LeadingAge Maryland - 2025 - SB 748 - alzheimers.p Uploaded by: Aaron Greenfield



TO:	Senate Finance Committee	
FROM:	LeadingAge Maryland	
SUBJECT:	Senate Bill 748, Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment	
DATE:	March 4, 2025	
POSITION:	Favorable	

LeadingAge Maryland <u>supports</u> Senate Bill 748, Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment.

LeadingAge Maryland is a community of more than 159 not-for-profit aging services organizations serving residents and clients through continuing care retirement communities, affordable senior housing, assisted living, nursing homes and home and community-based services. Members of LeadingAge Maryland provide health care, housing, and services to more than 20,000 older persons each year. Our mission is to be the trusted voice for aging in Maryland, and our vision is that Maryland is a state where older adults have access to the services they need, when they need them, in the place they call home.

Senate Bill 748 will establish annual data reporting on dementia prevalence through the Maryland Department of Health (MDH) and Chesapeake Regional Information Services for Patients (CRISP) and it will update requirements that dementia related public health outreach programs include information on treatment.

Dementia is a growing public health crisis in Maryland that demands urgent attention. Our state has the highest estimated prevalence of Alzheimer's disease in the nation, yet we lack comprehensive, state-specific data to guide policies and programs. Without accurate data, we cannot effectively monitor trends, identify disparities, or assess the impact of interventions.

To address this gap, we support this legislation to establish an annual, online dementia data dashboard. This dashboard would track prevalence and other key dementia-related metrics, ensuring policymakers, public health officials, researchers, and healthcare professionals have the information needed to drive effective strategies. This initiative directly aligns with Goal 5 of the State Plan to Address Alzheimer's Disease and Related Dementias—enhancing data capabilities to improve outcomes.

Recent FDA-approved treatments have the potential to alter the progression of Alzheimer's disease, offering hope beyond symptom management. Early intervention provides individuals

and families with crucial time to plan for the future, adopt beneficial lifestyle changes, participate in clinical trials, and maximize quality of life.

Building on the 2021 passage of HB 119/SB 313, which expanded outreach on dementia risk reduction and early detection, we support legislation ensuring state-led dementia awareness efforts also include information on newly available treatments. Marylanders deserve to be fully informed about all options following a diagnosis.

By advancing data-driven policymaking and improving public awareness, we can take meaningful steps toward a future without dementia.

For these reasons, LeadingAge Maryland respectfully requests a <u>favorable report</u> on Senate Bill 748.

For more information, please contact Aaron Greenfield at 410.446.1992 or aaron@agreenfieldlaw.com

SB748_Marylanders fro Patient Rights_fav.pdf Uploaded by: Anna Palmisano

MARYLANDERS FOR PATIENT RIGHTS REQUESTS A <u>FAVORABLE</u> REPORT ON SB748 Public Health-Alzheimer's Disease and Related Dementias, Information on Prevalence and Treatment

Marylanders for Patient Rights is the leading advocacy coalition for patients in our state, and we strongly support SB748. Having spent three years as primary caregiver for an elderly family friend who had Alzheimer's, I know from personal experience about the importance of this bill.

It is estimated that Maryland has the highest prevalence of Alzheimer's disease in the country. This legislation will raise awareness about Alzheimer's, improve data collection, and provide insights into Maryland residents' Alzheimer's incidences and outcomes. Scientists have linked different types of dementia not only to inherited genetics, but also to exposure to certain environmental chemicals. Marylanders need more information about risk assessment, diagnosis, and current treatment options when they or their loved ones are faced with this dreaded disease.

SB748 will establish an annual data reporting requirement on dementia prevalence in Maryland, as well as ensure that information on treatments approved by the Food and Drug Administration (FDA) for Alzheimer's disease and other dementias are included in relevant public health outreach programs States including MN, NY, OH, CA and others have websites for public outreach, and Maryland can follow these models.

Please provide <u>a favorable report on SB748</u>, and help to inform Maryland patients and families on the prevalence and treatment of those suffering from Alzheimer's and other types of dementia.

Thank you,

*A C Palmisano*Anna C. Palmisano, Ph.D, Director
Marylanders for Patient Rights
<u>palmscience@verizon.net</u>
301-529-0946

Maryland Catholic Conference_FAV_SB748.pdf Uploaded by: Diane Arias



March 4, 2025

Senate Bill 748 Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment Senate Finance Committee

Position: Favorable

The Maryland Catholic Conference (MCC) is the public policy representative of the three (arch)dioceses serving Maryland, which together encompass over one million Marylanders. Statewide, their parishes, schools, hospitals, and numerous charities combine to form our state's second largest social service provider network, behind only our state government.

Senate Bill 748 requires the Maryland Department of Health, in partnership with certain entities, to incorporate information regarding treatments approved by the Food and Drug Administration for Alzheimer's disease and related dementias and to increase understanding and awareness of treatment of Alzheimer's disease and related dementias into relevant public health outreach programs administered by the Department.

Making informed, data-driven decisions is essential, especially when caring for a loved one with Alzheimer's or dementia who may no longer have full cognitive capacity to make their own medical choices. It is critical to provide the best possible care while respecting the dignity of individuals with degenerative cognitive conditions. The U.S. Food and Drug Administration (FDA) has recently approved Kisunla (donanemab-azbt), a treatment that has demonstrated significant reductions in clinical decline for Alzheimer's patients.¹ While there is still no cure for Alzheimer's, ongoing advancements in treatment can help preserve cognitive function and coherence, allowing families to share more meaningful moments with their loved ones.

