

**Meeting of Virginia I. Jones Alzheimer's and Related Disorders Council
in conjunction with
Maryland Alzheimer's Advocacy Day
House Office Building, Room 145
March 10, 2016
10:00 AM—12:30 PM
Minutes**

Council Members Present:

Stevanne Ellis, Department of Aging, Co-Chair
Albert Zachik, M.D., Department of Health and Mental Hygiene, Behavioral Health
Administration, Co-Chair
The Honorable Joseline Pena-Melnyk
The Honorable Verna Jones-Rodwell
Cathy Grason, Maryland Insurance Administration
Suzanne Carbone
David Loreck, M.D.
Tabassam Majid, Ph.D.
William Mansbach, Ph.D.
Cass Naugle, Executive Director, Alzheimer's Association, Greater Maryland Chapter
William Neely
Ilene Rosenthal, Alzheimer's Association, Greater Maryland Chapter
Andres Salazar

Other Attendees:

Rona E. Kramer, Secretary, Department of Aging
The Honorable Nancy King
The Honorable Shelly Hettleman
Gloria Lawlah, former Secretary of Aging
Mary Lehman, Member, Prince George's County Council
Tishan Weerisooriya, Staff to Senator Ronald Young
Evan Greenwood, Staff to Delegate Jay Jalisi
Emily Gillebrand, Staff to Delegate Nicholas Kipke
Patrick Hughes, Staff to Delegate Andrew Platt
Michele Douglas
Chris Brouline, President and CEO, Alzheimer's Association, National Capital Area Chapter
Ana Nelson, Alzheimer's Association, National Capital Area Chapter
Aline Stone, Alzheimer's Association

Staff:

Michael Hawkins, DHMH, BHA
Rosanne Hanratty, MDoA

Council Members Not Present:

Jennifer Eastman, Designee of Secretary of Disabilities
Cynthia Fields
Ernestine Jones Jolivet
Karen Kauffman
Karin Lakin
Michelle McEyeson
Chiadi Onyike
Tonis Paide

Greetings and Introductions—Stevanne Ellis, Co-Chair; Albert Zachik, Co-Chair:

Dr. Zachik welcomed members and guests to the Council meeting and to the Advocacy Day. Ms. Ellis introduced herself as the new Co-Chair and explained her role as the State Ombudsman. Council member introductions followed.

Former State Senator Verna Jones-Rodwell provided background on the history of the Alzheimer's Disease and Related Disorders Council (ADRDC Council), which is named after her mother, Virginia I. Jones, who lived with Alzheimer's Disease for many years. Ms. Jones-Rodwell said that she has been involved in the work of the Alzheimer's Association for over forty years and that the work has grown in importance as the number of people affected by ADRDC has continued to grow.

Greetings from Alzheimer's Association—Cass Naugle, Executive Director, Alzheimer's Association, Greater Maryland Chapter; Chris Brouline, Executive Director, Alzheimer's Association, National Capital Area Chapter:

Ms. Naugle and Mr. Brouline greeted attendees on behalf of the Alzheimer's Association, Greater Maryland Chapter and the Alzheimer's Association, National Capital Chapter respectively. Mr. Brouline said that focus on advocacy and on an increase in research dollars are key to progress in meeting the needs of people affected by Alzheimer's Disease and Related Disorders. Ms. Naugle said that, while there has been an increase of \$350 million in federal funding for research for Federal Fiscal Year 2016, it is estimated that \$2 billion is needed to adequately fund treatment through 2020.

The State of Alzheimer's in Maryland—Cass Naugle:

Ms. Naugle provided an overview of the effects of Alzheimer's Disease. She stated that,

nationally, an estimated one-eighth of “baby boomers” will suffer from Alzheimer’s Disease, that it kills more people than diabetes annually, and that annually it also kills more people than breast cancer and prostate cancer combined. Medicare costs for services to people with Alzheimer’s are approximately three times higher than the average Medicare beneficiary cost and that Medicare beneficiaries with Alzheimer’s Disease are more likely to have comorbidities. Medicaid costs are estimated to be nineteen times higher for those with Alzheimer’s Disease compared to other Medicaid beneficiaries. Approximately \$1 billion is spent by Medicaid in long term care costs.

