## Congress of the United States Washington, DC 20515

October 26, 2021

The Honorable Xavier Becerra Secretary, U.S. Department of Health & Human Services 200 Independence Avenue, S.W. Washington, D.C. 20201

Dear Secretary Becerra:

We write today to urge the Department of Health and Human Services (HHS) to establish an ambitious national goal to prevent Alzheimer's disease and related dementias (ADRD) and to develop a plan to achieve this goal.

The proportion of the U.S. population over 55 years old is increasing at a rate 20 times larger than the growth rate of the collective population younger than 55.<sup>1</sup> Yet, our nation's health care system is not adequately investing in the long-term health and well-being of older adults.

Alzheimer's disease is a growing public health crisis with a projected 14 million people in the U.S. affected by the disease by 2050.<sup>2</sup> In 2021, Alzheimer's and other dementias will cost the nation \$355 billion, including \$239 billion in Medicare and Medicaid payments combined. Unless we prevent, slow, or adequately treat this disease, in 2050, Alzheimer's is projected to cost more than \$1.1 trillion (in 2021 dollars) – a three-fold increase both in government spending under Medicare and Medicaid and in out-of-pocket spending.<sup>3</sup>

Dementia is the only top-10 cause of death in the U.S. with no known cure. It is also one of the most urgent health inequities of our time. Communities of color and women bear a disproportionate burden. Black Americans are two to three times more likely, and Latinos are 1.5 times more likely, to have Alzheimer's disease than non-Hispanic whites. By 2030, nearly 40% of Americans diagnosed with Alzheimer's are projected to be Black or Latino.<sup>4</sup> Two-thirds of people living with Alzheimer's and other dementias are women.<sup>5</sup>

A significant percentage of dementia could be delayed - and in some cases prevented - by early intervention. In fact, studies indicate that more than approximately 40 percent of dementia cases are potentially preventable by addressing risk factors including hypertension, diabetes, depression, physical inactivity, poor nutrition, smoking, hearing loss, traumatic brain injury, sleep, air pollution and social isolation and loneliness.<sup>6-7</sup>

A recent survey of health care providers found agreement that a healthy lifestyle benefits brain health, and that adults in the general population are likely to engage in brain-healthy behaviors if they know it may help maintain their mental functioning. Further, 81% of people over the age of

40 would be motivated to have a healthier lifestyle to potentially slow the progression of the disease if they found out they had dementia at an early stage.<sup>8</sup>

Unfortunately, our current healthcare system falls woefully short in early intervention:

- Only 16 percent of Medicare beneficiaries report having received a cognitive assessment during a routine visit.<sup>9</sup>
- Fewer than half of primary care physicians include screening for memory and thinking in their standard protocol.<sup>10</sup>
- Primary care practitioners do not routinely promote dementia risk reduction.<sup>11</sup>
- Less than half of beneficiaries with a dementia diagnosis in their medical record are even informed of their diagnosis by their doctor.<sup>12</sup>

As legislators, we must commit to developing policies that encourage innovation, fund research, and create an environment that will eventually lead to a cure for these conditions. As we wait for that day, though, there is much more that can be done to mitigate the impact.

The Centers for Medicare and Medicaid Services (CMS) and other HHS agencies have a significant opportunity to encourage providers and payers to proactively address brain health among non-symptomatic, healthy adults and to strengthen early detection and risk-reducing interventions that delay disease progression. These levers include payment reforms, quality incentives, and beneficiary and provider education. Importantly, overcoming barriers to access and improving the quality of cognitive assessments would be an important first step that already can be taken within the existing authorities.

On July 19, the National Alzheimer's Project Act (NAPA) Advisory Council took an important first step. The Council's Risk Reduction Subcommittee formally proposed that a sixth goal – to reduce the burden of risk factors of Alzheimer's disease and related dementias - be added to the National Plan. The Subcommittee recommended commensurate strategies to achieve this goal for risk reduction, including formalizing the Risk Reduction Subcommittee within the Advisory Council, sustaining and strengthening public health infrastructure, and improving access to primary care. An aggressive 15 percent reduction in risk factors for Alzheimer's disease – including depression, diabetes, hearing loss and physical inactivity -could result in as many as 1.2 million fewer people living with ADRD in 2050. We urge you to accept the recommendation to add the risk reduction goal to the 2021 National Plan Update and prioritize its implementation within HHS.