Public awareness of these promising treatments is vital. Clear communication about FDAapproved medications enables families to consult healthcare providers about potential options for their loved ones. Additionally, the publication of data related to early detection, treatment outcomes, and public health trends can help families and healthcare professionals better understand the prevalence of Alzheimer's and make informed care decisions. Legislation that promotes the dissemination of this critical information can ensure that individuals with

¹ https://www.fda.gov/drugs/news-events-human-drugs/fda-approves-treatment-adults-alzheimers-disease

Alzheimer's receive the care they deserve while also helping to prevent instances of abuse or neglect. Regardless of cognitive state, every person has inherent dignity and ensuring access to the latest medical advancements that are developed with respect to life, is a fundamental aspect of their care.

For these reasons, the Maryland Catholic Conference asks for a favorable report on **SB 748**.

Thank you for your consideration.

2025 MOTA SB 748 Senate Side.pdf Uploaded by: Jennifer Navabi



MOTA Maryland Occupational Therapy Association

PO Box 36401, Towson, Maryland 21286 🕏 www.mota-members.com

Committee:	Senate Finance Committee
Bill Number:	Senate Bill 748 – Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment
Hearing Date:	March 4, 2025
Position:	Support

The Maryland Occupational Therapy Association (MOTA) supports Senate Bill 748 – Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and *Treatment*. The bill would require the Maryland Department of Health, in partnership with the Department of Aging, the Virginia I. Jones Alzheimer's Disease and Related Disorders Council, and the Greater Maryland Chapter of the Alzheimer's Association to incorporate information regarding treatments approved by the Food and Drug Administration for Alzheimer's disease and related dementias and to increase understanding and awareness of treatment of Alzheimer's disease and related dementias into relevant public health outreach programs.

Alzheimer's disease causes a continual loss of cognitive function including memory problems which have a significant impact on older adults' daily life and activities. Currently, there is no known cure for Alzheimer's disease. Occupational therapy is a non-pharmacological dementia intervention that helps manage the symptoms of Alzheimer's dementia, and occupational therapy practitioners can help people with Alzheimer's disease maintain their independence and quality of life. This bill will ensure that all Marylanders have access to information regarding treatments and management strategies that can help slow the progression of the disease and improve symptoms, ultimately improving health outcomes.

We ask for a favorable report. If we can provide any further information, please contact Michael Paddy at mpaddy@policypartners.net.

SB 748 1199SEIU_FAV_Alzheimer Treatment.pdf Uploaded by: Loraine Arikat



Testimony for SB 748 Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment March 4, 2025 Position: Favorable

Dear Chair Beidle and members of the Finance Committee:

My name is Ricarra Jones, and I am the Political Director with 1199SEIU- the largest healthcare union in the nation, where we represent over 10,000 healthcare workers in Maryland. 1199SEIU United Healthcare Workers East is Maryland's largest healthcare union, representing over 400,000 healthcare workers across the East Coast. We strongly support SB 748 to ensure we have accurate data on Alzheimer prevalence and hospitalization rates. SB 748 will also improve public health outreach and education that includes treatment options for Alzheimer's disease and dementia.

1199 SEIU is a proud partner of the Caring Across Maryland coalition which supports legislation that improves long term care services and care for those aging and with disability. Maryland has the highest prevalence of dementia in the country with higher proportion of prevalence among people of color. Maryland hospital systems, long term care, and home care service systems are caring for many patients that have Alzheimer's or dementia. SB 748 will improve public awareness of early treatment options and ensure accurate data of disease prevalence.

With over \$1 billion in annual Medicaid spending, addressing dementia requires a comprehensive approach. This legislation aims to improve public health education, data informed policy making, and put Maryland on the path towards lower prevalence and meeting patient needs with treatment options. 1199 SEIU urges a favorable report on SB 748.

Sincerely,

Ricarra Jones Political Director 1199 SEIU United Healthcare Workers East <u>Ricarra.jones@1199.org</u>

SB 748 - FAV - ALZ Association.pdf Uploaded by: Megan Peters

Bill: SB 748 - Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment
Committee: Finance
Position: Favorable
Date: March 4, 2025

On behalf of the Alzheimer's Association, the leading voluntary health organization in Alzheimer's care, support, and research, we support SB 748 - *Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment*. This bill will establish an annual data reporting requirement on dementia prevalence in Maryland, as well as ensure that information on treatments approved by the Food and Drug Administration (FDA) for Alzheimer's disease and other dementia are included in relevant public health outreach programs.

Dementia is a growing fiscal and public health concern in Maryland. In 2020, Maryland saw over \$1.23 *billion* in Medicaid costs caring for people living with Alzheimer's - a figure projected to rise 25% by 2025.¹ Based on a 2023 national study, our state has the highest estimated prevalence of Alzheimer's in the nation,² yet **we do not have state-specific data on dementia prevalence**. As a result, we cannot properly plan programs and policies, allocate resources, or support people living with dementia and their caregivers, many of whom are family members providing unpaid care.

