

Virginia I. Jones Alzheimer's Disease and Related Disorders Council
Spring Grove Hospital Campus, Dix Building Basement
7/18/2018 1:00pm-3:00pm
Minutes

Council Member Attendance

Quincy Samus
Ilene Rosenthal
Suzanne Carbone
Kirsten Robb-McGrath
Andre McDonald
Carole Friend
Cynthia Fields
Tabassum Majid
Ana Nelson
Chris Snell (for Sen. Roger Manno)
Ed Singer
William Neely
Dawn Seek
Marie McLendon
Andres Salazar
Arnold Bakker
David Loreck
Bonnie Glick (for Secretary Kramer)
Michele Williams (by phone)
Sadie Peters
Ernestine Jones Jolivet

Council Staff Attendance

Roseanne Hanratty
Annie Olle

Guest Attendance

Louise Dempsey
Joy Hall

1. Welcome and Introductions

- a. The meeting was called to order at 1:04pm by Dr. Peters. Dr. Peters introduced Bonnie Glick, Deputy Secretary of the Department of Aging as the representative for the Secretary, Rona Kramer. Dr. Peters introduced a new staff member for the Council: Annie Olle. Ms. Olle is with the Office of Support Services in the Prevention and Health Promotion Administration in the Maryland Department of Health and will provide staff support to the Council. Rosanne Hanratty from the Department of Aging continues to provide staff support the Council.

2. Council Vacancies, New Appointments, and Guests

- a. Dr. Peters discussed the following vacant Council positions:
 - i. A physician who conducts research in Alzheimer's disease and related disorders

- ii. An individual with early-onset Alzheimer's disease or a related disorder
- b. Dr. Peters introduced the following newly appointed Council members:
 - i. Andre McDonald: an attorney who works directly with disabled or elderly individuals. Mr. McDonald offered that he is a former Marine, whose interest in the elderly community started in law school. He is a former public defender and now practices in the areas of estate planning, long term care, and Medicare.
 - ii. Michele Williams: a registered nurse with expertise in Alzheimer's disease and related disorders. Ms. Williams has a doctorate in nursing and is a nurse practitioner for Shore Regional Health and Walter Hospice.
- c. Deputy Secretary Glick introduced Chris Snell, who represented Sen. Roger Manno at the meeting.
- d. Guests Louise Dempsey and Joy Hall introduced themselves. Dr. Peters noted that there would be an opportunity for them to speak at the end of the meeting.

3. Approval of April 18, 2018 Meeting Minutes

- a. Dr. Peters asked if there were any comments on the draft April 18th meeting minutes. Ms. Rosenthal requested an amendment to the minutes to add the word "diversion" to the sentence regarding the budget allocation in the Enhancing Supports for Persons Living with Alzheimer's disease and Related Disorders and their Families Subcommittee Update.
- b. Ms. Carbone made a motion to approve the April 18, 2018 meeting minutes as amended. Mr. Neely seconded the motion. The Council members approved the meeting minutes with the amendment proposed by Ms. Rosenthal. The minutes will be posted to the Council website: <https://health.maryland.gov/Pages/Alzheimers-Council.aspx>

4. Upcoming Council Meeting Dates and Times

- a. Dr. Peters reminded the Council members of the upcoming meeting taking place October 17, 2018 from 1-3pm. If there are any issues with the upcoming dates, please notify Council staff.

5. Speaker's Bureau Presentations

- a. **Alzheimer's Association Resources and Activities**
 - i. Ilene Rosenthal and Ana Nelson presented resources and activities of the Alzheimer's Association. In Fiscal Year 2017, 80 chapters merged into one cohesive group and there are two chapters that serve Maryland.
 - ii. The Association offers the following programs and services: a bilingual 24/7 Helpline, an online caregiver center, care consultation, education programs, support groups for a wide range of audiences, early-stage engagement, diversity outreach initiatives, and safety services.

- iii. Other resources offered are: physician outreach, including physician toolkits, professional development, and a rapid referral form; support for research; Trial Match (connecting patients with criminal trials); and a robust advocacy program.
- iv. There are a range of volunteer opportunities with the Association, including administrative support, advocacy, community outreach, education program delivery, support group facilitators, etc.
- v. The Association supports the Walk to End Alzheimer's. There are more than 600 walks across the county and 10 in Maryland and Washington, DC.
- vi. The Association receives almost no government money. It is funded by generous supporters, and supported by both individuals and volunteers.

