Virginia I. Jones Alzheimer's Disease and Related Disorders Council Call-in Meeting 1/17/2018 1:00pm-3:00pm Minutes

Council Attendance by Phone

Arnold Bakker Aquanetta Betts Suzanne Carbone Stevanne Ellis (co-chair) Cynthia Fields William Frank Ernestine Jones Jolivet David Loreck Tabassum Majid Cass Naugle Ana Nelson Sadie Peters (co-chair) Ilene Rosenthal Andres Salazar **Ouincy Samus** Ed Singer Stephen Vozzella

Council Staff Attendance by Phone Berit Dockter Rosanne Hanratty

Guest Attendance by Phone

Sadaf Ahmad Lesley Flaim Michelle Garcia (for Sheree Sample Hughes) Bonnie Glick Kristi Pier

1. <u>Welcome and Introductions</u>

- This meeting is call-in only due to inclement weather.
- Council members and guests introduced themselves and the organization they represent.
- Co-chairs Dr. Peters and Stevanne Ellis called the meeting to order at 1:03pm.
- Welcome new staff coordinator for Council, Berit Dockter. Dr. Peters introduced Ms. Dockter who will staff the Council with Rosanne Hanratty. Ms. Dockter is a health policy analyst at the Maryland Dept. of Health and works with Dr. Peters in the Center for Chronic Disease Prevention and Control.
- Council vacancies and recruiting. Ms. Ellis made a reference to the organization chart that went out in email.
 - i. Vacant positions include:
 - 1. A physician who conducts research in Alzheimer's disease and related disorders
 - 2. A licensed nurse practitioner (NP) with expertise in end–of–life care and pain management
 - 3. An individual with early–onset Alzheimer's disease or a related disorder

- 4. A representative of the medical adult day care industry
- ii. The chairs would like to remind the Council to remember to recruit for other "related disorders" beyond Alzheimer's as they think of candidates to encourage to apply for the Council vacancies. People who apply for the Council will go through the Governor's Appointments Office process. Final decisions on appointments are made by the Appointments Office.
- Reminder that Council staff and co-chairs are points of contact for any questions, concerns, or other communication. Ms. Ellis encouraged Council members to contact the staff and chairs for any issues that come up in between meetings. rosanne.hanratty@maryland.gov (staff)
 berit.dockter@maryland.gov (staff)
 stevanne.ellis@maryland.gov (Co-Chair)
 sadie.peters@maryland.gov (Co-Chair)

2. <u>Approval of October 11, 2017 minutes</u>

 Ernestine Jones Jolivet asked for a correction on the title of the forum held on November 4th. With this change, Ms. Jones Jolivet made a motion to approve the October 11, 2017 meeting minutes. Suzanne Carbone seconded the motion. The Council members approved the meeting minutes. The minutes will be posted to the Council website: <u>https://health.maryland.gov/Pages/Alzheimers-Council.aspx</u>

3. Upcoming Council Meeting Dates and Times

- Dr. Peters reminded Council members of the upcoming meetings from 1-3pm:
 - i. April 18, 2018
 - ii. July 18, 2018
 - iii. October 17, 2018

4. Speakers Bureau for this Council and addition to website

- Dr. Peters said the speaker today, Dr. Katherine Marx, was scheduled to present, but due to weather and today's meeting being call-in only, she will reschedule her presentation to a later date.
- Ms. Dockter announced the creation of a new Council "Speakers Bureau." The Council chairs like the idea of inviting a guest speaker to each Council meeting to present on a relevant topic for about one hour. Current Council members and guests are invited to be speakers.
- We will add a message to the Council webpage inviting people to contact Ms. Dockter if they are interested or know someone who would like to be a speaker. Ms. Dockter will keep track of potential speaker information on a spreadsheet.
- Ms. Carbone asked a question on whether the speakers will be dedicated to subcommittee work and how that will support the Council. Dr. Peters said we would like the speakers' presentations to support the Council and subcommittee work. The goal is to learn as a Council to use the information for our work as

servants of the general public, as well as for the work we do as part of the Council in our various subcommittees.