This is a gap that needs to be addressed, and was also identified in Maryland's *State Plan to Address Alzheimer's Disease and Related Dementias* (the State Plan).³ Specifically, 1 of the 5 goals in the State Plan is to "enhance data capabilities related to dementia and dementia impact and effects of interventions." The State Plan notes that effective methods for capturing and using population-based data are needed to improve care and support for Marylanders living with dementia and to adequately plan for the growth in both people at risk and who develop dementia in the future. **SB 748 aligns directly with Goal 5 of the State Plan to Address Alzheimer's Disease and Related Dementias**.

There are several ways that data will improve care and support for Marylanders living with dementia and drive risk reduction approaches to lowering prevalence. Examples include:

• **Planning and Resource Allocation:** Data will help organizations and stakeholders like policymakers and healthcare providers understand the number of people impacted by dementia. This will allow the allocation of resources more effectively, such as funding for memory care units, caregiver support, and medical support.

https://www.alz.org/getmedia/76e51bb6-c003-4d84-8019-e0779d8c4e8d/alzheimers-facts-and-figures.pdf

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<sup>3</sup> Maryland State Plan to Address Alzheimer's Disease and Related Dementias, 2022-2026
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https://health.maryland.gov/phpa/ccdpc/Pages/State-ADRD-Plan.aspx#:~:text=The%20updated%20State%20Plan%20is.health%20sys tems%2C%20and%20the%20community.&text=Goal%205%3A%20Enhance%20data%20capabilities,impact%20and%20effects%20of%2 Ointerventions.

¹ 2024 Alzheimer's Facts and Figures

² Dhana K, Beck T, Desai P, Wilson RS, Evans DA, Rajan KB. Prevalence of Alzheimer's disease dementia in the 50 US states and 3142 counties: A population estimate using the 2020 bridged-race postcensal from the National Center for Health Statistics. *Alzheimer's Dement.* 2023; 19: 4388–4395. https://doi.org/10.1002/alz.13081

- **Public Health:** Accurate data informs public health programs, early diagnosis campaigns, and more to improve the quality of life for people living with dementia and their caregivers.
- **Policy:** Data informs efforts to advocate for policy changes, funding, and improved care standards at both the state and federal levels.
- **Community Impact & Economic Costs:** Dementia affects not only those with a diagnosis, but also families, workplaces, and the economy. Understanding prevalence helps estimate the financial burden on the healthcare system and the workforce.
- **Research & Clinical Trials:** Localized data helps researchers track trends, identify risk factors, and develop targeted prevention and treatment strategies to Maryland's population.

This data will help Maryland advance towards a future where we are lowering our prevalence and effectively reaching those in need. While we work towards that future, **SB 748 also addresses a new era for Alzheimer's disease and other dementia – treatment.** FDA-approved treatments for Alzheimer's disease, which became available in the past few years, can slow disease progression in early stages, not just ease symptoms.⁴ Early intervention can provide time to plan for the future, adopt lifestyle changes, participate in clinical trials, and live more fully with a higher quality of life for as long as possible.

However, **many healthcare providers and Marylanders lack awareness of available treatment options.** This can be devastating, as the treatments available today are only effective in the early stages of Alzheimer's disease. Therefore, **it is critical to educate Marylanders**, including targeted outreach to healthcare providers, to ensure Marylanders are informed of their options as soon as possible so that they are not missing out on treatments.

With over \$1 billion in annual Medicaid spending, addressing dementia requires a comprehensive approach. SB 748 has negligible costs, particularly as treatment information can be incorporated into public awareness efforts in relevant programs in partnership with the Maryland Department of Aging, the Virginia I. Jones Alzheimer's Disease and Related Dementias Council, and the Alzheimer's Association. **Any costs related to data would be minimal and should be in line with other existing programs.** Similar reporting requirements for Parkinson's disease were adopted in SB 584 of 2023 and estimated start-up and operating expenses for data reporting were approximately \$25,000⁵ - less than 0.002% of the cost of Alzheimer's care to Maryland Medicaid.

The Alzheimer's Association strongly supports SB 748 and urges a favorable report. Please contact Megan Peters, Director of Government Affairs at <u>mrpeters@alz.org</u> with any questions.

⁴ <u>https://www.alz.org/alzheimers-dementia/treatments/navigating-treatment-options</u>

⁵ Chapter 383 of the Acts of 2023, Public Health - Parkinson's Disease - Advisory Committee and Website <u>https://mgaleg.maryland.gov/mgawebsite/Legislation/Details/sb0584/?ys=2023rs</u>

Written Testimony SB 748 (1).pdf Uploaded by: Patricia Joralemon

Written Testimony SB 748 - Favorable

Patricia Joralemon-Selko

Constituent, District 42A

Dear Chair Beidle and members of the Committee,

My name is Patricia Joralemon-Selko from District 42A, Baltimore County. I urge you to support SB748, Public Health – Alzheimer's Disease and Related Dementias – Information on Prevalence and Treatment.

This bill is particularly important to me because it will ensure that dementia-related public health outreach educates Marylanders on Alzheimer's treatment. I believe this will encourage earlier diagnoses, allow individuals to receive treatment sooner, and promote healthier lifestyle choices.

