



NHCSL

THE NATIONAL HISPANIC CAUCUS OF STATE LEGISLATORS

RESOLUTION

No. 2022-02

Coverage of Advanced Diagnostic Tests and Treatments for Alzheimer's Disease

Reported to the Caucus by the NHCSL Healthcare Task Force
Rep. Alma Hernández (AZ), Chair

**Sponsored by Rep. Louis Ruiz (KS), Rep. Lillian Ortiz-Self (WA) and
Rep. Fred Crespo (IL)**

Unanimously ratified by the Caucus on December 1, 2022

I. Prevalence of Alzheimer's Disease

WHEREAS, Alzheimer's disease is a relentless and progressive neurodegenerative disease that causes individuals to lose their memories, their independence, their relationships and, ultimately, their lives;¹ and,

WHEREAS, Alzheimer's disease impacted as many as 5.8 million Americans as of 2020 and is projected to more than double its impact to 14 million people by 2060;² and,

¹ [What is Alzheimer's Disease? | CDC](#)

² *Ibid.*

WHEREAS, Hispanic Americans are about 1.5 times as likely to develop Alzheimer's or other dementias compared to their white counterparts;³ and,

WHEREAS, Alzheimer's disease is the 4th leading cause of death among Hispanic females of all ages; the 6th leading cause of death among Hispanic women ages 65-84; and the 2nd leading cause of death among Hispanic women age 85 and older;⁴ and,

WHEREAS, Alzheimer's disease is the 9th leading cause of death among Hispanic men of all ages; the 9th leading cause of death for Hispanic males age 65-84 and; the 3rd leading cause of death for Hispanic males 85 years and older;⁵ and,

WHEREAS, the projected number of Hispanic Americans living with Alzheimer's disease is expected to increase more than nine fold from 379,000 in 2012 to 1.1 million by 2030 and to 3.5 million by 2060;⁶ and,

WHEREAS, the total direct and indirect costs for Hispanic Americans living with Alzheimer's disease will reach approximately \$105.5 billion by 2060 and will cost the U.S. economy a total of \$2.35 trillion through 2060;⁷ and,

II. Early detection is the key to delaying cognitive decline until there is a cure

WHEREAS, there is no cure for Alzheimer's disease and very few existing FDA-approved treatments that either modify the course of Alzheimer's disease or address the symptoms of Alzheimer's disease;⁸ and,

WHEREAS, the potential to prevent or delay the decline of Alzheimer's disease lies in early detection and treatment; and,

WHEREAS, beta amyloid plaque, a hallmark of Alzheimer's disease, begins to accumulate in the brain 10-20 years before patients begin to experience cognitive symptoms of the disease;⁹ and,

WHEREAS, a "reduction in amyloid plaques is reasonably likely to result in clinical benefit;"¹⁰ and,

WHEREAS, the Food and Drug Administration (FDA) recently accelerated approved anti-amyloid therapy that reduces those amyloid plaques among people living with

³ Alzheimer's Association. *2022 Alzheimer's Disease Facts and Figures*, at 25. Available at <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>

⁴<https://www.cdc.gov/women/lcod/2018/hispanic/index.htm#age-group> (most recent data available).

⁵<https://www.cdc.gov/healthequity/lcod/men/2018/hispanic/index.htm> (most recent data available).

⁶ [Latinos-and-AD_USC_UsA2-Impact-Report.pdf \(usagainstalzheimers.org\)](#)

⁷ [Latinos-and-AD_USC_UsA2-Impact-Report.pdf \(usagainstalzheimers.org\)](#)

⁸ <https://www.alz.org/alzheimers-dementia/treatments>

⁹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3828456/>

¹⁰ Alzheimer's Association. *2022 Alzheimer's Disease Facts and Figures*, at 79. Available at <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>

mild cognitive impairment (MCI) due to Alzheimer's disease and mild Alzheimer's dementia, and there are other similar treatments in the pipeline;¹¹ and,