5. <u>Subcommittees Updates</u>

- 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 recently took over as chair for this subcommittee. He thanked Dr. Salazar for drafting a letter to all medical providers in the state to encourage primary care physicians (PCPs) to use the Medicare Wellness Visit to enhance their ability to identify cognitive impairment and dementia in the elderly population. While it is undecided under whose signature the letter will be sent, possibilities include the Department of Health or a senior state official. Dr. Loreck sent the letter to the Center for Medicare and Medicaid Services (CMS). He would like CMS involved in the letter to support dementia education and identification. Dr. Loreck has heard from PCPs that they are busy and hesitant to take-on a "case management" type of cognitive problem. The letter could help remove some of the concerns of PCPs and help them decide where in their daily practice they can start to incorporate this important screening. Dr. Loreck is impressed with the support of the Alzheimer's Association and work of Cass Naugle. A goal for next meeting is to have a working draft of the letter to share with the Council.
 - ii. For the next meeting, they will have a working draft of the letter and perhaps a one-page attachment with a list of useful resources and recommended screening tools. Dr. Loreck asked the sub-committee members to be responsive to emails and other communications between meetings, and would like a monthly phone meeting to be sure the work gets done.
 - iii. Dr. Salazar discussed the same letter, addressing the epidemiology and causes of Alzheimer's Disease, reiterating recommendations in the letter, and suggesting how the Maryland Department of Health (MDH) could help support health professionals. He described the intent to include resources and links for health care providers to encourage screening, and re-emphasized the potential to use of the Medicare Wellness Visits to improve screening in clinical settings. He looks forward to the Council's final recommendations. He would like to see clarification on screening parameters for "cognitive impairment," perhaps using a cognitive assessment test along with and assessment of functional status. He spoke about a need to determine what test to use and how to measure activities of daily living that might more comprehensively describe cognitive status. He emphasized there is also need to decide which resources to use, such as the Alzheimer's Association or the United States Preventive Services Task

Force (USPSTF). He expressed hope that by the next meeting the Council could provide feedback on the final product.

- iv. Ilene Rosenthal discussed a presentation at Grand Rounds at Good Samaritan Hospital hosted by the Alzheimer's Association and conducted by Dr. Jessica Colburn, a geriatrician at Johns Hopkins; the topic of the presentation was supporting prevention and early detection. The Alzheimer's Association provided trainings conducted by Dr. Ann Morrison, a consultant to the Alzheimer's Association, at Mercy and Sinai Hospitals for nurses and social workers, and trainings at Northwest Hospital for a transition to home initiative. They are working with Peninsula Regional Medical Center for upcoming grand rounds.
- v. Ana Nelson discussed a new physician outreach program from the Alzheimer's Association. The National Capital Area Chapter and the Maryland chapter are two of 80 chapters that offer the physician outreach services. She is working on Grand Rounds at various institutions and reaching other medical providers to discuss early detection. She also discussed pilot programs on care practice and recruiting physicians as ambassadors to increase early detection awareness. They hope to work with residents on an ambassador program to promote the message of why early detection matters. Ms. Nelson's Association chapter is ready to help with physician outreach.
- vi. Dr. Salazar added his desire to pilot the letter with about 50 physicians, and see the results of the recommendations provided in the letter; i.e. screening test. This will help better design a plan for the medical community.
- vii. Dr. Loreck expressed that he would like the subcommittee's and Council's work to be meaningful. He agreed with a pilot and real-time feedback. At a future meeting he would like to discuss USPSTF guidelines for dementia and what people understand, which could orient the Council on the standard of care for screening and early detection.
- viii. Dr. Peters agreed a presentation at future meeting, with a draft of the letter, would be appropriate. She suggested a Doodle poll could help organize another meeting for the subcommittee. She expressed support for regular meeting times and action steps outlined at each meeting.
 - ix. Dr. Loreck mentioned communication from the MDH on Hepatitis C or other diseases as examples of how to increase clinician awareness. For the next meeting, he would like Council members to take a look at the communication.
- Enhance Quality of Care (Ms. Ellis, Dr. Majid, Ms. Seek (Chair), Mr. Vozzella)
 - i. Lesley Flaim (reporting on behalf of Dawn Seek who is unable to participate today) reported on the Beacon Institute grant. Participation was not what they hoped it would be. They offered two free training modules

and an opportunity to take the Alzheimer's Association CARES TM certification for dementia care. Two hundred individuals started the basic training, 169 completed it, and 120 went on to complete the certification. The advanced training was started by 131 individuals. One hundred eight completed the advanced training and 84 went on to get the certification. The percentage of those achieving certification by those who initiated training ranged from 7% to 94% for the basic module, and from 11% to 100% among those taking the advanced module. Beacon Institute will finalize the grant report with recommendations for future trainings. Ms. Flaim recommended the Council send a certificate of completion coming from the Council and signed by Dr. Peters and Ms. Ellis, the co-chairs, as an additional recognition for the participating staff. A draft of the certificate to be mailed to those who participated in the training.