My mother silently struggled for several years with memory loss. She was terrified of Alzheimer's after witnessing her own mother endure an eight-year battle with the disease. My mother never sought help due to this fear. Unfortunately, she wasn't alone—many people fear Alzheimer's more than cancer. We tried to intervene, but the fear gripped her too tightly. She now lives in a memory care facility; I often wonder if we could have had more time with her if there had been more public awareness and if doctors were better equipped to talk to patients about their symptoms and educate their caregivers. Perhaps then, she could have stayed in her home longer. Not to mention the toll it took on my stepfather as well.

During this same time, my husband kept telling me he felt something was off with his memory. Over the course of six months, we went to three different primary care doctor appointments. In the first two, he was prescribed anti-anxiety medication for what was labeled as "anxious aging." In the second visit, the doctor directly told him, "You don't have dementia," without even conducting a cognitive assessment. After the third visit, we pushed harder and finally received a referral to a memory clinic. However, it took another six months to get an appointment.

At the clinic, he was given a cognitive assessment, which confirmed the need for further testing. Over the next five months, he underwent blood work, an MRI, and a PET scan, all of which showed that he had Mild Cognitive Impairment due to Alzheimer's. Those five months were terrifying and increased his anxiety, which in turn worsened his symptoms. There is very little support available for those going through this process. Unlike my mother, my husband was proactive in seeking early help early, as recommended for more effective intervention. However, without proper education for both primary care doctors and the general public, many individuals often wait until it's too late.

My husband and I have done a lot of research on our own, with the help of the Memory clinic, friends, and family. He has started an FDA-approved treatment, Leqembi, and we have made many lifestyle changes, which we are seeing some improvement. As it stands now, the current system creates anxiety, which worsens the disease. It doesn't have to be this way. We need more education and a centralized website for both the public and healthcare workers to easily access information about available services.

During our follow-up appointments at the memory clinic, the nurse partitioner noted down the information we found online—such as educational resources for caregivers and support groups. I give them credit for trying to find the information, too. But when we first asked the clinic, "What now? This is really hard to process!" They directed us to the Alzheimer's Association, which was wonderful. However, we needed help then, not after the disease progressed further.

If the healthcare community wants the public to seek treatment early and not ignore symptoms, they need to provide more accessible support and information for those navigating the diagnosis process. There were many times when we just wanted to give up because it was so overwhelming and scary. My husband has faced this challenge with remarkable courage, but he is not the norm, many are frozen in fear and never talk to their doctors.

Maryland has the highest estimated prevalence of Alzheimer's in the nation. However, we do not collect state-specific data on dementia prevalence that could inform our programs and policies. A diagnosis of Alzheimer's or dementia is challenging for a family regardless of the circumstances. Having access to information on treatment and services can make the situation a little more hopeful. I urge the committee to support this bill. Thank you for taking the time to read our story.

Sincerely,

Patricia Joralemon-Selko

SB 748 Alzheimers Bill - Finance 030525 BD FULL F

Uploaded by: Robert Doyle Position: FAV



Statement of the Maryland Federation of National Active and Retired Federal Employees Senate Finance Committee Hearing, March 4, 2025 On SB 748 – Public Health – Alzheimer's Disease and Related Dementias – Information on Prevalence and Treatment

(Position – FAV)

Good Afternoon, Chair Beidle and Vice-Chair Hayes and members of the Finance Committee. I am Robert Doyle, Co-Chair of the State Legislative Committee of the Maryland National and Active and Retired Federal Employees Association (NARFE), representing approximately 317,000 federal annuitants and employees in Maryland. I am pleased to provide our written statement and to testify today on behalf of our Maryland NARFE members – over 317,000 annuitants and active Federal employees - asking for your support and a favorable report on SB 748 – Public Health – Alzheimer's Disease and Related Dementias – Prevalence and Treatments. We thank Delegate Kramer for introducing this Bill. SB 748 will require the Maryland Department of Health, in partnership with the Department of Aging, the Virginia I. Jones Alzheimer's Disease and Related Disorders Council, and the Greater Maryland Chapter of the Alzheimer's Association, to incorporate information into relevant public health outreach programs administered by the Department on new treatments approved by the Food and Drug Administration for Alzheimer's Disease and related dementias. Additionally, the Department, in collaboration with the State-designated health information exchange (HIE), must establish and maintain a publicly accessible website that includes specified information regarding Alzheimer's disease and related dementias in a downloadable format, which must be updated annually to include any newly available data.

Why SB 748 Is Needed

Alzheimer's Disease is an irreversible, progressive brain disorder that slowly destroys memory and thinking skills and, eventually, the ability to carry out simple tasks. Alzheimer's is the most common disease that causes dementia, an umbrella term that describes a collection of symptoms (cognitive, functional and behavioral) that are caused by specific diseases.

To learn statistics about Alzheimer's disease can be discouraging and frightening. An estimated 6.9 million Americans age 65 and older are living with Alzheimer's dementia today. This number could grow to 13.8 million by 2060, barring the development of medical breakthroughs to prevent or cure AD. In 2020 and 2021, when COVID-19 entered the ranks of the top ten causes of death, Alzheimer's was the seventh-leading cause of death in the United

States. Official counts for more recent years are still being compiled. Alzheimer's remains the fifth-leading cause of death among Americans age 65 and older.¹

Since 1983, NARFE membership has contributed over \$16 million to the Alzheimer's Association to help its care, support and research programs, and to sponsor 94 research grants examining wide-ranging, disease-related research. During this time, NARFE has distinguished itself as one of the Alzheimer's Association top research funders. Additionally, Kathy Siggins, the current Alzheimer's Coordinator for NARFE Region II, was instrumental in the development of two USPS stamps to fight this disease, a 2008 commemorative stamp, and the 2017 Alzheimer's research.

