



**HB1004 Public Health – Alzheimer’s Disease and Related Dementias –
Information on Prevalence and Treatment
House Health and Government Operations Committee
February 28, 2025
Position: 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 HB1004 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, <https://lumindidsc.org/down-syndrome-alzheimers-disease>, and Alzheimer’s Association, <https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/down-syndrome>

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,

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