We urge HHS to also ensure that health systems, researchers, and advocates have access to accurate and representative data on Alzheimer's and related dementias and the social determinants of health that shape Alzheimer's risk. Further, HHS should make targeted investments – through the National Institutes of Health (NIH) and the Health Resources and Services Administration (HRSA) – in research and treatment infrastructure in communities with a high burden of Alzheimer's and related dementias, including a strong focus on community health centers which are underequipped to provide dementia related health services.

We are confident that a clear goal and strategic investments in health equity will benefit families, society, our economy, and the nation. Any success in preventing or delaying dementia will increase the likelihood that adults can thrive and remain independent into their later years; decrease the cognitive, physical, psychological, and economic burden of those living with symptoms; improve the quality of life of patients and caregivers; and reduce financial pressure on Medicare and Medicaid. We look forward and stand ready to work with you to support this effort and appreciate your attention to this important matter.

Sincerely,

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Doris Matsui Member of Congress

Darin LaHood Member of Congress

<sup>&</sup>lt;sup>1</sup> Report: Brookings, What the 2020 census will reveal about America: Stagnating growth, an aging population, and youthful diversity, William H. Frey, Monday, January 11, 2021 <u>https://www.brookings.edu/research/what-the-</u>2020-census-will-reveal-about-america-stagnating-growth-an-aging-population-and-youthful-diversity/

<sup>&</sup>lt;sup>2</sup> Matthews, K. A., Xu, W., Gaglioti, A. H., Holt, J. B., Croft, J. B., Mack, D., & McGuire, L. C. (2018). Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015–2060) in adults aged≥ 65 years. *Alzheimer's & Dementia*. <u>https://doi.org/10.1016/j.jalz.2018.06.3063</u>

<sup>&</sup>lt;sup>3</sup> Alzheimer's Association. 2021 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2021;17(3).

<sup>&</sup>lt;sup>4</sup> Matthews KA, Xu W, Gaglioti AH, Holt JB, Croft JB, Mack D, McGuire LC. Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015-2060) in adults aged ≥65 years. Alzheimers Dement. 2019 Jan;15(1):17-24. doi: 10.1016/j.jalz.2018.06.3063. Epub 2018 Sep 19. PMID: 30243772; PMCID: PMC6333531.

<sup>&</sup>lt;sup>5</sup> Mielke M. M. (2018). Sex and Gender Differences in Alzheimer's Disease Dementia. *The Psychiatric times*, *35*(11), 14–17.

<sup>&</sup>lt;sup>6</sup> Livingston et al. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, DOI: <u>https://doi.org/10.1016/S0140-6736(20)30367-6</u>.

<sup>&</sup>lt;sup>7</sup> Risk reduction of cognitive decline and dementia: WHO guidelines. Geneva: World Health Organization; 2019. Licence: CC BY-NC-SA 3.0 IGO.

<sup>&</sup>lt;sup>8</sup> Mehegan, Laura, and Chuck Rainville. 2021 AARP Survey on the Perceptions Related to a Dementia Diagnosis: Adults Age 40+. Washington, DC: AARP Research, June 2021. <u>http://doi.org/10.26419/res.00471.001</u>

<sup>&</sup>lt;sup>9</sup> Alzheimer's Association. 2021 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2021;17(3).

<sup>&</sup>lt;sup>10</sup> Alzheimer's Association. 2021 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2021;17(3).

<sup>&</sup>lt;sup>11</sup> Godbee, K., Gunn, J., Lautenschlager, N. T., Curran, E., & Palmer, V. J. (2019). Implementing dementia risk reduction in primary care: a preliminary conceptual model based on a scoping review of practitioners' views. *Primary health care research & development, 20*, e140. https://doi.org/10.1017/S1463423619000744 <sup>12</sup> Alzheimer's Association. 2021 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2021;17(3).