

December 23, 2020

The Honorable Nancy Pelosi  
Speaker  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Kevin McCarthy  
Republican Leader  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Mitch McConnell  
Majority Leader  
U.S. Senate  
Washington, DC 20510

The Honorable Charles Schumer  
Minority Leader  
U.S. Senate  
Washington, DC 20510

Dear Speaker Pelosi, Leader McConnell, Leader Schumer, and Leader McCarthy:

Our nation is falling short of the steps needed to reach the 2025 national goal of effectively treating and preventing Alzheimer's disease (AD), and the new Congress and incoming Administration can – and must – give this issue the urgent priority that it requires.

A good starting point for this renewed commitment is the set [of critical recommendations](#) to Congress and the Administration made by the Federal Advisory Council on Alzheimer's Research, Care and Services. Unfortunately, many of the Council's important recommendations, summarized below, were not included earlier this month in the Secretary of Health and Human Services' (HHS) official update of the National Plan to Address Alzheimer's Disease.

We believe these recommendations should be addressed as vital parts of the plan to meet the 2025 goal and prioritized by the Administration and Congress for urgent action in 2021.

Alzheimer's disease and related dementias (ARD) are a national emergency that threaten to bankrupt families and state budgets if concerted action is not taken.

The National Alzheimer's Project Act (NAPA), which was signed into law nearly 10 years ago, charged HHS with developing and revising a National Plan to reach our nation's goal of effectively treating and preventing Alzheimer's by 2025 and directed the Secretary to provide a progress report and plan update to Congress annually. Additionally, as required by NAPA, the Federal Advisory Council on Alzheimer's Research, Care and Services provides annual recommendations for updating the plan to the HHS Secretary and to Congress.

On October 22, 2020, the Advisory Council transmitted to Congress and the Secretary its 2020 recommendations to inform the National Plan to Address Alzheimer's Disease. The Advisory Council made a number of very important recommendations to strengthen our nation's ability to respond and adequately address our shared Alzheimer's challenge. However, the official Plan update submitted by the HHS Secretary to Congress on December 11, 2020 did not include these crucial updates.

## Recommendations and Actions that should be Addressed

For the first time, the Advisory Council included in its recommendations crosscutting actions to prioritize risk reduction, health equity and emergency response – all actions necessary for improving our public health response to ADRD. Specifically, the Council recommended:

- 1. Development of a National Goal to reduce the burden of risk factors in order to prevent or delay onset of AD/ADRD.**
- 2. Advancement of health equity by addressing racial and ethnic disparities in AD/ADRD.**
- 3. Improvement and expansion of emergency preparedness, response, and recovery to better address the needs of individuals living with AD/ADRD and their caregivers.**

In addition, the Council made important recommendations for improving clinical care, long term services and supports, and research.

Most of these recommendations are notably absent in the National Update, and as such, we call to your attention to the following guidance from the Council:

### **Development of a National Goal to reduce the burden of risk factors in order to prevent or delay onset of AD/ADRD.**

We urge you to advance this recommendation by directing the Secretary of HHS to make preventing Alzheimer’s and dementia a priority by setting a national goal to reduce the number of people projected to be living with ADRD. This goal should be accompanied by a clear plan to achieve it that includes both clinical and public health actions.

Setting a timebound, national goal to reduce the number of people who develop Alzheimer’s and related dementias is long overdue. In 2013, more than one hundred scientists from 36 countries [called upon](#) governments of highly-industrialized nations to make prevention of dementia a top priority. Nearly a decade later none of nations in the G8 at that time has done this, despite the increasing evidence that protective measures and risk reduction steps can delay onset of dementia and in some cases, prevent it. [More than 170 organizations](#) and experts in the United States have called for establishing a national goal to prevent ADRD, including the American Heart Association, Volunteers of America, the National Urban League, UnidosUS, the Milken Institute, and AARP.

In 2020 alone, three important studies augmented the growing evidence that prevention may be possible. The [Lancet Commission](#) on Intervention, Prevention and Care reported that up to 40 percent of dementia cases could be delayed or prevented by modifying 12 risk factors—less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury, and air pollution. Another [large-scale systematic review](#) of more than 395 studies identified a total of 21 evidence-based suggestions that can be used in life-course practices to prevent Alzheimer’s; and an [NIH supported study](#) concluded that combining more healthy lifestyle behaviors was associated with a 60% lower risk for Alzheimer’s disease.