Ms. Naugle said that, in response to such trends, Maryland developed a state plan in 2012 that identified the following goals:

1. Support Prevention and Early Identification of ADRD
2. Enhance the Quality of Care
3. Enhance Supports for Persons living with ADRD and their Families
4. Enhance Public Awareness
5. Improve Data Capacity to Track Progress

With regard to goal one, she noted that an estimated half of people with Alzheimer’s Disease do not receive a diagnosis and that this lack of diagnosis makes treatment of comorbid conditions more complex and/or ineffective. She stated that the *Imaging Dementia – Evidence for Amyloid Scanning Study (IDEAS)*, a joint effort of the Alzheimer’s Association and the American College of Radiology, is designed to determine the clinical usefulness and value in diagnosing Alzheimer’s and other dementias by using a brain positron emission tomography (PET) scan that detects a core feature of Alzheimer’s disease. The study protocol received approval by the Centers for Medicare & Medicaid Services (CMS). Participating providers will be reimbursed for PET scans under the CMS Coverage with Evidence Development (CED) policy that requires research study participation as a condition of Medicare payment.

With regard to goal two, she stated that efforts to enhance general quality of care, as well as care for people with Alzheimer’s Disease who are in residential facilities are issues of concern to the Maryland Culture Change Coalition. The Maryland Culture Change Coalition has received grants from DHMH, Office of Health Care Quality (OHCQ) to facilitate enhancement of quality of care for residents. These grants are funded by the civil money penalties that OHCQ collects from facilities in which deficiencies in quality of care are identified during periodic licensure surveys. [**Note:** OHCQ is the licensing authority for nursing homes and assisted living facilities in the state of Maryland.]

With regard to goal three, Ms. Naugle noted that about two-thirds of people with Alzheimer’s are cared for in their homes and that, while the federal budget for research about Alzheimer’s disease has doubled in the past five years, there are significant challenges to meet the requirements of, and increase the quality of life of, community-dwelling people with Alzheimer’s Disease, such as addressing the need for establishing “dementia-capable” communities and a “dementia-friendly” workforce.

With regard to goal four, Ms. Naugle said that members of the public may have a misapprehension about the fatal nature of Alzheimer's Disease and that bodies such as faith-based communities could be key in enhancing public awareness and accurate information about Alzheimer's Disease and its effects. The impact of stigma and denial on early detection and the amount of research in relation to the scope of the disease is a significant barrier.

With regard to goal five, Ms. Naugle said collecting and analyzing accurate data are important to understand both the effect of Alzheimer's Disease and the adequacy of strategies to address the impacts of, and treatments for, the disease.

Secretary Kramer observed that there is a discontinuity between the prevalence and impact of Alzheimer's Disease and the federal research dollars appropriated to its study. She said that, while approximately \$5 billion is spent annually on cancer research, expenditures for research about Alzheimer's disease is just under \$1 billion annually and that the latter level of spending had been achieved only in federal fiscal year 2016. She said that the Department of Aging's (MDoA) focus on healthy aging and delayed onset of chronic diseases and the effect of other morbidities on community-dwelling older adults is consistent with the goal of enhancing community capabilities to address the effects of specific diseases such as Alzheimer's Disease. She further stated that the same community supports put in place to address the needs of older adults generally will also enable communities to better address the needs of people with Alzheimer's Disease.

National Policy Update-- Aline Stone, Advocacy Senior Specialist, Public Policy Division, Alzheimer's Association:

Ms. Stone emphasized the importance of advocacy to members of Congress to enhance awareness of Alzheimer's Disease and to address its effects on a national level. She cited two pieces of legislation as examples of the success of such advocacy: The National Alzheimer's Project Act (NAPA) [Public Law 111-375] and the Alzheimer's Accountability Act (AAA.) [Public Law 113-235]

1. NAPA called for a National Plan for ADRD with input from a public-private Advisory Council on Alzheimer's Research, Care and Services.
2. AAA requires the National Institutes of Health (NIH) to submit through 2025, an annual Alzheimer's research budget proposal directly to Congress. The proposed budget is to represent the level of investment scientists believe is needed to achieve the milestones of the 2012 National Alzheimer's Plan and its goal of preventing and effectively treating Alzheimer's disease by 2025.

Overview of Maryland State Plan on ADRD and the Work of the ADRD Council—Albert Zachik, M.D. and The Honorable Verna Jones-Rodwell:

Senator Jones-Rodwell acknowledged former Secretary of Aging Glorlah Lawlah, and praised her recognition of the needs of Marylanders with ADRD and their families and her efforts to ameliorate the impact of ADRD on people with ADRD and on the communities in which they live.

