By: Delegates Pena-Melnyk, Barnes, Braveboy, Cane, Costa, Cullison, Frush, Healey, Hubbard, A. Kelly, Kipke, Lafferty, McIntosh, Morhaim, Murphy, Nathan-Pulliam, Oaks, Ready, Reznik, Sophocleus, Swain, Tarrant, V. Turner, and Vaughn Introduced and read first time: February 4, 2013

Assigned to: Health and Government Operations

A BILL ENTITLED

1 AN ACT concerning

2 Virginia I. Jones Alzheimer's Disease and Related Disorders Council

3 FOR the purpose of establishing the Virginia I. Jones Alzheimer's Disease and Related 4 Disorders Council; providing for the membership of the Council; requiring the $\mathbf{5}$ Secretary of Health and Mental Hygiene and the Secretary of Aging to cochair 6 the Council; requiring the Department of Health and Mental Hygiene to provide 7 staff support for the Council; authorizing the Department to request certain 8 staffing assistance; providing that a member of the Council may not receive 9 certain compensation but is entitled to certain reimbursement; providing for the 10 duties of the Council; defining a certain term; and generally relating to the Virginia I. Jones Alzheimer's Disease and Related Disorders Council. 11

- 12 BY adding to
- 13 Article Health General
- Section 13–3101 through 13–3106 to be under the new subtitle "Subtitle 31.
 Virginia I. Jones Alzheimer's Disease and Related Disorders Council"
- 16 Annotated Code of Maryland
- 17 (2009 Replacement Volume and 2012 Supplement)
- 18

Preamble

WHEREAS, There are more than 5.4 million Americans living with Alzheimer's
 disease and someone new is added to that number approximately every 68 seconds;
 and

WHEREAS, There are an estimated 86,000 individuals in Maryland with Alzheimer's disease, and this number is expected to increase with the general aging of the population; and

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW. [Brackets] indicate matter deleted from existing law.

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1 WHEREAS, Alzheimer's disease and related disorders are also associated with 2 a number of seriously disabling illnesses, including high blood pressure, high 3 cholesterol, and other cardiovascular diseases; and

WHEREAS, Individuals with Alzheimer's disease and related disorders live many years after diagnosis and are at increased risk for high health care costs, social isolation, and institutionalization; and

7 WHEREAS, Family members and caregivers of individuals with Alzheimer's 8 disease and related disorders commonly do not have access to services or knowledge of 9 the resources and information needed to provide effective and efficient care and 10 treatment of the disease; and

11 WHEREAS, The lack of access to and utilization of information results in less 12 effective treatment of Alzheimer's disease and related disorders and increases the 13 burden of care, leading to poorer outcomes for individuals living with the disease or 14 related disorders and their caregivers; and

WHEREAS, There is a need for more successful collaborative efforts in Maryland, such as the annual Pythias A. and Virginia I. Jones African American Community Forum on Memory Loss, created in the memory of Virginia I. Jones, a Marylander committed to public service, who lived with the devastation of Alzheimer's disease for approximately 10 years prior to diagnosis and for 17 years after diagnosis, and her husband, who was also an Alzheimer's victim and her primary caregiver for all of those 17 years; and

WHEREAS, The Forum brings together a public, private, and community collaboration to inform the community and others about Alzheimer's disease and related disorders, to support caregivers, to share information on services available, and to bring the promise of research and opportunities to network with others who share similar concerns; and

WHEREAS, Many Maryland agencies, associations, and institutions have
 Alzheimer's disease and related disorders expertise but gaps remain in the
 coordination of services and information relating to these chronic diseases; and

WHEREAS, The Governor established by Executive Order the Maryland
 Alzheimer's Disease and Related Disorders Commission; and

32 WHEREAS, The Maryland Alzheimer's Disease and Related Disorders 33 Commission released its 2012 Maryland State Plan on Alzheimer's Disease and 34 Related Disorders which recommended the establishment of a permanent Alzheimer's 35 Disease and Related Disorders Council; now, therefore,

