

Pennsylvania (PA) Alzheimer's Disease (AD) Public Meeting
Harrisburg, PA
Minutes
November 21, 2013

Planning committee members in attendance

Chair - Secretary Brian Duke, Pennsylvania Department of Aging (PDA)

Legislative members

Clarissa Freeman for Shirley Kitchen, Minority Chair of Senate Public Health and Welfare

Erin Raub, for Tim Hennessey, Chair of House Aging and Older Adult Services Committee

Constituent representatives:

Dr. Carrie DeLone, Physician General and Department of Health representative

Michael Ellenbogen, Person with AD representative

Susan Heinle, Homecare representative

Beth Herold, Area Agency on Aging representative

Bob Marino, Statewide Alzheimer's Association representative

Heidi Owen, Hospice representative

Maura Pelinsky, Adult Day representative

Dr. Charles Reynolds, Medical Care Provider Community representative

Jill Schwartz, Caregiver representative

Dr. Stuart Shapiro, Nursing Facility representative

Kathy Jedrzejewski for Dr. John Trojanowski, AD Researcher Representative

PDA Staff in attendance:

Ken Brubaker, M.D.

Amy Comarnitsky

Paul McCarty

Steven Horner

Kelly O'Donnell

Dan Smedley, intern

Christina Reese

Lisa Bain, consultant

Others

Leah Kithcart, Alzheimer's Association

Kevin Tucker, Alzheimer's Association

Melissa Myers, Pennsylvania House of Representatives

Ryan Pysler, Alzheimer's Association

Gail Roddie-Hamlin, Alzheimer's Association

Lauren Merlie, Pennsylvania Department of Health

Amy Szydowski, Pennsylvania Department of Health

Angela Geiger, Alzheimer's Association, National Office

Minutes prepared by Lisa J. Bain

- I. Welcome and thanks to Committee, PDA team, and Governor's Office (Brian Duke).

- II. In recognition of November being National AD Awareness month:
 - a. Representatives Samuelson, Hennessey, and Watson introduced a resolution on the House floor on November 18, 2013. Tomorrow PDA will be releasing a video featuring Dr. Steve Zarit of Pennsylvania State University about stress and caregiver support.
 - b. Leah Kithcart from the Alzheimer's Association said they had advocates on the House floor. The Capital is purple (although for epilepsy, not AD); next year we will ask to be included.
 - c. Next Tuesday (November 26, 2013) the Governor will visit Phoebe Ministries in Lehigh Valley. They have received a grant to promote their work.
 - d. Bob Marino reported that from September to November 2013, the Alzheimer's Association held 30 walks in Pennsylvania. In Philadelphia alone, about 15,000 people took part.
 - e. Angela Geiger is here from the Alzheimer's Association National Office in Chicago. Ms. Geiger thanked the Committee for its commitment, and reported that 35 states have already published Alzheimer's plans with momentum from the National Plan. As the world's largest private funder of AD research, the Association is looking for the best research; advancing early detection, care and support; raising awareness.
 - f. Secretary Duke thanked the Governor for his commitment to older Pennsylvanians. Earlier this month, the Governor issued a proclamation recognizing those living with disease, caregivers, scientists, providers, and those who have gone before us. A copy of the proclamation was handed out to all Committee members.

- III. Guest speaker – Mike Splaine; introduced by Paul McCarty. Mr. Splaine is owner and principal at Splaine Consulting, a small advocacy and government affairs firm in D.C. He was formerly Director of State Government Affairs in the Public Policy Division of the Alzheimer's Association, and works with Alzheimer's disease International.
 - a. Rationale for plans – worldwide dementia prevalence currently 36 million; expected to grow to 115 million by 2050. Most growth will be in lower and middle income countries. Dementia was recognized as a public health priority by the World Health Organization in 2012.
 - b. State plans need to address public misunderstanding of AD and related disorders (ADRD) and the high cost of caring for people in nursing homes.
 - c. More people are getting diagnosed at earlier stages, which have public health implications in terms of risk reduction and prevention.

- d. Supportive services needed across the continuum of disease. Plans written in the '80s focused more on middle stages e.g. respite programs. In earlier stages patients and families have different needs.
- e. ADRD differs from other chronic diseases in several ways:
 - i. Families are usually caregivers
 - ii. Diagnosis usually late in disease process
 - iii. Many co-morbidities
 - iv. Long disease process; need for long term specialty care
 - v. Lack of attention to population health risks and confusion about risk reduction
 - vi. Even when people have cognitive change, they are reluctant to take action.
 - vii. Compared to other diseases, the costs per person are 60-300% higher
 - viii. Niche populations (e.g. DS)
 - ix. Racial and ethnic disparities
 - x. Stigma, nihilism
- f. Options suggested in other plans:
 - i. Public awareness intertwined with anti-stigma campaigns
 - ii. Telemedicine and telephone-based support
 - iii. Dementia friendly communities (e.g., 15 in Minnesota) – key aspects:
 - (1) Public awareness/access to information
 - (2) People with dementia first, caregivers 2nd, providers 3rd
 - (3) Changes needed to physical environment
 - (4) Dementia friendly businesses (very tough)
 - (5) Access to innovative services
 - (6) Gathering places for socialization
 - (7) Mobility/transportation
- g. Post-diagnostic support – family caregiver support, pharmaceuticals, etc.
- h. Prevention
- i. Mr. Splaine's thoughts about what we may be overlooking in our plan:
 - i. Health disparities
 - ii. Competencies
 - iii. Consumer power
 - iv. Plan needs to stay evergreen. One way states have done that is to designate a single staff person as Alzheimer's policy coordinator for the State.

IV. Closing

- a. A thank you to Mike Splaine for speaking and for everyone who attended today's meeting
- b. Next meeting is December 19th.