## Stakeholder Advisory Council Meeting MINUTES December 9, 2019

## Holiday Party and Informational Session Alzheimer’s Association 10223 McAllister Fwy

1. **Food & introductions**There were several new members in attendance at the group this month (attendance on last page). This is a new location based on feedback from the council that the location in the medical center was too difficult to access.

We have rearranged our meeting date and location to accommodate people who wish to attend the early-stage support groups at the Alzheimer’s Association.

1. **Show Alzheimer’s Society video:** [***The impact of involving people with dementia in research***](https://www.youtube.com/watch?v=NV6v4OYcQj8)

We watched this video to show an example of the type of work our SAC does and how it is being done around the world.

1. **Mike & Kiki Foster**
   1. *Why we are on this council and why it is important to us to have a voice in research and the care that affects us.*

Mike and Kiki shared about how important it has been for them to be vocal about their experience with dementia and how it has improved their lives. Kiki shared that she feels more confident in their decision making and that they have better quality of life and care because they have chosen to open about their diagnosis.

1. **Show ADI video:** [***Advancing dementia research: Perspectives of people with dementia***](https://www.youtube.com/watch?v=77yCBtlFi8M)
2. **Bill and Janet**
   1. *Why we are on this council and why it is important to us to have a voice in research and the care that affects us.*

Bill and Janet shared that they find it is important for Bill to speak out to support his wife in her diagnosis. Janet expressed that she feels as though it is her calling by God to use her diagnosis to support other people in her community. Their activism and community service has helped them feel as though they are part of a bigger cause and have contributed to helping others and hopefully finding a cure one day.

1. **Breakouts (see back of page)**
   1. How to be sure all voices are heard
   2. Break into small groups of 4-5 to discuss the question on the back of this sheet

The larger group broke out into smaller groups to answer the question “What are gaps in care that you think should be answered by research?”

What are gaps in care that you think should be answered by research?

Early diagnosis

Better information

Raising awareness

Research to support the caregivers

Counseling

What is going to happen to me if something happens to my caregiver

RAISE

What are supports that will keep people living at home longer?

How so we help families adjust to having someone in their home?

Training for home care around dementia

Supporting the relationship

Support groups – how early or late does it matter and are the effects different when using support groups at different stages

Don’t only research the financial and medical sides but also focus on quality of life

How do we get people to be connected to resources? “unless you are connected you are not”

Relationship building with the community and medical centers

Is early diagnosis the most important thing when there isn’t a cure or treatment? Focus on improving quality of life for those currently living with it.

What about people who can’t afford care and how do we provide social services to them that matter?

Marketing approaches for dementia and caregiving resources

Why do primary care physicians wrongly diagnose people so often

Stigma – how do we stop it? To prevent stigma, participants raised multiple approaches they tried. Mike described posting his story in a church bulletin. Another woman living with dementia described sharing her experience of the disease on Facebook to help their family understand the disease.

A caregiver said a visualization of the brain showing the effects of the disease would really help her understand that it's a disease that is causing new behaviors.

James raised the point that most of the advertisements about dementia are dreary-- why not show people with dementia still celebrating their birthday parties? Generally, it was agreed that the more we talk about it, the less stigma there is.

Participants also noted the value of using humor to cope with the disease and their desire to still effect change in the community (i.e., purposefulness). Messaging from awareness campaigns should encapsulate the idea: "Yes I have Alzheimer's disease, but I still have quality of life and something to contribute." (Not being defined by AD but recognizing it is there.)

1. **Next meeting January 27 2020 – Alzheimer’s Association 10223 McAllister Fwy**

Attendees

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| --- | --- | --- |
| # | First Name | Last Name |
| 1 | Jim | Beach |
| 2 | Yolanda | Forney |
| 3 | Kiki | Foster |
| 4 | Mike | Foster |
| 5 | Ginny | Funk |
| 6 | Debbie | James |
| 7 | Charlie | Mason |
| 8 | Ryan | McGuire |
| 9 | Mayra | Mendoza |
| 10 | Bob | Parker |
| 11 | Sheran | Rivette |
| 12 | Linda | Sendaula |
| 13 | Robert | Suacek |
| 14 | James | Butler |
| 15 | Bill | Zinsmeyer |
| 16 | Janet | Zinsmeyer |
| 17 | Regina | Raba |
| 18 | Larry | Raba |
| 19 | Kimberly | Johnson |
| 20 | Julius | Johnson |
| 21 | Debra | Doss |
| 22 | Dayna | Parker |
| 23 | Phyllis | Beach |
| 24 | Jean | O'Brien |
| 25 | Bill | Bailey |
| 26 | Paula | Bailey |
| 27 | Sheran | Rivette |
| 28 | Carole | White |
| 29 | Sara | Masoud |
| 30 | Debbie | James |
| 21 | Michelle | Porras |