Regarding our Alzheimer's research efforts, NARFE National President William Shackelford has noted "We're extremely proud of this accomplishment in our continued efforts to find a cure. We remain steadfast in our fundraising commitment in helping change the trajectory of Alzheimer's disease in this country. Our members bear the weight of caring and grieving for someone afflicted with this devastating disease, We support the Alzheimer's Association to not only aid the progressive medical research, but also to offer our members resources to cope."

Dr. Joanne Pike, president and CEO of Alzheimer's Association, said the NARFE's members' generosity and commitment inspired them to raise an additional \$1 million for their mission by the end of 2026. Dr. Pike declared "by raising more than \$16 million to date for the Alzheimer's Association, NARFE has funded critical research toward treatment, prevention and, ultimately, a cure for Alzheimer's and all other dementia while also providing vital funding for our care and support services through their participation in Walk to End Alzheimer's."²

The Maryland Department of Health has active dementia prevention and care programs in the state. The Department collaborates with the Virginia I. Jones Alzheimer's Disease and Related Disorders Council to track and report activities in the Maryland State Plan to Address Alzheimer's Disease and Related Dementias and build upon its Healthy Brain Aging awareness campaign to increase early detection and diagnosis and promote healthy brain aging. In 2023, Maryland was awarded a five-year, \$2.5 million grant from the U.S. Centers for Disease Control and Prevention to expand Alzheimer's and related dementias prevention and care programs in Maryland. The grant period is from September 30, 2023 to September 29, 2028.

"Alzheimer's disease and related dementias represent an urgent and costly public health crisis," said Maryland Department of Health Secretary Laura Herrera Scott. "This grant will help

¹ 2024 Alzheimer's Disease Facts and Figures, https://pubmed.ncbi.nlm.nih.gov/38689398/

² NARFE Celebrates Exceeding \$16 Million Alzheimer's Fundraising Goal, April 5, 2024, https://www.narfe.org/blog/2024/04/05/narfe-celebrates-exceeding-16-million-alzheimers-fundraising-goal/

Maryland provide support and resources within communities most impacted by this devastating disease and lessen the burden on caregivers and families."³

HB 1004 will add to the Department's existing programs important information on the Alzheimer's treatments which have FDA approval, including the drugs Lecenemab and Donanemab which received traditional FDA approval in 2023 and 2024, respectively.⁴ Both of these are for people living with mild cognitive impairment or mild dementia due to Alzheimer's disease. These drugs can slow disease progression and the decline of memory and thinking, as well as function, in people living with Alzheimer's disease.⁵

Maryland NARFE applauds the current efforts of the Maryland Department of Health and its partner organizations in educating caregivers and individuals about the impacts of Alzheimer's and the news of progress in research to find a cure. Under the new requirements of SB 748, the MDH will enhance the information it provides to all in Maryland who are fighting the battle against this insidious disease.

We respectfully ask that you give a favorable report to HB 1004.

³ Maryland Department of Health receives a \$2.5 million Grant to address Alzheimer's Disease and related dementias, October 18, 2023, https://health.maryland.gov/newsroom/Pages/Maryland-Department-of-Health-receives-\$2.5M-grant-to-address-Alzheimer%E2%80%99s-disease-and-related-dementias.aspx

⁴ Traditional approval requires that clinical benefit be shown before approval can be granted. Accelerated approval is given to some new drugs for serious and life-threatening illnesses that lack satisfactory treatments. This allows a new drug application to be approved before measures of effectiveness that would usually be required for approval are available. https://www.fda.gov/drugs/information-consumers-and-patients-drugs/fdas-drug-review-processcontinued

⁵ https://www.alz.org/alzheimers-dementia/treatments/navigating-treatment-options

Thank you.

Robert M. Doyle, Co-Chair Maryland Federation – NARFE State Legislative Committee 4226 Carvel Lane Edgewater, MD 21037 bdoyle47@verizon.net H (410) 798-0079 C/Text (301) 693-1774 Virginia Bender MD Fed. NARFE Alzheimer's Coordinator 854 Tern Lane, Apt 204 Salisbury, MD 21804 vbender21804@gmail.com (860) 823-9312

SB 748 - FAV - MSCAN.pdf Uploaded by: Sarah Miicke



Maryland Senior Citizens Action Network

MSCAN

AARP Maryland

Alzheimer's Association, Maryland Chapters

Baltimore Jewish Council

Catholic Charities of Baltimore

Central Maryland Ecumenical Council

Church of the Brethren

Episcopal Diocese of Maryland

Housing Opportunities Commission of Montgomery County

Lutheran Office on Public Policy in Maryland

Maryland Association of Area Agencies on Aging

Maryland Catholic Conference

Mental Health Association of Maryland

Mid-Atlantic LifeSpan

National Association of Social Workers, Maryland Chapter

Presbytery of Baltimore

The Coordinating Center

MSCAN Co-Chairs: Carol Lienhard Sarah Miicke 6102460075 Testimony in Support of SB 748 - Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment Senate Finance Committee March 4, 2025

The Maryland Senior Citizens Action Network (MSCAN) is a statewide coalition of advocacy groups, service providers, faith-based and mission-driven organizations that supports policies that meet the housing, health and quality of care needs of Maryland's low and moderate-income seniors.

