

**OPTN Patient Affairs Committee
Meeting Minutes
June 21, 2019
Conference Call**

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

Introduction

The Patient Affairs Committee (PAC) met via Citrix GoTo teleconference on 05/21/2019 to discuss the following agenda items:

1. Proposed OPTN Policy Terminology Conventions
2. Constituent Council Debrief

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

1. Proposed OPTN Policy Terminology Conventions

UNOS staff discussed terminology challenges within OPTN policy language, along with possible solutions for developing consistent convention language that is respectful and sensitive to patient, donor families and recipients.

Summary of discussion:

UNOS staff discussed the current verbiage issues within OPTN Policy language, including inconsistent terminology and a lack of awareness or understanding amongst UNOS staff of more contemporary vernacular. In order to address these issues, UNOS staff suggested that the PAC develop guiding principles to determine when, how, and where to use language conventions. Beginning to define these principles will assist UNOS staff in using the "correct" terminology that is consistent with the transplant community.

In response, PAC members asked whether these terms will be communicated to the public. UNOS staff replied that for now, the terms are intended as an internal resource document for staff, though the principles may be communicated to the public at a later time. One PAC member was confused as to why the verbiage had to be different for different audiences. In their opinion, verbiage should be consistent across all venues (e.g. the same terms being used both in scholarly articles and in OPTN policies). In reply, another PAC member stated that the medical field is already accustomed to using certain terms, such as "harvest". However, other PAC members stated that such words can be triggering and offensive for the community. A clinical PAC member also stated that terms should not be used that are considered offensive unless absolutely necessary. Furthermore, though medical staff may use such terms now, there needs to be a lengthy process in place for reminding them to be more sensitive. As such, PAC members agreed that the document presented will be a good starting point to addressing all these issues, with a suggestion to include other national organizations into this process (such as the International Transplant Nurses Society).

Another PAC member stated that the verbiage used should be very precise, especially if terms are associated with a "must do". In this way, precision and consciousness should both be maintained, especially as terms evolve over time. A clinical PAC member then stated that there is also a lack of understanding and education in the community regarding sensitive terminology. Because of this, the news media and clinicians should use the same vernacular. In this way, standard terminology may

increase transparency and therefore lead to better reception and implementation within the broader community. For example, there is confusion in the marketing field around the term “component” when describing living donor programs, because “component” is too restrictive and does not adequately describe what is occurring at a national level. In the end, most Committee members agreed that there should be universal language, precision, and terms that honor the personhood of donors and recipients.

Next, the PAC Chair asked whether the Committee could develop a white paper and send it out for public comment. UNOS staff stated that this might be possible, but that the PAC would still need to follow the policy development process, including articulating the problem and provide evidence there is a problem. Still, another PAC member asked how to advance this project as a white paper. UNOS staff replied that they would need to discuss any further steps with UNOS policy leadership.

Next steps:

UNOS staff to meet with policy leadership and discuss the project’s next steps. PAC members encouraged to continue to provide staff feedback on the presented terms.

2. Constituent Council Debrief

UNOS staff provided a very brief update on the Constituent Council, including the decision to terminate the constituent council on June 30, 2019. UNOS staff encouraged PAC members to reach out with any questions or feedback related to this decision.

Upcoming Meeting

- June 18, 2019

Attendance

- **Committee Members**
 - Julie Siegel
 - Melissa McQueen
 - Luis Mayen
 - Hamang Patel
 - Randee Bloom
 - Terry Box
 - Julia Coleman
 - Garrett Erdle
 - William Freeman
 - Patrick Dean
 - Robert Goodman
 - Jeff Graham
 - Joseph Hillenburg
 - Carolyn Light
 - Stephanie Little
 - Timothy Mose
 - Molly McCarthy
 - Nancy Metzler
 - Jennifer Muriett
 - Sarah Sampsel
 - James Sharrock
 - Tara Torch
 - Heather Wertin
 - Mary Callahan
 - Laura Depiero
 - Kristie Lemmon
 - Kathy Schwab
 - Rosemary Berkery
- **HRSA Representatives**
 - Marilyn Levi
 - Melanie Deal
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Hannah Byford
 - Rebecca Murdock
 - Kim Uccellini
 - Susan Tlusty
 - Shannon Edwards
 - Elizabeth Suskind
 - Alison Wilhelm