## Stakeholder Advisory Council Meeting Minutes November 11, 2019 Academic Learning and Teaching Center, room 2.206

*Attendees:*

Carole White

Sara Masoud (note taking)  
Mike Foster

Kiki Foster

James Butler

Nashyra Butler

Bill Zinsmeyer

Janet Zinsmeyer

Ginny Funk

Angelica Davila

Deborah James

Yolanda Forney

Byron Cordes

Mayra Mendoza

1. **Group updates** 
   1. **Happy birthday, Bill!**

The group had cake to celebrate Bill’s birthday.

1. **Mike and Kiki video:** [*A Tribute to Nursing: To the community, with love*](https://www.youtube.com/watch?v=P6QKSjszfOg)

We watched the recently produced video featuring an interview with Mike and Kiki and they took a few minutes to share their thoughts and feelings that motivated them to be open with the community about their experiences.

Kiki expressed that they had always been open to difficult conversations and had already established a solid communication system between their family which helped them be more open when Mike was diagnosed. Kiki emphasized the need to be open so that others can benefit from what she has learned and hopefully be more comfortable to share their experiences as well. This is how we fight stigma.

Mike shared that when he talks about his condition, he also learns more about different types of dementia and their effects. He feels like it is important to stay active in your community and to be part of groups like the SAC to continue to learn and feel like you are contributing to future generations.

**Janet and Bill video:** [*Why I Walk*](https://www.ksat.com/news/2019/10/17/why-i-walk-couple-married-for-53-years-shares-journey-with-alzheimers-disease/)

* 1. Mike, Kiki, Janet, and Bill will share about why they choose to be open and active about their diagnoses and caregiving roles

Bill shared that they have difficulties talking about their experience with some (but not all) of their children. By being involved with the Alzheimer’s Association they have been connected to a peer support system that has heavily impacted their ability to manage their roles.

Janet shared how grateful she is to have Bill and to have her weekly support group. She is committed to talking about her condition because she believes it is Gods trust in her to help others.

1. **PCORI Annual Meeting**
   1. James, Sara, and Carole will summarize their favorite sessions from the annual meeting
   2. Access the recordings and transcripts here: [www.pcori.org/2019AnnualMeeting](http://www.pcori.org/2019AnnualMeeting)

James could not pick just one favorite session so he summarized his feelings about the conferences as whole. He was moved by how many people are committed to practical change in their communities and how important research that involves the voices of people who might otherwise not be included in the process.

He highlighted the importance of patient centered research in black communities to address the disparities that are unique to their culture and experiences with other health conditions in addition to dementia. His wife was able to attend along with him and as an occupational therapist was able to learn a lot from the sessions.

Carole highlighted the session “Navigating Complex Choices: Shared Decision Making across the Care Continuum”. She offered a brief summary of the presentation which featured various speakers who discussed how they are addressing complexities of shared decision making in different settings and populations. This session was informative for the SAC and the end-of-life decision making app the group had discussed in a recent meeting.

Sara highlighted a session called “Patient Perspective: Learnings and Strategies for Partnership in Research”. This sessions stood out to her because it resonated with a lot of the work we are doing with the SAC. It was helpful to compare what we are doing well and the areas in which we can improve based on guidance and advice from experts in this area, especially because the panelists featured mostly patient partners.   
  
Sara shared the link to the recorded sessions and showed everyone how to find it on the computer.

1. **Webinar**
   1. December 10th

Instead of a webinar in December, the group will meet at the Alzheimer’s Association following their weekly dyadic support groups so they can invite new members to join the SAC to include wider stakeholder representation.   
  
Carole and Sara will show a series of videos to help the new attendees conceptualize the work the SAC has been doing and how they can be involved as well.

1. **Online Community:** [**utcaregivers.org**](file:///\\cfs\links\SON\NursingDean\Caring%20for%20the%20Caregiver\Grants\PCORI\Stakeholder%20Advisory%20Council\Meetings\utcaregivers.org) 
   1. Corrected the notifications issue and commenting limitations
2. **Moving forward**
   1. Meetings at the Alzheimer’s Association, third Thursdays of the month after support group
3. **Next meeting December 10th, 2019 – ALT-C 2.206**