MSCAN supports SB 748. This legislation will establish an annual data reporting requirement on dementia prevalence in Maryland, as well as ensure that information on treatments approved by the Food and Drug Administration (FDA) for Alzheimer's disease and other dementia are included in relevant public health outreach programs.

Maryland has the highest estimated prevalence of Alzheimer's disease in the nation among those 65 and older, yet **Maryland lacks comprehensive state-specific data on dementia to inform program and policy decisions**. Without accurate data, we cannot effectively monitor trends, identify disparities, or assess the impact of interventions statewide. **MSCAN supports ensuring access to state-specific dementia data**, including prevalence data and other key data points, via an online website. This initiative directly aligns with Goal 5 of the State Plan to Address Alzheimer's Disease and Related Dementias - enhancing data capabilities to improve outcomes.

Recent FDA-approved treatments have the potential to alter the progression of Alzheimer's disease, offering hope for people impacted by this disease. Early intervention through treatment can provide time to plan for the future, adopt lifestyle changes, participate in clinical trials, and live more fully with a higher quality of life for as long as possible. However, **many Marylanders and their healthcare providers lack awareness of available treatment options.** SB 748 will ensure that existing state-led dementia public health outreach includes information on treatment. **Marylanders deserve to be informed of their treatment options** as soon as possible so that they are not missing out on treatments.

Overall, SB 748 will advance data-driven decisions on dementia policy and programs in Maryland and improve public awareness about treatments – ultimately moving the State one step closer to a future without dementia.

For all these reasons, MSCAN urges a favorable report on SB 748. Thank you for your consideration.

SB 748 - FIN - ADRD Council - LOS.pdf Uploaded by: State of Maryland (MD)

VIRGINIA I. JONES ALZHEIMER'S DISEASE AND RELATED DEMENTIAS COUNCIL

MEMBERS

Halima Amjad, MD, PhD, MPH, Chair Senator Benjamin Brooks Cunthia Fields, MD Ernestine Jones-Jolivet Megan Peters Lynn Phan Pamela Williams, MHA Nancy Rodriguez-Weller, RPh, FASCP Quincy M. Samus, PhD, MS Claudia Thorne, PhD, LCSW, LISW Evie Vander Meer Ravi Gupta, MD Caitlin Houck Mark Tesoro Amanda Mummert

March 4, 2025

The Honorable Pamela Beidle Chair, Finance Committee 3 East Miller Senate Office Building Annapolis, MD 21401-1991

RE: Senate Bill 748 – Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment/ House Bill 1004 – Public Health - Alzheimer's Disease and Related Dementias -Information on Prevalence and Treatment – Letter of Support

Dear Chair Beidle and Committee members:

The Virginia I Jones Alzheimer's Disease and Related Dementias Council (the Council) respectfully submits this letter of support for Senate Bill (SB) 748/ House Bill (HB) 1004 – Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment. This bill would require the Council to work in partnership with the Maryland Department of Health to provide healthcare provider training on available tools and Medicare benefits to facilitate timely cognitive impairment diagnosis and support and treatments approved by the Food and Drug Administration (FDA). It also creates an Alzheimer's Data dashboard to report information on the prevalence, hospitalizations, and demographics related to Alzheimer's Disease and Related Dementias (ADRD), in collaboration with the Maryland Health Data Exchange.

Currently, an estimated 127,200¹ Marylanders are living with ADRD. Maryland is estimated to have the highest prevalence of ADRD in the nation, and Baltimore City and Prince George's County are among the highest prevalence cities/counties nationwide. The exact numbers of individuals and families affected by ADRD in Maryland are not known, nor is the impact of this progressive, disabling condition on our hospitals and health systems. At the same time, health care provider and public knowledge of ADRD, including warning signs, tools to make a diagnosis, and available treatments, is limited. This bill will address these important issues and align with goals and strategies that the Council laid out in our 2022-2026 Maryland State Plan to Address Alzheimer's Disease and Related Dementias.

¹ Dhana, K., Beck, T., Desai, P., Wilson, R. S., Evans, D. A., & Rajan, K. B. (2023). Prevalence of Alzheimer's disease dementia in the 50 US states and 3142 counties: A population estimate using the 2020 bridged-race postcensal from the National Center for Health Statistics. Alzheimer's & dementia : the journal of the Alzheimer's Association, 19(10), 4388–4395. https://doi.org/10.1002/alz.13081

The Council fully supports SB 748/ HB 1004 because it will expand public access to ADRD prevalence and hospitalization data, thereby helping to guide the work being done by doctors, researchers, and public health policy makers in supporting the ADRD community in Maryland. This data will assist in identifying trends and disparities in how ADRD affects different communities in different ways. Additionally, broadening access to ADRD data will help ensure that resources are allocated efficiently to the communities most impacted by the disease. This data will be an essential asset in conversations about funding for research, caregiver assistance, and healthcare services. This bill could be strengthened by incorporating the collection of disaggregated data on the various types of dementia. It will also advance much-needed health care provider education on ADRD.