## **Advancement of health equity by addressing racial and ethnic disparities in AD/ADRD.**

The Advisory Council recommended several actions Congress and the Administration should take to improve health equity in ADRD health services, research, and care supports.

Communities of color and women are at the center of the ADRD public health crisis due to a range of factors, including higher rates of comorbidities such as heart disease and diabetes as well as social determinants such as lagging educational attainment, exposure to air pollution, and income inequality. Combined with advanced age, these factors contribute to Black Americans being twice as likely as non-Hispanic whites to develop the disease, and Latinos being 1.5 times more likely. Women are especially impacted, comprising two-thirds of those living with Alzheimer's and 60 percent of all caregivers. Unless these factors are addressed, by 2030, nearly 40 percent of all Americans living with Alzheimer's will be Black or Latino. Given the shifting demographics of the ADRD patient population, we urge you to advance these recommendations:

- Congress should fund the Administration for Community Living (ACL) to expand dementia grants targeting organizations that directly serve and/or are led by people of color or of diverse ethnic groups.
- Congress should appropriate funds through the Indian Health Services that will be used to enhance care provided to tribal elders, including improvement in early diagnosis, assessment, care, and in efforts to encourage early recognition in tribal communities and support for family caregivers.
- NIH should fund community-based participatory research that involves people of color in the development, recruitment of participants, implementation, and evaluation of studies. Congress should appropriate funding for new approaches, interventions, and services that address the social and medical determinants of chronic conditions in people of color that emerge through community-based research.
- NIH should increase funding for research into how the social determinants of health, including persistent or life-long adverse exposure of people of color to economic, environmental and social adversity, influence prevalence and incidence of dementia in communities of color, and identify strategies that can effectively respond to and prevent similar adverse exposure in future generations.
- It is crucial that our nation increases the number of research investigators from diverse racial and ethnic backgrounds. Congress should appropriate funds for NIA to expand Resource Centers for Minority Aging Research.

### Early Intervention

The Advisory Council advised the Secretary that their work should include clarifying the U.S. Preventive Services Task Force's Final Recommendation Statement on Cognitive Impairment in Older Adults. While more clinical evidence is needed to assess the benefits and harms of screening in asymptomatic adults, there are important reasons to assess and diagnose early symptoms of cognitive impairment.

## Caregivers

More than 16 million Americans provide more than 18.5 billion hours of unpaid care for family and friends with ADRD valued at \$244 billion. The impact of unpaid family care on families is tremendous, particularly on families of color. In fact, Black caregivers and Latino caregivers are more likely to report negative financial impacts as a result of providing care compared to non-Hispanic White caregivers

In order to protect the financial security of caregivers, the Advisory Council recommended that:

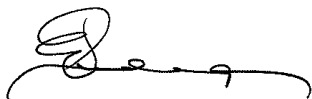
- Congress should expand the Family and Medical Leave Act;
- States should expand support for paid caregiving leave and consider creating voluntary long-term care savings accounts;
- Both Congress and states should expand tax credits for caregivers.

These recommendations deserve immediate action from Congress and Administration to help ease the economic and emotional hardship of ADRD caregiving on families, communities, and the economy. For example, the expansion of paid family and medical leave to cover caregiving for older adults would help millions of family caregivers balance dementia care while staying in the workforce. According to a survey conducted by UsAgainstAlzheimer's on employed dementia caregivers, nearly 60% reported that the utilization of paid leave benefits improved their health and emotional well-being as they provided care while working.

As we approach the ten-year anniversary this January of the National Alzheimer's Project Act being signed into law, it is time for renewed energy and commitment to 5.8 million Americans living with Alzheimer's disease or dementia, more than 16 million caregivers, and their families.

We stand ready to work with you as you accelerate our nation's commitment to ending Alzheimer's disease. Please contact me if you have any comments or questions.

Sincerely,



George Vradenburg  
Chairman and Co-Founder  
UsAgainstAlzheimer's

cc: Members of the Senate Committee on Health, Education, Labor and Pensions  
Members of the Senate Committee on Appropriations  
Members of the Senate Committee on Finance  
Members of the Senate Committee on Aging  
Members of the House Committee on Ways and Means  
Members of the House Committee on Energy and Commerce  
Members of the House Committee on Appropriations