## Stakeholder Advisory Council Meeting Minutes September 10, 2019 Academic Learning and Teaching Center, room 2.206

*In attendance:*

Carole White

Sara Masoud  
Michele Porras (taking notes)

Bill Zinsmeyer

Janet Zinsmeyer

Michael Foster

Kiki Foster

Neela Patel

Angelica Davila

Sheran Rivette

Deborah James

James Butler

Ginny Funk

Mayra Mendoza

1. **Group updates**
   1. Bill & Janet – updates on the Walk

Bill and Janet are chair members for the Alzheimer’s Association Walk Committee. They gave the group an update on the walk and why they are motivated to volunteer for this specific event. The walk is on October 19th at Paolo Alto College. 4,600-5,000 people are expected to walk.

1. **Advance Care Planning research grant application**The group discussed challenges around discussing end-of-life planning as a family living with dementia. Bill and Janet highlighted that some family members are more sensitive about the subject and that even the most prepared families do not want to talk about the issue.

Carole and Sara shared ideas for an NIH grant submission they are drafting to create and test an app that would support families living with dementia to better communicate their goals for care – which would allow for better quality of life (and death). Carole asked the group their thoughts on what barriers they might face as families living with dementia attempting to communicate about end-of-life and how an app might (if at all) be helpful to them.   
  
Families living with dementia on the SAC expressed that there doesn’t seem to be one ideal time to start communicating, but the sooner the better. Ideally the family has been discussing those issues for a long time, but if not, an app might assist families and doctors to begin the conversation and create a space to revisit the conversation as needed.

Bill highlighted that the app should be mindful that dementia is “a disease of the family” not just the person with the diagnosis. Janet shared that in many ways she believes it is harder for Bill than for her to cope with her diagnosis.

When asked about the practical side of using an app for this purpose, the group shared that an i-pad or tablet is the ideal platform over a phone or a computer. They also recommended that it be focused heavily on education within the app. They recommended that a tablet could be positioned in their physicians offices where they can set up their accounts at the appointment and then continue working on it from home in their comfortable environments.

They expressed the weakest communication link is often between the patient and the physician and the app might help with this.

1. Topic for webinars  
   The SAC agrees there should be a caregiver focus at the webinar and that the primary goal should be to educate other family members who are not as familiar with the disease and symptoms.   
     
   The SAC has agreed that Carole and Sara can prepare a list of potential speakers and they will review and approve at the next meeting.
2. **Goals for care paper**
   1. Take a print copy to review for next meeting

At the next meeting we will discuss the Goals for Care publication provided to the group by Carole. She will work with co-chair, Mike, to create a presentation that summarizes the article and facilitates discussion among the group.

1. **Online Community:** [**utcaregivers.org**](file:///\\cfs\links\SON\NursingDean\Caring%20for%20the%20Caregiver\Grants\PCORI\Stakeholder%20Advisory%20Council\Meetings\utcaregivers.org) 
   1. Pass out flyers to get others to join

Sara walked the group through the online community, showed them how to make discussion posts, and handed them printed instructions to take home. Also provided were flyers they can share with friends and family who might also want to join in on the discussions.

1. **Happy birthday Carole & Kiki!**
2. **Next meeting October 8, 2019 – ALT-C 2.206**