- ii. Ms. Rosenthal asked if there is a quality measure from those who took the training and feedback. Ms. Flaim answered each member had a point of contact in the training and did a survey on the training. Most of the surveys were not returned. Verbal feedback from staff said the training was easy to follow and helpful. Challenges included getting management support to allow staff to participate or to facilitate access to technology for online training. As a follow-up to this grant, the Beacon Institute plans to offer a classroom training to have a group go through the modules. They may find it easier to schedule one full day of training rather than 8 hours during different days as they are available. They hope to get more individuals to complete the training while the licenses are available. Those interested can check the Beacon Event Calendar: http://www.lifespannetwork.org/beacon/event-calendar.
- iii. Ms. Jones Jolivet asked that the certificate be re-sent in an email. Dr. Peters suggested that a deadline for comments be provided in the email requesting Council member comments on the draft certificate. Ms. Flaim agreed by the end of January to hopefully hear back on comments and feedback. Dr. Peters discussed the co-chairs needing to discuss having their signatures on the certificate.
- iv. Ms. Ellis asked this subcommittee's members how often they would like to meet.
- Enhancing Supports for Persons Living with Alzheimer's Disease and Related Disorders and their Families (Ms. Carbone, Ms. Rosenthal (Chair))
 - i. Ms. Rosenthal reported that the Alzheimer's Association Greater Maryland and Capital Area chapters and the State Aging Network provide various services to support families and caregivers. She asked that a future meeting agenda include a presentation from Ms. Nelson and herself to

share the services that are offered by the Alzheimer's Association and invited the Department of Aging to also share their resources available.

- ii. Bonnie Glick commented that it was a great idea to have a presentation at a future meeting for the Council members could learn more about the resources available through Alzheimer's Association. She also agreed with the idea to include the Department of Aging.
- iii. Ms. Rosenthal said she and Ms. Nelson can provide a high-level summary of services provided around the year and calendar of events.
- iv. Ms. Carbone asked if the coverage around the state could also be addressed to understand who is being served.
- v. Ms. Nelson agreed with Ms. Carbone's idea. The National Capital Area Chapter is putting together an info graphic on services provided in Maryland. They work closely with community-based organizations. They do not want to duplicate services, but to support each other's work. She thanked Ms. Rosenthal for the opportunity to promote the services.
- vi. Ms. Rosenthal discussed "memory cafes" in Montgomery County. She suggested press coverage of the presentation and the work of the Council and Association.
- vii. Dr. Peters agreed the Council members would benefit from hearing about the programs offered. She encouraged using the new Speakers Bureau and to use July and October meetings to use as an opportunity for this presentation.
- viii. Ms. Rosenthal shared upcoming events hosted by the Alzheimer's Association:
 - March 20th in Salisbury: Registration: <u>https://www.communityresourcefinder.org/Default.as</u> <u>px?TabId=1623&fid=1016051</u> Flyer: <u>https://www.alz.org/maryland/documents/2018_Salisbury_C</u> <u>onf_Alz_Dem_Caregivers_1-17.pdf</u>
 - April 13th in Towson: Registration: <u>https://www.communityresourcefinder.org/Default.a</u> <u>spx?TabId=1623&fid=1040711</u> Flyer: <u>https://www.alz.org/maryland/documents/2018_Conf_Alz_Dem_Caregivers_(1).pdf</u>
 - 3. June in Easton: the Alzheimer's Association will host conferences geared toward caregivers and the professional community.

She noted that education programs provided by various chapters are available in the community where there is an interest and need. These programs can be offered at hospitals, churches, or anywhere there is an interested audience. The programs have a trainer and the content is used nationally, so it has already been tested across the country. The content has been developed with a range of subjects and can be used for many panel-type discussions. They would like to include attorneys, like Aquanetta Betts for example, when legal issues come up.