Senator Jones-Rodwell recounted her personal experience with the impact of ADRD on families; her mother and father both lived with Alzheimer’s Disease. She said that the effects of ADRD on individuals and communities are experienced locally and nationally and observed that President Ronald Reagan’s openness about his own diagnosis with Alzheimer’s Disease encouraged others affected by ADRD to become open themselves.

She said that during the 2009 Maryland legislative session, legislation was introduced to address the needs of Marylanders affected by ADRD but that the legislation failed to be approved by the General Assembly. However, in 2011, through Executive Order, Governor Martin O’Malley established the Virginia L. Jones Commission on ADRD. In 2012 the Commission submitted to the Governor the Maryland State Alzheimer’s Plan--an evaluation of ADRD’s impact on Marylanders, with recommendations on how the state can meet the needs of people with Alzheimer’s, their families, and caregivers. In 2013, the Virginia L. Jones ADRD Council was established to continue the work of the Maryland ADRD Commission (Chapter 305, Acts of 2013). [Note: The original sunset date of the Council was September 30, 2016 but legislation enacted in during the 2016 session (SB 549) extends the Council’s life by three years and expands its membership to include experts in research on ADRD, public health services, the state Medicaid program, as well as other stakeholders such as the Alzheimer’s Association of the National Capital Area.] Senator Jones-Rodwell emphasized that public awareness and advocacy are essential to such legislative achievements and expansion of resources to address ADRD.

Dr. Zachik stated that the ADRD Council has formed five active subcommittees which correspond to the goals of the Maryland State Plan:

1. Support Prevention and Early Identification of ADRD
2. Enhance the Quality of Care
3. Enhance Supports for Persons living with ADRD and their Families
4. Enhance Public Awareness
5. Improve Data Capacity to Track Progress

He said these goals are consistent with broader public health principles and the concept of “system of care,” a framework that is widely used in providing supports and services for children and youth with serious emotional difficulties. The “system of care” framework involves collaboration among agencies providing home and community based services, affected youth, and their families—with families and youth as full partners in assessing and determining

the need for, and types of, services. Dr. Zachik said that a similar concept might fruitfully be applied to services for people with ADRD and their families.

Overview of Legislation—Michele Douglas:

Ms. Douglas outlined the provisions of the then-pending legislation (SB 549) to extend the life of the ADRD Council and expand its membership. She emphasized that there is wide bipartisan support for efforts to address the effects of ADRD on Marylanders and their communities. She observed that her experience indicates that most Marylanders have experienced the impact of ADRD personally, in their families, and/or in their wider communities and workplaces.

Listening Session facilitated by Senator Verna Jones-Rodwell --Members of the Public Addressed the ADRD Council:

Several members of the public in attendance recounted their experiences with the impact of Alzheimer's Disease on their families, their family's unmet needs, and their suggestions for addressing those and other needs and concerns. These concerns include the cost of care; the inadequacy, or lack, of long-term care insurance to cover the cost of care; the impact of the requirement to "spend-down" resources in order to become eligible for Medicaid benefits; the restrictive criteria for qualifying for Medicaid waivers for home- and community-based services; and the lack of provisions in the tax codes to help ameliorate the negative economic effects of Alzheimer's Disease on families and caregivers. In addition, attendees observed that younger-onset Alzheimer's Disease may present unique challenges to the person with the disease and to his or her family. These unique challenges include economic and other negative effects from the premature termination of the career of the person with the disease and possibly that of the person's spouse.

Other concerns raised include understaffing of day programs and residential and respite facilities; inadequate training of staff in programs and facilities; and the impact on quality of life of the person with Alzheimer's Disease and caregivers and families, even when family members are educated about the disease and services available. One attendee stated that she would like to see goal three of the State ADRD Plan (Enhance Supports for Persons living with ADRD and their Families) take priority over goals two, four and five because she believes that each person with Alzheimer's Disease has a right to live at home. Another attendee said that her professional experience in the field of rehabilitation leads her to recommend enhanced cognitive stimulation for residents in, and more frequent surveys of, residential memory care units.

Secretary Kramer responded to an observation by one participant that the state should address the poor quality of care in state-run facilities. She said that the state does not run day programs, and assisted living or nursing home facilities but that the state regulates facilities. Such regulation and licensure is the responsibility of DHMH/OHCQ, which conducts periodic inspections of the facilities.

Adjournment: The Council adjourned at 12:30 PM

Minutes submitted by Rosanne B. Hanratty

The Council meeting was followed by visits to individual legislators by participants who sought to inform their representatives about the impacts of ADRD and lobby for improvements to strategies in Maryland to address these impacts.