For these reasons, the Council respectfully requests a favorable report on SB 748/ HB 1004.

Sincerely,

AzAI

Halima Amjad, MD, PhD, MPH, Chair, Virginia I. Jones Alzheimer's Disease and Related Dementias Council

SB 748 Alzheimer's Disease and Related Dementias.F

Uploaded by: Tammy Bresnahan Position: FAV



SB 748 Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment Senate Finance Committee March 4, 2025 FAVORABLE

Good afternoon, Chair Beidle and Members of the Senate Finance Committee. My name is Tammy Bresnahan, and I am the Senior Director of Advocacy for AARP Maryland. On behalf of AARP Maryland and our more than 850,000 members, I am pleased to submit testimony in strong support of SB 748 – Public Health - Alzheimer's Disease and Related Dementias -Information on Prevalence and Treatment. We thank Senator Kramer for introducing this bill.

AARP is committed to advocating for policies that promote the health, independence, and wellbeing of older adults. Alzheimer's disease and related dementias pose a significant public health challenge, affecting not only individuals diagnosed but also their families and caregivers. SB 748 is a critical step forward in ensuring that Marylanders have access to the latest, most accurate information about FDA-approved treatments and public health resources related to Alzheimer's and dementia.

This legislation will require the Maryland Department of Health to collaborate with key stakeholders to incorporate updated treatment information and increase public awareness through its health outreach programs. Access to reliable, evidence-based information is essential to empowering individuals and families to make informed decisions about brain health and dementia care.

AARP believes that brain health is fundamental to healthy aging. The more we understand about cognitive function and dementia prevention, the better we can support individuals in aging well. AARP is a leading voice in brain health education and offers a variety of resources to help people maintain cognitive function as they age, including:

- Staying Sharp AARP's online program that helps people develop brain-healthy habits.
- Brain Health Resource Center A hub for information on brain diseases, including Alzheimer's, stroke, and Parkinson's disease.
- Global Council on Brain Health A collaborative effort of leading experts that provides science-based recommendations on brain health.
- Ongoing Research AARP conducts studies to better understand cognitive health and dementia risk factors, helping to shape policy and improve public awareness.

By passing SB 748, Maryland has an opportunity to enhance public education efforts, expand access to crucial information, and improve the lives of those affected by Alzheimer's and related

dementias. AARP respectfully urges the committee to support this important legislation. For questions or follow up, you can contact me at <u>tbresnashan@aarp.org</u> or by calling 410-302-8451.

MDAC - 2025 - SB748 - FWA.pdf Uploaded by: Liz Zogby



SB748 Public Health – Alzheimer's Disease and Related Dementias – Information on Prevalence and Treatment Senate Finance Committee March 4, 2025 <u>Position</u>: Favorable with Amendments

The Maryland Down Syndrome Advocacy Coalition (MDAC) is a coalition of the five Down syndrome organizations in Maryland as well as individuals with Down syndrome and their family members who have come together to advocate for improved quality of life for all individuals with Down syndrome throughout the state of Maryland.

MDAC strongly supports SB748 which would increase understanding and awareness of available FDA treatments for Alzheimer's disease and related dementias and require the Maryland Department of Health to establish and maintain a website that includes disaggregated data on the prevalence of Alzheimer's disease and related dementias. Our Down syndrome community has a particular interest in this bill due to the unique connection between Alzheimer's disease and Down syndrome and, therefore, proposes an amendment to advance knowledge of this connection and opportunities for future research and policy responses.

As the leading cause of death of adults with Down syndrome, Alzheimer's disease is an urgent medical concern for the Down syndrome community. According to the LuMind IDSC, a national organization that serves as a bridge between the Down syndrome and research communities, "the lifetime risk of developing Alzheimer's disease by age 65 in people with Down syndrome is over 90%." This elevated prevalence exists because chromosome 21 (which is triplicated in individuals with Down syndrome) is the site of the Amyloid Precursor Protein gene that produces amyloid protein. This protein makes up the amyloid beta plaques that are closely associated with the appearance of symptoms of memory loss and other forms of cognitive decline. Because people with Down syndrome have an extra copy of this gene, they have an extra amount of amyloid protein—and develop Alzheimer's disease at such a high rate and at a younger age than the general population. "By age 40, the brains of almost all individuals with Down syndrome have significant levels of amyloid plaques, one of the hallmarks of Alzheimer's disease." It is notable, however, that despite the presence of these brain changes, not everyone with Down syndrome develops Alzheimer's symptoms.¹

For these reasons, it is important to our Down syndrome community that the prevalence and hospitalization rate of Alzheimer's disease and related dementias in Maryland be tracked – and that the data be disaggregated based on the demographics included in the bill. In addition, MDAC

¹ See LuMind IDSC, <u>https://lumindidsc.org/down-syndrome-alzheimers-disease</u>, and Alzheimer's Association, <u>https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/down-syndrome</u>

suggests adding "co-occurrence of Down syndrome (Trisomy-21)" as a data element. This information could lead to additional opportunities for research and to targeted policy or programs to meet the needs of this population.

MDAC appreciates the introduction of this important bill and strongly supports its passage, while suggesting this amendment to highlight the connection between Alzheimer's disease and Down syndrome.