36 SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF 37 MARYLAND, That the Laws of Maryland read as follows:

1	Article – Health – General
$2 \\ 3$	SUBTITLE 31. VIRGINIA I. JONES ALZHEIMER'S DISEASE AND RELATED DISORDERS COUNCIL.
4	13-3101.
$5 \\ 6$	IN THIS SUBTITLE, "COUNCIL" MEANS THE VIRGINIA I. JONES ALZHEIMER'S DISEASE AND RELATED DISORDERS COUNCIL.
7	13-3102.
8 9	THERE IS A VIRGINIA I. JONES ALZHEIMER'S DISEASE AND RELATED DISORDERS COUNCIL.
10	13-3103.
11	THE COUNCIL CONSISTS OF THE FOLLOWING MEMBERS:
12 13	(1) ONE MEMBER OF THE SENATE OF MARYLAND, APPOINTED BY THE PRESIDENT OF THE SENATE;
$\begin{array}{c} 14 \\ 15 \end{array}$	(2) ONE MEMBER OF THE HOUSE OF DELEGATES, APPOINTED BY THE SPEAKER OF THE HOUSE;
16	(3) THE SECRETARY OF HEALTH AND MENTAL HYGIENE;
17	(4) THE SECRETARY OF AGING;
18 19	(5) THE SECRETARY OF DISABILITIES, OR THE SECRETARY'S DESIGNEE;
$\begin{array}{c} 20\\ 21 \end{array}$	(6) THE MARYLAND INSURANCE COMMISSIONER, OR THE COMMISSIONER'S DESIGNEE; AND
22	(7) THE FOLLOWING MEMBERS, APPOINTED BY THE GOVERNOR:
$\begin{array}{c} 23\\ 24\\ 25 \end{array}$	(I) A REPRESENTATIVE OF THE U.S. DEPARTMENT OF VETERANS AFFAIRS WITH EXPERTISE IN ALZHEIMER'S DISEASE AND RELATED DISORDERS;
$\frac{26}{27}$	(II) AN ATTORNEY WHO WORKS DIRECTLY WITH DISABLED OR ELDERLY INDIVIDUALS;

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1 (III) A REPRESENTATIVE OF THE **ALZHEIMER'S** $\mathbf{2}$ **ASSOCIATION, GREATER MARYLAND CHAPTER;** CONDUCTS 3 (IV) A PHYSICIAN WHO RESEARCH IN ALZHEIMER'S DISEASE AND RELATED DISORDERS; 4 $\mathbf{5}$ (V) A HEALTH PROFESSIONAL WITH EXPERTISE IN 6 ADDRESSING RACIAL AND ETHNIC HEALTH DISPARITIES; 7 (VI) A SOCIAL WORKER WITH EXPERIENCE WORKING WITH 8 INDIVIDUALS AND FAMILIES AFFECTED BY ALZHEIMER'S DISEASE AND 9 **RELATED DISORDERS;** 10 (VII) A PSYCHOLOGIST OR PSYCHIATRIST WITH EXPERTISE IN 11 ALZHEIMER'S DISEASE AND RELATED DISORDERS; 12(VIII) A PHYSICIAN WITH EXPERIENCE IN END-OF-LIFE CARE 13 AND PAIN MANAGEMENT; 14(IX) A REGISTERED NURSE WITH EXPERTISE IN 15**ALZHEIMER'S DISEASE AND RELATED DISORDERS;** 16 **(X)** A LICENSED NURSE PRACTITIONER WITH EXPERTISE IN 17END-OF-LIFE CARE AND PAIN MANAGEMENT; 18 (XI) A REPRESENTATIVE OF THE NURSING HOME AND 19**ASSISTED LIVING INDUSTRY;** 20(XII) AN INDIVIDUAL WITH EARLY-ONSET ALZHEIMER'S 21DISEASE OR A RELATED DISORDER; AND 22(XIII) TWO FAMILY CAREGIVERS, ONE OF WHOM IS A FAMILY 23MEMBER OF AN INDIVIDUAL WITH ALZHEIMER'S DISEASE OR A RELATED 24**DISORDER.** 13-3104. 2526(A) THE SECRETARY OF HEALTH AND MENTAL HYGIENE AND THE SECRETARY OF AGING SHALL COCHAIR THE COUNCIL. 2728**(B)** A MEMBER OF THE COUNCIL:

1 (1) MAY NOT RECEIVE COMPENSATION AS A MEMBER OF THE 2 COUNCIL; BUT

3 (2) IS ENTITLED TO REIMBURSEMENT FOR EXPENSES UNDER THE 4 STANDARD STATE TRAVEL REGULATIONS, AS PROVIDED IN THE STATE 5 BUDGET.

6 **13–3105.**

7 (A) THE DEPARTMENT SHALL PROVIDE STAFF SUPPORT FOR THE 8 COUNCIL.

9 (B) THE DEPARTMENT MAY REQUEST STAFFING ASSISTANCE FROM 10 PUBLIC HEALTH ENTITIES WITH AN INTEREST IN THE DUTIES OF THE COUNCIL.

- 11 **13–3106.**
- 12 **THE COUNCIL SHALL:**

(1) CONTINUE THE WORK INITIATED BY THE MARYLAND
 ALZHEIMER'S DISEASE AND RELATED DISORDERS COMMISSION, INCLUDING
 THE DEVELOPMENT AND MONITORING OF THE 2012 MARYLAND STATE PLAN
 ON ALZHEIMER'S DISEASE AND RELATED DISORDERS;

17(2) INCLUDE IN THE STATE PLAN STRATEGIES AND ACTIONS18THAT:

19 (I) SUPPORT PREVENTION AND EARLY DETECTION OF 20 ALZHEIMER'S DISEASE AND RELATED DISORDERS, INCLUDING EARLY STAGE 21 IDENTIFICATION;

22 (II) ADDRESS CHRONIC DISEASE FACTORS CONTRIBUTING 23 TO DISPARITIES IN ALZHEIMER'S DISEASE; AND

24 (III) ENHANCE THE QUALITY OF CARE THROUGH:
25 1. BUILDING A WORKFORCE TRAINED TO CARE FOR
26 AND TREAT ALZHEIMER'S DISEASE AND RELATED DISORDERS;

272.EDUCATING PRIMARY CARE PROVIDERS ON BEST28PRACTICES; AND

13.PROMOTINGALZHEIMER'SDISEASEAND2RELATEDDISORDERSCAREGUIDELINESANDPATIENT-CENTERED3APPROACHES IN ALL CARE SETTINGS;

4 (3) REVIEW STATE STATUTES, POLICIES, AND PROGRAMS TO 5 IMPROVE AND ENHANCE QUALITY OF LIFE AND SUPPORT AND SERVICES FOR 6 INDIVIDUALS LIVING WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS 7 AND THEIR FAMILIES BY PROMOTING AND EXPANDING THE AVAILABILITY AND 8 ACCESSIBILITY OF HOME- AND COMMUNITY-BASED SUPPORT AND SERVICE 9 PROGRAMS;

- 10
- (4) **CONDUCT A PUBLIC EDUCATION CAMPAIGN ON:**
- 11 (I) THE RISK FACTORS FOR DEMENTIA;
- 12 (II) THE IMPORTANCE OF SCREENING FOR DEMENTIA;
- 13 (III) THE AVAILABLE SUPPORT SERVICES AND RESOURCES;
- 14(IV) THE NEED FOR ADVANCE PLANNING AND DECISION15MAKING; AND
- 16

(V) THE MARYLAND ACCESS POINT; AND

17 (5) IMPROVE DATA COLLECTION CAPACITY ON ALZHEIMER'S 18 DISEASE AND RELATED DISORDERS IN THE STATE TO BETTER TARGET 19 SUPPORT, SERVICES, AND NEEDS.

20 SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect 21 October 1, 2013.

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