b. The HOPE4MCI Trial

- i. Dr. Arnold Bakker, PhD presented on the HOPE4MCI Trial. The presentation included an overview of drug development around Alzheimer's disease so far, approved treatments, the Amyloid Hypothesis, and drug investigations to reduce amyloids. The drug investigations were largely unsuccessful. Aducanumab by Biogen showed modest results.
- ii. Dr. Bakker explained that amyloid can be seen in healthy patients, are not specific to Alzheimer's disease, and are directly associated with age. The emerging consensus is that Alzheimer's disease has a long prodromal phase, individuals are symptomatic for many years prior to dementia (i.e. they have memory problems and mild cognitive impairment (MCI), Alzheimer's disease pathology exists in individuals with normal cognition, and late intervention is less effective, so there is a need to improve early intervention at MCI stage.
- iii. Prior clinical trials in MCI have not been successful. The Alzheimer's disease research at Johns Hopkins focuses on memory, which is the key symptom to meet the criteria for dementia. Memory function is associated with the hippocampus and temporal lobe.
- iv. Amyloid accumulation is spiked by neuronal activity. Research seems to indicate that hyperactivity in the hippocampus drives amyloid activity. If high activity is associated with worse memory function, so how can you lessen activity? Treatment for epilepsy regulates activity in the hippocampus. In a clinical trial, a low dose of Levetiracetam was tried in 54 patients with MCI. The drug drove down hyperactivity and patients showed better memory function.
- v. HOPE4MCI is a stage 3 clinical trial focusing on patients with MCI. Patients will be treated with a low dose (less than 250 milligrams BID in an extended release form) of Levetiracetam for 18 months. The study will include PET scans, MRI scans, and cognitive testing. Recruitment starts in August 2018. Mr. Neely asked if the trial needed a specific male/female ratio. Dr. Bakker replied that the goal is 50/50 and individuals should be over 55 years of age.

- vi. Identification of individuals in the earliest phases of the disease is critical. Dr. Bakker suggested that screening for MCI could start as early as age 25. Dr. Salazar asked why you could not treat a patient with mild dementia. Dr. Bakker said that there would already be too much neuronal loss.
- vii. Ms. Seek asked if MCI always leads to dementia. Dr. Bakker explained that MCI can be caused by several things including depression or concussion, but if you treat the underlying condition, the MCI should improve.
- viii. Dr. Salazar asked how use of Aricept along with an antipsychotic could be reconciled with these findings. Dr. Loreck replied that there is a risk because antipsychotic medications are not good for cognition, but sometimes you need them. There are no FDA approved medications for agitation associated with dementia.
- ix. Ms. McLendon asked if anything has gone out to providers regarding this treatment. Dr. Bakker said no, that it has not been communicated in the context of the study. Dr. Salazar mentioned that questions about memory and function could be included in the annual well visit covered by Medicare.
- x. Ms. Olle will email the slides from the presentation out to the Council.

6. Subcommittee Updates

- a. **Support Prevention and Early Detection of Alzheimer's and Related Disorders** (Dr. Loreck (Chair), Ms. Naugle, Dr. Peters, Dr. Salazar, Dr. Bakker, Ms. Nelson)
 - i. Dr. Loreck updated the Council on the letter to providers proposed at the last meeting. He recalled the debate from the past meeting about whether it should come from the Council. He also mentioned sending primary care providers an orientation on prevention and early detection of Alzheimer's disease, but because primary care providers are overwhelmed, communication should be disseminated in a way that it will not result in it being thrown in the trash.
 - ii. These efforts can augment what the Alzheimer's Association is already doing. Dr. Peters added that the Council could combine provider awareness with the efforts of the Enhance Public Awareness Subcommittee.
- b. **Enhance Quality of Care** (Ms. Ellis, Dr. Majid, Ms. Seek (Chair), Mr. Vozzella)
 - i. The subcommittee has not met due to scheduling issues. Dr. Peters reminded the Council that staff can help set up meetings and that the Council meeting room is available before and after the full Council meeting for subcommittee meetings.
- c. **Enhancing Supports for Persons Living with Alzheimer's Disease and Related Disorders and their Families** (Ms. Carbone, Ms. Rosenthal (Chair), Dr. Samus)
 - i. A full page advertisement was recently taken out in *Maryland Family Doctor*, a magazine published by the Maryland Academy of Family Physicians.
 - ii. Dr. Samus submitted an application to the National Institutes for Health for a phase 3 trial of a senior companion program (MemoryCore). The program would be a respite for caregivers, but caregivers would also be trained to provide activity-based care in the

home. The program would include tailored activities to reduce agitation. Planning for the program started in December and 250 families are participating. Families are sorted into two groups: 12 weeks of care or a waitlist. The program will take place in Baltimore City and Baltimore County.