Respectfully submitted,

Liz Zogby Maryland Down Syndrome Advocacy Coalition katzogby@gmail.com 443-691-1755

INF - SB748 MDOA ADRD - Info on Prevalence and Tre

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Wes Moore | Governor

Aruna Miller | Lt. Governor

Carmel Roques | Secretary

Date: February 28, 2025

Bill Number: SB748

Bill Title: Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment

Committee: Senate Finance

The Department of Aging (MDOA) respectfully submits this letter of information on Senate Bill (SB) SB748 - Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment.

The Maryland Department of Aging (MDOA) serves as Maryland's State Unit of Aging, administering federal funding for core programs, overseeing the Area Agency on Aging (AAA) network at the local level that provides services, and planning for Maryland's older adult population. Pursuant to state legislation in 2023, MDOA has established a long-term care and dementia care navigation program with effective strategy to address the needs of individuals with Alzheimer's Disease and Related Dementias (ADRD) and their caregivers in Maryland's rapidly growing older adult population. MDOA conducts this work in partnership with the AAAs and in alignment with Maryland's Virginia I. Jones Alzheimer's Disease and Related Dementias Council and Maryland's State Plan on Aging.

MDOA is acutely aware of Maryland's relatively high rates of Alzheimer's, particularly in Baltimore City and Prince George's County.¹ These rates underscore the need for new concerted, collaborative state action in the future. MDOA is thus supportive of the concept of the enhanced

¹ "Researchers Reveal First Ever County-Level Alzheimer's Prevalence Estimates," Alzheimer's Association Press Release, July 17, 2023, *available at:* https://aaic.alz.org/releases 2023/us-county-level-alzheimers-prevelance-estimates.asp



Wes Moore | Governor

Aruna Miller | Lt. Governor

Carmel Roques | Secretary

ADRD prevalence data collection and public reporting by appropriate state agencies in the future, when significant implementation challenges could be addressed.

If you have any questions, please contact Andrea Nunez, Legislative Director, at <u>andreah.nunez@maryland.gov</u> or (443) 414-8183.

Sincerely,

Comel Roger

Carmel Roques Secretary Maryland Department of Aging

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Position: INFO



Wes Moore, Governor · Aruna Miller, Lt. Governor · Ryan Moran, Dr.PH, Acting Secretary

March 4, 2025

The Honorable Pamela Beidle Chair, Finance Committee 3 East Miller Senate Office Building Annapolis, MD 21401-1991

RE: Senate Bill 748 – Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment – Letter of Information

Dear Chair Beidle and Committee members:

The Maryland Department of Health (the Department) respectfully submits this letter of information for Senate Bill (SB) 748 – Public Health - Alzheimer's Disease and Related Dementias - Information on Prevalence and Treatment. This bill would require the Department to work in partnership with the Virginia I. Jones Alzheimer's Disease and Related Disorders (ADRD) Council (the Council) to provide healthcare provider training regarding treatments approved by the Food and Drug Administration (FDA). Additionally, this bill requires the Department to create and maintain an Alzheimer's Data dasSBoard reporting ADRD-specific prevalence, hospitalization, and demographic data in collaboration with the Maryland Health Data Exchange.

Alzheimer's disease is a progressive neurodegenerative disorder that leads to memory loss, cognitive decline, and behavioral changes. It is the most common form of dementia, affecting millions of people worldwide, and its impact increases as the population ages. Alzheimer's causes irreversible damage to brain cells, impairing daily functioning and ultimately leading to a loss of independence¹. The 2022-2026 Maryland State Plan to Address Alzheimer's Disease and Related Dementias (ADRD State Plan) outlines a comprehensive approach to improving care, services, and support for individuals living with Alzheimer's and related dementias in Maryland.² The ADRD State Plan emphasizes enhancing public awareness; expanding caregiver support, strengthening the healthcare system; enhancing data capabilities related to dementia, dementia impact, and effects of interventions; and advancing research. SB 748 would contribute to the objectives outlined in the ADRD State Plan, particularly Goal 5: Enhance data capabilities related to dementia and dementia impact and effects of interventions.

¹ Centers for Disease Control and Prevention. (2024, August 15). About Alzheimer's. Alzheimer's Disease and Dementia. https://www.cdc.gov/alzheimers-dementia/about/alzheimers.html

² Virginia I. Jones Alzheimer's Disease and Related Disorders Council, & Samus, Q. M. (2022). Maryland State plan to address Alzheimer's disease and related dementias: 2022-2026. In Maryland State Plan to Address Alzheimer's Disease and Related Dementias: 2022-2026. https://health.maryland.gov/phpa/ccdpc/Documents/FINAL_ADRD%20STATE%20PLAN%202022-2026.pdf

The Department recognizes the contribution that data access makes to our ongoing efforts to address ADRD in Maryland. However, the Department notes that the fiscal impact of SB 748 is significant, and the bill does not include a source of funding to support the required work of creating and maintaining the dasSBoard and required outreach. Costs to implement the data dasSBoard and conduct the required outreach will be significant, and cannot be absorbed with existing resources.

If you would like to discuss this further, please do not hesitate to contact Sarah Case-Herron, Director of Governmental Affairs at <u>sarah.case-herron@maryland.gov</u>.

Sincerely,

Augan K. Moran

Ryan B. Moran. Dr.P.H., MHSA Acting Secretary