WHEREAS, despite that, there is often no diagnosis,^{12,13} an incorrect diagnosis,¹⁴ or a very late diagnosis^{15,16} of Alzheimer's disease, thus preventing patients at the early stages from benefiting from those anti-amyloid therapies; and,

WHEREAS, delays in diagnosis at the mild cognitive impairment (MCI) stage are worse for Hispanics and other people of color;¹⁷ and,

WHEREAS, the main current method for diagnosing Alzheimer's disease and MCI associated with it relies largely on documenting mental decline,¹⁸ and the main challenge cited by practitioners in diagnosing MCI is "difficulty in differentiating MCI from normal aging,"¹⁹ which could point to one of the reasons for the disparity in Hispanic early diagnosis being lack of culturally competent care, among other social determinants of health; and,

WHEREAS, the key to the earliest diagnosis will be equitable access to novel Alzheimer's disease diagnostic and screening tools that do not rely on documenting mental decline but instead focus on biomarkers, such as measuring beta-amyloid and tau levels in cerebrospinal fluid and other brain changes detectable by imaging along with blood-based biomarkers;²⁰ and,

WHEREAS, as with the current anti-amyloid therapy, the FDA's accelerated approval pathway, which facilitates the approval of medicines that treat serious and life-threatening diseases and conditions for patients who have no adequate treatment options,²¹ will continue to be critical to bringing new Alzheimer's disease therapies to patients; and,

III. State and CMS policies impact Alzheimer's disease outcomes

WHEREAS, all states, except Ohio, along with the District of Columbia and Puerto Rico currently have the State Alzheimer's Disease Plan recommended by the Alzheimer's Association;²² and,

¹¹ Ibid.

¹² Boustani M et al. *Ann Intern Med.* 2003;138:927-937

¹³ Lang K et al. *BMJ Open.* 2017;7(2):e011146

¹⁴ Rabinovici GD et al. *JAMA.* 2019;321(13):1286-1294

¹⁵ Boise L et al. *Am J Alzheimers Dis Other Demen.* 1999;14:20-26

¹⁶ Balasa M et al. *Neurology.* 2011;76:1720-1725

¹⁷ Alzheimer's Association. *2022 Alzheimer's Disease Facts and Figures*, at 25-26. Available at <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>

¹⁸ https://www.alz.org/alzheimers-dementia/research_progress/earlier-diagnosis

¹⁹ Alzheimer's Association. *2022 Alzheimer's Disease Facts and Figures*, at 84. Available at <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>

²⁰ https://www.alz.org/alzheimers-dementia/research_progress/earlier-diagnosis

²¹ <https://www.fda.gov/drugs/information-health-care-professionals-drugs/accelerated-approval-program>

²² <https://alzimpact.org/media/serve/id/5d23af19258fb>

WHEREAS, to help address the problem of delayed and incorrect diagnosis, the state of Massachusetts “requires physicians to complete a one-time continuing education course on the diagnosis and treatment of patients with cognitive impairments. It also requires hospitals to develop and carry out a plan for recognizing and managing patients with dementia. The law allows doctors to share an Alzheimer’s diagnosis and treatment plan with a family member or legal representative according to existing federal and state privacy laws;”²³ and,

WHEREAS, “Oregon requires all direct care staff employed by a residential care facility to complete training in dementia care before caring for residents”²⁴ and “Illinois established minimum training requirements for employees of organizations that advertise or verbally offer to provide Alzheimer’s and dementia related services;”²⁵ and,

WHEREAS, states and the Centers for Medicare & Medicaid Services (CMS) can ensure that Medicare and Medicaid beneficiaries living with Alzheimer’s disease have access to FDA-approved diagnostic and screening tools and therapies to treat Alzheimer’s disease, including therapies approved under the FDA’s accelerated approval pathway; and,