- iii. Ms. Seek asked if the families could have paid help. Ms. Samus replied that they have to have a family caregiver but could have other supports in place. Ms. Rosenthal mentioned that the trial will hopefully develop evidence for respite care. Ms. Jones-Jolivet asked if the VA is doing anything like this. Dr. Loreck said no, but maybe we could get them to go in that direction.
- d. **Enhance Public Awareness** (Dr. Fields, Ms. Jones Jolivet (Chair), Mr. Neely)
 - i. Ms. Jones-Jolivet told the Council that they were still looking for sources to distribute the Alzheimer's Council Palm Card and asked it would be possible to use the media to get the word out about the Council. Mr. Neely suggested mentioning the Mobile Engagement Asset Journey on July 28th. The subcommittee encouraged Council members to come and to bring friends and family.
 - ii. Ms. Carbone asked how many Palm Cards could be printed if there was no budget for them. The Alzheimer's Association printed 6000 cards. Ms. Carbone said she could take them to the central Montgomery County library. Palm Cards could also be distributed to senior centers. An electronic version is already on the Council website. Ms. Glick said that the Palm Card could be posted on the Department of Aging's website.
 - iii. Dr. Peters expressed interest in a joint meeting between this subcommittee and the Support Prevention and Early Detection of Alzheimer's and Related Disorders subcommittee.
- e. **Improve Data Capacity to Track Progress** (Dr. Majid, Ms. Naugle (Chair), Ms. Nelson, Dr. Bakker)
 - i. Ms. Rosenthal said that the Behavioral Risk Factor Surveillance System (BRFSS) is currently deciding on which optional questions to ask in this year's survey. Ms. Rosenthal made a motion for the Council to submit a Letter of Support for questions on cognitive decline.
 - ii. Ms. Glick asked if questions on cognitive decline are already in one of the categories of optional questions. Ms. Rosenthal replied that they are part of one of the optional modules, but that she would like to see the data. Ms. Glick asked if there was a particular age range. Ms. Rosenthal replied that it is prescribed by the CDC: 45 years of age and older.
 - iii. Dr. Peters told the Council there is a BRFSS Steering Committee which reviews all applications, and request reasons and rationale for optional modules. There are several different modules which can be chosen year to year. The Council could send a letter or email to the committee supporting the inclusion of the module on cognitive decline in the BRFSS. Ms. Carbone and Mr. Neely seconded the motion. All Council members

present were in favor with no votes against. An email will be sent to the BRFSS coordinator.

f. **Other reports/updates**

- i. Ms. Rosenthal asked if someone from the MDH Primary Care Program would present at a Council meeting. Dr. Peters informed that Council that a presentation on the Primary Care Program (aka the Total Cost of Care Program) is scheduled for the October meeting.

7. **Public Comment**

- a. Louise Dempsey told the Council that Pat Kasuda has been working with a legislator on standards for memory care. Ms. Dempsey asked if standards for memory care could be on agenda for the next Council meeting. Dr. Peters reminded the Council that there were several presentations on memory care at the last Council meeting.
- b. Ms. Carbone mentioned that she had met with Stevanne Ellis after the last Council meeting regarding legislation or regulations on this issue.
- c. Ms. Rosenthal offered to discuss new dementia practice care recommendations.
- d. Dr. Salazar asked what role the ombudsman plays in creating the standards and mentioned that CMS is creating a dementia survey. Ms. Carbone asked who the expert in this is and Ms. Rosenthal suggested the MDH Office of Health Care Quality.
- e. Ms. Seek commented that education and training on standards need to be moved into home care and Ms. Rosenthal commented that progressive agencies have put standards in place. Ms. Seek offered to work with the Alzheimer's Association to put forward legislation and that the Maryland National Capital Home Care Association would be supportive.
- f. Dr. Peters commented that conversations around memory care standards are already happening and that the Council may be able to do a letter of support. Ms. Rosenthal suggested that Dr. Nay from the Office of Health Care Quality come and do an abbreviated version of her report on quality of care issues for the Council.
- g. Dr. Salazar commented that assisted living facility staff has to do training.
- h. Dr. Majid informed that Council that the CMS Dementia Survey is out and that her institution met all the education requirements. The CMS standards are based on evidence-based training programs and focus on a practical hands-on approach.
- i. Joy Hall, Associate State Director for Community Outreach with AARP Maryland introduced herself. She told the Council that this year is the 60th anniversary of AARP and that AARP would pledge \$60 million for dementia research. Ms. Hall said that she was looking forward with working with the Council and is also looking forward to what is happening in the dementia community.

8. **Adjournment**

- a. Dr. Peters thanked everyone for contributing. Dr. Peters called for a motion to close the meeting. Ms. Jones-Jolivet made a motion to adjourn the meeting at 3:27pm. Ms. Seek seconded.

**The next meeting of the Virginia I. Jones Alzheimer's Disease and Related Disorders
Council will be held on October 18, 2018
Spring Grove Hospital Campus, Dix Building Basement
1:00pm-3:00pm
Call-in Number: 1-240-454-0887 Access Code: 640 712 548**