



President Joseph R. Biden  
The White House  
1600 Pennsylvania Ave  
Washington, D.C. 20500

March 7, 2022

Dear President Biden:

On behalf of the Alzheimer's Association and the Alzheimer's Impact Movement (AIM), including our nationwide network of advocates, thank you for your continued leadership on issues important to Americans with Alzheimer's and other dementias, as well as their caregivers. Millions of Americans witnessed you address Congress and our nation during the State of the Union which included an emphasis on the importance of improving safety and quality of care in the nation's nursing homes as well as the importance of the Advanced Research Project Agency - Health (ARPA-H) to drive breakthroughs in Alzheimer's research. The Association applauds the Administration's focus on nursing homes that directly addresses both the needs of individuals living with Alzheimer's and dementia and their communities of support, including caregivers.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. The Alzheimer's Impact Movement (AIM), the advocacy arm of the Alzheimer's Association, is a nonpartisan, nonprofit organization and works in strategic partnership with the Alzheimer's Association to make Alzheimer's a national priority. Today, there are more than six million Americans living with Alzheimer's. As the size and proportion of the United States population age 65 and older continue to increase, the number of Americans with Alzheimer's and other dementias will grow: 12.7 million people 65 and older may have the disease by 2050. Caring for individuals with Alzheimer's cost an estimated \$355 billion in 2021 with Medicare and Medicaid bearing \$239 billion--67 percent--of that figure.

### **Nursing Homes**

Overall, 48 percent of nursing home residents have Alzheimer's or other dementias. Ten percent of Medicare beneficiaries with Alzheimer's or other dementias reside in a nursing home, compared with one percent of Medicare beneficiaries without the condition. One group of researchers has estimated that approximately 75 percent of surviving Alzheimer's disease patients diagnosed at age 70 will reside in a nursing home by age 80, compared with only four percent of the general population surviving to age 80. Due to our constituents' reliance on these settings, we applaud the changes to come.

As advocates for these individuals, we have long experience in trying to improve care delivery in nursing facilities. One example of this is the 2018 [Alzheimer's Association Dementia Care Practice Recommendations](#), which outline quality care practices based on a comprehensive review of current evidence, best practice, and expert opinion. They were developed to better define quality care across all care settings and throughout the disease course. They are intended for professional care providers who work with individuals living with dementia and their families in long-term and community-based care settings. We hope you find them useful.

### **Advanced Research Projects Agency for Health**

The Alzheimer's Association and AIM support efforts to establish the Advanced Research Projects Agency for Health (ARPA-H). We are glad to see Alzheimer's listed as one of the disease areas of focus. However, we urge your Administration to ensure ARPA-H does not duplicate or supplant current Alzheimer's research

efforts at NIH. There are still many important unfunded targets that NIH can and should fund, as outlined in the [NIH Professional Judgment Budget for Alzheimer's Disease and Related Dementias for Fiscal Year 2023](#). One example of this great work is the Accelerating Medicines Partnership Alzheimer's Disease (AMP AD). The AMP AD program is a precompetitive partnership among government, industry, and nonprofit organizations that focuses on discovering novel, clinically relevant therapeutic targets and on developing biomarkers to help validate existing therapeutic targets. AMP AD 2.0 launched in February 2021, with the goal of enabling a precision medicine approach to the discovery of novel targets and biomarkers.

ARPA-H can fill an important role in supplementing the current work at NIH by driving transformational innovation in research and speeding the application and implementation of cutting edge breakthroughs. Examples of Alzheimer's-related projects ARPA-H could undertake are accelerating the discovery of brain imaging, eye imaging and blood or fluid biomarkers capable of measuring synaptic loss, neuronal death, and glial inflammatory pathways, as a means of tracking responses to potential Alzheimer's disease therapies. There are also opportunities to explore the use of digital technologies for diagnosis, assessment and disease monitoring, such as novel ways to measure and evaluate cognition and function of an individual, develop tools focused on voice recognition and other passive ways to measure changes that may be reflective of brain diseases, such as Alzheimer's. In addition, opportunities that will enable the complex modeling of contributions to risk are additional areas ripe for investment; such opportunities may help develop risk assessments based on the individual - including genetic, biologic, and clinical measures. We also urge ARPA-H to focus on activities that include providing a validated algorithm for disease risk using all available data, like biomarker, digital and emerging technology, to support a translatable resource for clinicians and drug discovery experts.

We caution that ARPA-H should not operate in silos or in isolation. Transparency surrounding the activities at ARPA-H will be key, as will data sharing and the open resources development of data and information.

The Alzheimer's Association and AIM deeply appreciate your continued leadership on behalf of all Americans living with Alzheimer's and other dementias. We look forward to continuing to work with you and your Administration to improve care and support for individuals and families affected by Alzheimer's disease and other dementias. If you have any questions about this or any other legislation, please contact Rachel Conant, Vice President, Federal Affairs, at [rconant@alz-aim.org](mailto:rconant@alz-aim.org) or at 202.638.7121.

Sincerely,



Robert Egge  
Chief Public Policy Officer  
Executive Vice President, Government Affairs  
Alzheimer's Association