- ix. Dr. Peters said the information can be forwarded to all Council members by email.
- Enhance Public Awareness (Ms. Betts, Dr. Fields, Ms. Jones Jolivet (Chair), Mr. Neely)
 - i. Ms. Jones Jolivet said at the last Council meeting the palm cards developed by the subcommittee were handed out for distribution. She asked the subcommittee members to share what they did with their cards in their community. She reported that she shared her palm cards at church, doctor's office, golf course, a chiropractic Board from around the state of Maryland to use in their offices, and with individuals she knows personally.
 - Ms. Carbone took her cards to the Walk to End Alzheimer's in Washington D.C. and to the Montgomery County Department of Public Libraries. She got permission from the County to distribute in the branches. She would like the palm cards to be delivered in bulk to a County then distributed to branches.
 - iii. Dr. Majid distributed her palm cards at a physician meeting.
 - iv. Ms. Carbone would like clarification on how to send them out in bulk.
 - v. Ms. Ellis has distributed the cards to various ombudsman offices and staff across the state.
 - vi. Ms. Jones Jolivet would like all Council members to keep track of the cards they distribute so that they can share exactly where the cards were distributed. All 3,000 palm cards that were printed were given out. Ms. Ellis said Dr. Peters and Ms. Dockter can look into where more can be printed. Ms. Jones Jolivet is interested in 6,000 cards to distribute more in the community. Ms. Naugle has 6,000 cards ready to distribute at a future meeting or in the mail. The subcommittee members will look into how many to distribute at libraries. Movable Feast has agreed to support the distribution. Subcommittee members would like to enhance public awareness in the media. Ms. Jones Jolivet asked for suggestions and resources from the Council.
 - vii. Dr. Peters commented that she was impressed with the subcommittee's work and reiterated that 3,000 palm cards were made. She is excited about the network and collaboration reported by the subcommittee and the rest of the Council.
- Improve Data Capacity to Track Progress (Dr. Majid, Ms. Naugle (Chair), Ms. Nelson, Dr. Bakker)
 - Ms. Naugle discussed a recent CDC report on deaths from Alzheimer's. Deaths at home increased from 14% to 25% from 1999 to 2014. She is unsure whether it is due to higher cost of long term care, such that people are unable to afford to spend their last days in a facility and she emphasized that the increased number of deaths at home means that other

care and more supports are needed for families who care for these patients at the end of their lives. Dr. Loreck said medical staff are more willing to put Alzheimer's disease as cause of death on death certificates than in the past.

- ii. Ms. Naugle encouraged going to the Centers for Disease Control and Prevention (CDC) website for the report. More facts and figures will be out in March, which she will send to the subcommittee when available.
- Other reports
 - Ms. Rosenthal reminded the Council that the Alzheimer's Association is hosting an advocacy day on March 14th in Annapolis. More information will be coming soon.
 - ii. Ms. Nelson discussed the Dementia Friendly America initiative out of Montgomery County. The initiative is growing. Volunteers will engage with the business sector to increase the understanding of how to approach customers and clients who may have a form of dementia. An awareness program will be presented to the Chamber of Commerce in Montgomery County. Prince George's County held a conference titled "Challenges and Opportunities for Addressing the Mobility Needs of Individuals with Dementia and their Caregivers" that was videotaped. The National Aging and Disability Transportation Center can send the link to the video.

6. Adjournment

- Dr. Peters encouraged Council members to meet before the April 18th meeting so subcommittees can carry-out action steps on their work. She encouraged the use of the Dix Building space which is reserved 12-4pm for people to use the space before or after the 1-3pm Council meeting.
- Mr. Vozzella asked for a conference call line that could be used for members in between meetings to continue subcommittee work. Dr. Peters will investigate call options from IT and send an email to members.
- Dr. Peters discussed the certificate and letter that still need to be approved, to be discussed at a later meeting. She encouraged Council members to reach out to the chairs and staff for support.
- The meeting was adjourned at 2:13pm after a motion by Ms. Jones Jolivet, which was seconded by Dr. Majid.

The next meeting of the Virginia I. Jones Alzheimer's Disease and Related Disorders Council will be held on April 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