

## THE CASE FOR PROMOTING BRAIN HEALTH EQUITY

UsAgainstAlzheimer's (UsA2) is leading efforts in communities and nationally to achieve brain health equity - a commitment to reduce—and, ultimately, eliminate—disparities in cognition, Alzheimer's and other dementias. We are advocating for the highest possible standard of brain health for all people with focused attention on the needs of those at greatest risk of Alzheimer's and other dementias.

By 2030, nearly half of all Americans living with Alzheimer's will be African American or Latino. African Americans are twice as likely as non-Hispanic whites to develop the disease, while Latinos are 1.5 times as likely. And women make up two-thirds of those living with Alzheimer's and 60% of their caregivers.<sup>1</sup>

### The toll of dementia on people of color and women is destabilizing communities:

The total cost of women living with dementia and those serving as their informal caregivers will reach **\$5 trillion through 2040.**

**Alzheimer's death rates among Latinos increased 107% between 1999 and 2017**, the greatest increase of any group according to the Centers for Disease Control (CDC).<sup>2</sup>

African Americans make up 13.4% of the population yet they **bear 33% of the national cost** of Alzheimer's and other dementias.<sup>3</sup>

If unaddressed, Alzheimer's and other dementias will cost the Latino community a total of **\$2.3 trillion by 2060.**<sup>4</sup>

**African Americans and Latinos make up just 5% and 1% of clinical trial participants nationwide** – respectively - despite being at higher risk for diseases like Alzheimer's and other dementias.

There are social determinants and comorbidities at play that put these communities at higher risk for cognitive decline, including barriers to educational attainment, exposure to pollution, and higher rates of heart disease and diabetes.<sup>5</sup> However, emerging science suggests that we can all take proactive, risk-reducing actions to improve brain health and build resistance to cognitive impairment as we age. For example, the NIH funded SPRINT Study found that lowering blood pressure can reduce risk of mild cognitive impairment by 19% and risk of probable dementia by 17%.<sup>6</sup> And recent research from the University of California Davis suggests that vascular disease plays a much stronger role in the Latino population's risk for dementia compared to non-Hispanic whites, and is a contributing factor in African Americans.<sup>7</sup>

If we're going to fully address our shared Alzheimer's challenge, we must promote proactive brain health, early detection, better care, and research engagement for all communities, but particularly communities at highest risk for Alzheimer's and other dementias.

## Our Policy Priorities

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Promote access to brain health care throughout the lifespan as more and more evidence emerges that lack of care and social determinants of health may exacerbate the inequities that already exist in the detection, diagnosis, care and research of Alzheimer's.

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Address the underdiagnoses and misdiagnosis of Alzheimer's and other dementias among women and people of color by encouraging early assessment and the promotion of reliable and culturally sensitive cognitive impairment detection tools.

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Ensure federal funding for Alzheimer's research and public health promotion is at adequate levels by increasing Alzheimer's research funding by \$350 million for FY2020. While funding for NIH research on Alzheimer's has increased significantly in the past 5 years, the total level of funding is still inadequate to bring an end to this epidemic. Importantly, adequate funds should be directed to improve the diversity of Alzheimer's research by supporting improved community engagement and recruitment practices in federally funded research.

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Lower the burden of participation in Alzheimer's clinical trials for women, people of color, and caregivers by addressing barriers to access and retention at agencies like the National Institutes of Health and the Centers for Medicare and Medicaid Services.

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Ease the economic hardship of Alzheimer's on high risk populations by supporting smart economic and care policies that improve quality of care and life for individuals living with dementia and their caregivers.

## Legislation the We Support

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### **The CHANGE Act 2019 [H.R.2283/S.1126]**

To provide better care and outcomes for Americans living with Alzheimer's disease and related dementias and their caregivers while accelerating progress toward prevention strategies, disease modifying treatments, and, ultimately, a cure.

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### **The Clinical Treatment Act [H.R.913]**

To amend title XIX of the Social Security Act to promote access to life-saving therapies for Medicaid enrollees by ensuring coverage of routine patient costs for items and services furnished in connection with participation in qualifying clinical trials, and for other purposes.

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### **Improving HOPE for Alzheimer's Act [S. 880/H.R. 1873]**

To educate clinicians on Alzheimer's and dementia care planning services available through Medicare. This will give clinicians the knowledge and tools to better help their patients and families living with dementia.

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### **Younger-Onset Alzheimer's Disease Act of 2019 [H.R. 1903/S. 901]**

To allow individuals living with dementia under the age of 60 to access supports and services from programs under the Older Americans Act (OAA).

## Legislation We Would Like to See Introduced for the Alzheimer's Community

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Legislation to direct the Comptroller General of the United States to complete a study of barriers to participation in federally funded Alzheimer's trials by populations that have been traditionally underrepresented in such trials. *Inspired by the Henrietta Lacks Enhancing Cancer Research Act of 2019 [H.R.1966 / S.946].*

1 Latinos and Alzheimer's Disease: New Numbers Behind the Crisis. (2016). USC Edward R. Roybal Institute on Aging and the LatinosAgainstAlzheimer's Network.

2 CDC <https://www.cdc.gov/mmwr/volumes/66/wr/mm6620a1.htm>

3 Key Findings and Policy Recommendations: The Cost of Alzheimer's and Other Dementias for African Americans. (2015). Darrell J. Gaskin, PhD, Johns Hopkins Bloomberg School of Public Health and Stephanie Monroe, UsAgainstAlzheimers.

4 Latinos and Alzheimer's Disease: New Numbers Behind the Crisis. (2016). USC Edward R. Roybal Institute on Aging and the LatinosAgainstAlzheimer's Network.

5 A. Eid, I. Mhatre and J.R. Richardson, Gene-environment interactions in Alzheimer's disease: A potential path to precision medicine, *Pharmacology & Therapeutics*, <https://doi.org/10.1016/j.pharmthera.2019.03.005>

6 <https://www.health.harvard.edu/blog/intensive-treatment-of-blood-pressure-helps-prevent-memory-decline-in-older-adults-2019050616554>

7 <https://www.sciencedaily.com/releases/2019/03/190312103647.htm>