WHEREAS, despite accelerated approval drugs consistently accounting for less than 1% of annual Medicaid spending, states like “Massachusetts and Tennessee, have sought federal waivers from Medicaid coverage requirements to limit patient access to these medicines,” presuming, incorrectly, “that any savings to be had are worth restricting access for these patients,” when in fact “data support preserving access to accelerated approval drugs for the seriously ill;”²⁶ and,

WHEREAS, CMS first reviewed coverage of one of those screening tools almost a decade ago and concluded that evidence at the time was “insufficient to conclude that the use of positron emission tomography (PET) beta amyloid (also referred to as amyloid-beta (A β)) imaging is reasonable and necessary for the diagnosis;”²⁷ and,

WHEREAS, earlier this year, CMS declined to cover monoclonal antibodies that target amyloid (or plaque) for the treatment of Alzheimer’s disease and their associated biomarker tests, until the treatments receive traditional, not accelerated, approval from the FDA.²⁸

²³ <https://www.ncsl.org/research/health/diagnosis-alzheimer-s.aspx>

²⁴ Ibid.

²⁵ Ibid.

²⁶ Kenneth E. Thorpe, PhD, Douglas Holtz-Eakin, PhD; Limiting Medicaid Access to Accelerated Approval Drugs: Costs and Consequences, *Am J Manag Care*. June 2021;27(6):e178-e180. Available at <https://doi.org/10.37765/ajmc.2021.88596>

²⁷ CMS National Coverage Determination 220.6.20 (Effective 09/27/2013). Available at <https://www.cms.gov/medicare-coverage-database/view/ncd.aspx?ncdid=356&ncdver=1>

²⁸ CMS will cover the treatments and their associated biomarker testing for clinical trials. See *CMS Finalizes Medicare Coverage Policy for Monoclonal Antibodies Directed Against Amyloid for the Treatment of Alzheimer’s*

THEREFORE, BE IT RESOLVED, that The National Hispanic Caucus of State Legislators recognizes the importance of early and accurate diagnosis of Alzheimer's disease in order to identify patients before symptoms of Alzheimer's disease develop; and,

BE IT FURTHER RESOLVED, that The National Hispanic Caucus of State Legislators calls on states to take action on Alzheimer's disease awareness and early and accurate diagnosis, including efforts to educate patients and caregivers about screening and diagnosis options, and requiring physicians to complete culturally competent Continuing Medical Education (CME) on Alzheimer's disease; and,

BE IT FURTHER RESOLVED, that The National Hispanic Caucus of State Legislators calls on states to ensure that they have a state plan to address Alzheimer's disease and that those plans are updated regularly to include the latest scientific understanding of Alzheimer's disease; and,

BE IT FURTHER RESOLVED, that The National Hispanic Caucus of State Legislators calls on states and CMS to ensure that Medicare plans and state Medicaid programs cover Alzheimer's disease diagnostic and screening tests, including PET scans and blood-based biomarker testing; and,

BE IT FURTHER RESOLVED, that The National Hispanic Caucus of State Legislators calls on states to ensure that state Medicaid programs cover FDA-approved medicines that treat Alzheimer's disease, including medicines approved under the FDA's accelerated approval pathway; and,

BE IT FINALLY RESOLVED, that The National Hispanic Caucus of State Legislators calls on the CMS and the federal government as a whole to ensure that coverage policies that hinder a patient, caregiver, or physician's ability to access FDA-approved treatments for Alzheimer's disease be revised, including in the case of accelerated approvals.

THE HEALTHCARE TASK FORCE UNANIMOUSLY RECOMMENDED THIS RESOLUTION TO THE EXECUTIVE COMMITTEE FOR APPROVAL. THE EXECUTIVE COMMITTEE UNANIMOUSLY APPROVED THIS RESOLUTION AT ITS MEETING OF AUGUST 12, 2022.

THE NATIONAL HISPANIC CAUCUS OF STATE LEGISLATORS UNANIMOUSLY RATIFIED THIS RESOLUTION ON DECEMBER 1, 2022 AT ITS ANNUAL MEETING IN LAS VEGAS, NEVADA