Alzheimer’s Association and Alzheimer’s Impact Movement Statement for the Record

United States House Committee on Energy and Commerce, Health Subcommittee
Hearing on “ARPA-H: The Next Frontier of Biomedical Research”

February 8, 2022

The Alzheimer’s Association and Alzheimer’s Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the House Committee on Energy and Commerce, Health Subcommittee hearing on “ARPA-H: The Next Frontier of Biomedical Research.” The Association and AIM thank the Subcommittee for its continued leadership on issues important to the millions of people living with Alzheimer’s and other dementia and their caregivers. This statement provides an overview of how ARPA-H can play an important role in revolutionizing how we prevent, treat, and cure diseases like Alzheimer’s, which affects millions of families across the country.

The Alzheimer’s Association is the world’s leading voluntary health organization in Alzheimer’s care, support, and research. It is the nonprofit with the highest impact in Alzheimer’s research worldwide and is committed to accelerating research toward methods of treatment, prevention, and, ultimately, a cure. AIM is the advocacy affiliate of the Alzheimer’s Association, working in strategic partnership to make Alzheimer’s a national priority. Together, the Alzheimer’s Association and AIM advocate for policies to fight Alzheimer’s disease, including increased investment in research, improved care and support, and development of approaches to reduce the risk of developing dementia.

Alzheimer’s Impact on American Families and the Economy

Alzheimer’s is a progressive and fatal brain disorder that damages and eventually destroys brain cells, leading to a loss of memory, thinking, and other brain functions. There are no survivors.

Alzheimer’s is emotionally, physically and financially draining for individuals and families. In addition, Alzheimer’s is creating an enormous strain on the health care system, and federal and state budgets. The annual cost for caring for individuals living with Alzheimer’s or other dementia will total $355 billion including health care, long-term care, and hospice care in 2021. The U.S. taxpayer-funded federal health care programs Medicare and Medicaid are expected to cover $239 billion, or 67 percent, of these costs this year. In addition, American families provide an estimated $250 billion in unpaid care. While an estimated 6.2 million Americans age 65 and older are currently living with Alzheimer’s, nearly 13 million Americans will have Alzheimer’s by 2050 and costs will exceed $1.1 trillion (in 2021 dollars). Alzheimer’s and other dementia threaten to bankrupt families, businesses, and our health care system.
Advanced Research Projects Agency for Health

The Alzheimer’s Association and AIM support Congressional 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 Congress 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.

Conclusion

The Alzheimer’s Association and AIM appreciate the steadfast support of the Subcommittee and its continued commitment to advancing legislation important to the millions of families affected by Alzheimer’s and other dementia. We look forward to working with the Subcommittee on legislative efforts to establish ARPA-H, which could make pivotal investments in breakthrough technologies that benefit people living with Alzheimer’s and other dementia.