

**Submitted Public Comment of George Vradenburg
Chairman and Co-Founder, UsAgainstAlzheimer's**

**To the Senate Finance Subcommittee on Health Care
Hearing on "Alzheimer's Awareness: Barriers to Diagnosis, Treatment and
Care Coordination"
November 20, 2019**

Chairman Toomey, Ranking Member Stabenow, and other Members of the Subcommittee,

Thank you for holding this hearing today on "Alzheimer's Awareness: Barriers to Diagnosis, Treatment and Care Coordination." This topic is immensely important to the work of UsAgainstAlzheimer's, a disruptive non-profit organization that is laser-focused on accelerating our nation towards a cure for Alzheimer's and dementia.

Alzheimer's disease and dementia constitute the top public health crisis of our time, according to four former U.S. surgeons general who made this point in an editorial last month. Currently, about 5.8 million Americans are living with this disease – 5.6 million of whom are over the age of 65 – at a 2019 cost to our healthcare system of \$290 billion. It is the only top-10 cause of death in America without an effective treatment or cure.

Age remains the No. 1 risk factor for this disease, and neither the disease pathology nor the demographics are in our favor. The rate of incidence for Alzheimer's doubles every five years after age 65, and we know that between 2010 and 2030, the number of Americans age 65 and older is expected to grow 81 percent. By comparison, the growth rate is 16 percent for the next fastest-growing demographic, 35-44, over the same time period.

This disease disproportionately affects women and people of color. Two-thirds of Americans living with Alzheimer's are women, and 60 percent of those caring for someone with the disease are women. Further, research from UsAgainstAlzheimer's, Johns Hopkins, and the USC Edward R. Roybal Institute on Aging projects that by 2030, nearly 40 percent of Americans living with Alzheimer's will be Latino or African American. This is an urgent health equity issue.

These trends are only going to continue, and our nation is fast approaching a tipping point from which it will have immense difficulty recovering.

This disease is expensive, disproportionately hurts women and minorities, and is growing as our population ages. Those are all at the population level. As patient advocates, we know that it is devastating for each individual person living with the disease and for their families.

One of the reasons dementia is so devastating is that it is often diagnosed when it is too late. Studies tell us that doctors miss the diagnosis about half of the time until patients have serious symptoms. We would not accept a system that only diagnoses cancer at Stage 4, but that is more or less where we are with Alzheimer's and related dementias.

Further, we know that communities of color face acute challenges with accessing an accurate and timely diagnosis. African Americans are three times more likely to develop Alzheimer's than non-Hispanic whites and Latinos are one and a half times more likely to develop Alzheimer's than non-Hispanic whites. Despite this higher risk, African Americans and Latinos living with dementia are, on average, less likely than non-Hispanic whites to have actually been given a diagnosis by a provider.

Senators Shelley Moore Capito and Debbie Stabenow, along with Senators Bob Menendez and Roger Wicker, have introduced S. 1126, also known as the CHANGE Act, which would drive early detection and diagnosis for a vulnerable population. The bill now has 17 cosponsors. It is a groundbreaking bill that fights Alzheimer's disease on multiple fronts, and I urge every Member of the Subcommittee to support it.

The CHANGE Act would incentivize and equip providers with tools they need to accurately detect and diagnose Alzheimer's at its earliest stages - the stages where something can be done. It requires testing for cognitive impairment or progression of cognitive impairment in both the "Welcome to Medicare" initial exam and annual Medicare wellness visits using assessments identified by the National Institutes of Health. If cognitive impairment or progression of cognitive impairment is detected, patients would be referred for additional diagnostic services to specialists trained in diagnosis or treatment of Alzheimer's disease and related dementias, community-based support services and appropriate clinical trials. We now know that there is much we can do for people who are in the early stages of dementia, and it is time for Medicare to make that possible for more people.

We urge the Senate Finance Committee to pass the CHANGE Act and, as part of this effort, obtain a Congressional Budget Office score and the necessary technical assistance from CMS to enact the measure.

Our focus is – and should be – on those living with the disease. But because of the way this disease works, it also creates turmoil for families and other caregivers.

Thanks to modern medicine and technology, people are living longer than ever before. Our nation benefits from these advancements, but it must also respond to what they mean for a rapidly aging – and even more rapidly growing – segment of the population.

For example, in 2017, 16.1 million family – that is, unpaid – caregivers in our country provided an estimated 18.4 billion hours of care. That is an extraordinary economic cost – but I want to make another point very clearly.

Alzheimer's is not like other diseases. It is not like cancer. It is not like heart disease. It is not like diabetes. While millions of Americans and their families grapple with these conditions, they are supported with treatments and even cures that ultimately allow many people to be able to live "normal" lives. They are living with or surviving their disease, even years after initial diagnosis.

That is simply not the case with Alzheimer's – there is no remission from this disease once it reaches a certain stage. The longer the disease has to take hold, the more insidious its symptoms

become. The emotional and economic toll this levies on families and caregivers is, in actuality, unquantifiable. This is a good enough reason, in my mind, to support the CHANGE Act, comprehensive paid family leave and other legislation that promotes innovative approaches to supporting family care partners.

This disease affects patients, their families, and caregivers, and there is an immense fiscal cost to our nation as well. Much of the \$290 billion in 2019 economic costs that I referenced earlier is in Medicare and Medicaid payments. Medicaid payments are on average 23 times higher for those with Alzheimer's compared to those without, and Medicare payments are three times greater on average. By 2050, estimates show that direct costs alone will increase to \$1.1 trillion over a projected 14 million people living with the disease – unless there is a treatment or cure for Alzheimer's.

This brings me to the U.S. Preventive Services Task Force, which has issued draft guidance that the latest scientific evidence is “insufficient” to justify screening for mild cognitive impairment in older Americans. Frankly, this couldn't be further from the truth. UsAgainstAlzheimer's fiercely rebutted that draft guidance with our own public comments. I mention it here to you today as yet another example of an underappreciation of the magnitude of the crisis we are facing in Alzheimer's and dementia and the progress we have made to understanding what can be done if it is caught early enough. The task force should understand the importance of cognitive screening for a highly vulnerable segment of the population – especially when there is a growing body of mainstream scientific evidence which states that we can, potentially, do something to slow or even stop the progression of cognitive decline. The American Academy of Neurology joined with us and more than 150 dementia-patient-serving organizations in calling for early detection and screening.

The Committee has gathered today to talk about Alzheimer's awareness and barriers to diagnosis, treatment and care coordination. This is an important and timely hearing as November is Alzheimer's Awareness Month, and at a time when Alzheimer's is the top public health crisis of our time.

UsAgainstAlzheimer's and others throughout our movement are seeking a national and global response to Alzheimer's equal to the attention and urgency given to AIDS, cancer and climate change. I hope it leads to the day when we finally eliminate the risk of Alzheimer's and dementia. For patients, for caregivers, for families and for our nation, the stakes are too high to accept anything less than complete victory over this disease.

Thank you.