

**OPTN Patient Affairs Committee
Meeting Summary
June 15, 2021
Conference Call**

**Darnell Wuan, M.S.N., Chair
Garrett Erdle, M.B.A., Vice Chair**

Introduction

The Patient Affairs Committee met via Citrix GoToMeeting teleconference on 06/15/2021 to discuss the following agenda items:

1. OPTN Website Update
2. OPTN Committee Nominations & Recruitment
3. Cross Committee Workgroup Update – Pancreas Medical Urgency
4. Webinar Review – “COVID-19 Vaccine Antibody Response in Transplant Patients”
5. Recognition of Outgoing Members

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

1. OPTN Website Update

Staff from the UNOS Communications Department presented updates and improvements to the OPTN website following a period of information gathering from the transplant community in February 2020. UNOS staff previewed and requested feedback on story boards for patient focused animations.

Data summary:

What’s been done: developed patient brochures, evaluated content for plain language, and redesigned policy development and public comment

What’s being worked on: developing Spanish patient content, clarifying site navigation, and designing animations to better explain complex topics

Summary of discussion:

A member asked if site traffic increased as a result of these website changes and how this information should be interpreted. UNOS staff responded that while the website has not received more traffic at this time, it has experienced increased levels of engagement. The Communications Department uses a range of different metrics, such as downloading a PDF, watching a video, time spent, to determine levels of engagement. A member inquired about the average annual page views, which are currently 3.4 million. Since the OPTN website is a .gov site it does tend to receive more page views in general. Members inquired if UNOS mapped engagement geographical, which they do by region. A member inquired if there were certain topics that were accessed more often. UNOS staff informed the Committee that MELD and PELD are top search terms while information on kidney and data tend to see higher levels of traffic overall.

A member expressed gratitude for the focus in developing patient centric materials and suggested renaming continuous distribution to a points based allocation system to be more patient friendly. The Chair emphasized a marketing push to develop name recognition between the OPTN and transplant

recipients akin to that of the American Cancer Society for cancer patients, especially as an information hub.

A member inquired if UNOS paid for Search Engine Optimization (SEO). UNOS staff responded that altering the menu structure and associated web links should result in a natural boost in SEO, but there are restraints in dedicating further resources to SEO. A member asked if UNOS paid for promoted ads on search engines, which they do not currently do.

A member inquired if the connection between medical urgency of a patient and the time spent on the waiting list should be more clearly indicated early in the animation. A member inquired about the metrics associated with the animations and UNOS staff responded that the department will be able to see how long viewers watch the animation to determine what the drop off point is.

2. OPTN Committee Nominations & Recruitment

UNOS staff presented the Board and Committee Needs Assessment and their Outreach Efforts, specifically for patients and families. Currently, the 2022 Call for Nominations is open until September 30, 2021. UNOS staff requested feedback from the Committee on how they can get more patient and donor families involved in the OPTN.

Summary of discussion:

Multiple members shared their experience getting involved with their local Organ Procurement Organization (OPO) and being recommended there to volunteer with the OPTN. A member suggested engaging with transplant centers since the transplant team knows their patients the most and can recommend patients to the OPTN. A member mentioned timing of outreach and suggested targeting patients early while they are attending regular visits with their transplant team. Members suggested connecting with dialysis centers and cystic fibrosis clinics and encouraging them to share information about the OPTN. The Chair highlighted the work done by the UNOS Ambassadors and identified them as a launching point for further volunteering in the OPTN.

Next steps:

If anyone has questions about the nomination process or recommendations for specific patient organizations to engage with, please reach out to UNOS staff.

3. Cross Committee Workgroup Update – Pancreas Medical Urgency

Two members provided an overview of the work that has been done by the workgroup thus far, however, this work has been put on hold in anticipation for the development of a continuous distribution framework for pancreas transplant.

4. Webinar Review – “COVID-19 Vaccine Antibody Response in Transplant Patients”

UNOS staff was planning on facilitating a conversation about the recent webinar hosted by the Barth Syndrome Foundation, but due to time constraints leadership agreed to push this conversation to the July Committee meeting.

5. Recognition of Outgoing Members

UNOS staff praised the Chair for his leadership and commitment to the Committee. The Chair thanked outgoing members for their years of hard work and dedication and encouraged them to continue volunteering with the OPTN. Outgoing member's term will conclude on June 30, 2021.

Upcoming Meetings

- July 20, 2021
- August 24, 2021 – In Person Meeting
- September 21, 2021
- October 19, 2021
- November 15, 2021
- December 21, 2021

Attendance

- **Committee Members**
 - Anita Patel
 - Christopher Yanakos
 - Darnell Wuan
 - David Skinner
 - Diego Acero
 - Earl Lovell
 - Eric Tanis
 - Garrett Erdle
 - James Sharrock
 - Julie Ice
 - Julie Siegel
 - Molly McCarthy
 - Sarah Koohmaraie
 - Stephanie Little
- **HRSA Representatives**
 - Adriana Martinez
 - Raelene Skerda
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Andrew Swartz
 - Anna Wall
 - Bobby Holliday
 - Bridgette Huff
 - Cindy Young
 - Heather James
 - Joel Newman
 - Laura Schmitt
 - Matt Roop
 - Sara Rose Wells
 - Susan Tlusty
 - Tina Rhodes
- **Other Attendees**
 - Betsey Brada
 - Julie Spear
 - Justine Van Der Pool
 - Kristen Ramsay
 - Sejal Patel