raelene Skerda
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Kim Uccellini
 - Hannah Byford
 - Craig Connors
 - Alison Wilhelm
 - Jill Finnie
 - Liz Suskind
 - Chris Wholley
- **Other Attendees**
 - James Sharrock
 - Molly McCarthy