Testimony of Maria Shriver Hearing on The Arc of Alzheimer's: From Preventing Cognitive Decline in Americans to Assuring Quality Care for those Living with the Disease

Special Committee on Aging United States Senate

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Thank you Chairman Collins, Ranking Member Casey and members of the Committee for the opportunity to testify today on the importance of doing everything we can to prevent Alzheimer's and other dementias while also ensuring the best quality care for those living with the disease.

As some of you know, Alzheimer's is a deeply personal issue for me. As some of you know, I've been here before — eight years ago to be exact.

In March of 2009, I sat here and testified about how Alzheimer's had taken up residence in what had been my father's beautiful brain.

My Dad, Sargent Shriver, was an idealistic, intelligent, optimistic, and dedicated public servant. His mind was sharp — a beautifully-tuned instrument that left people in awe and inspired. He was an expert at sharing his passions with the general public, thought leaders, *and* lawmakers. He often came here to the Hill to advocate for increased funding for his beloved Peace Corps and all the War On Poverty programs he created, including Head Start, Vista, Job Corps, and Legal Services for the Poor.

He loved working this building, and he was *really* good at it. He knew every Senator and Congressman by name. If he were here today, he'd know everything about each one of you: about your careers, your interests, your politics, your families — and, yes, your soft spots.

So imagine how painful it was to watch when this walking encyclopedia of a man went from knowing every fact about *every*thing that had ever happened . . . to *not* knowing what a spoon or a fork was, or even what *my* name was, let alone his own.

Two years after I testified, my father died of Alzheimer's disease — and now . . . I'm back. Back again to testify — back *again* to focus *your* brains on this killer ravaging brains *and* families across this country. We need to continue to raise the profile of Alzheimer's in order to make progress in ending this disease.

We know the facts -- Alzheimer's is the most expensive disease in America. It is the sixth leading cause of death in the U.S. and the only one of the top ten without a means to prevent, cure or slow its progression. According to the Alzheimer's Association, an estimated 5.5 million Americans are currently living with Alzheimer's or another dementia and that number could rise to as many as 16 million Americans by 2050. Let me be clear: that means by mid-century, the number of people living with Alzheimer's in this country could nearly triple.

Every 66 seconds, another brain will develop Alzheimer's disease. And according to the Alzheimer's Association, two-thirds of those brains will belong to women. A woman in her early 60s is twice as likely to get Alzheimer's as she is to get breast cancer in her lifetime — and the statistics are even more alarming for women of color. African-American women are twice as likely to get Alzheimer's as Caucasian women, and Latinas 1.5 times more likely. That's why I founded the Women's Alzheimer's Movement — I believe that determining why women are more affected by Alzheimer's will help us unlock some of the mysteries of this disease. Instead of focusing only on the formation of plaques and tangles in the brain, let's also start focusing on women's brains and on their bodies — on chromosomes and hormones and inflammation.

We know what we need to do to fight this national crisis — we must continue to prioritize investments in scientific research to find a disease modifying treatment and one day, a cure. We must focus on ways to prevent and delay the onset of this fatal disease by living healthier lives. We must support caregivers of those living with Alzheimer's and provide them with the resources they need to provide care for their loved ones. And we must ensure there is a well-trained workforce ready to provide quality care to the increasing number of people living with Alzheimer's and other dementias who will need these services.

The stakes are high, and that is exactly why I want to continue to add my voice to the fight. I last testified on the importance of Alzheimer's before this Committee in 2009. I spoke about the importance of making Alzheimer's a national issue. As I stated then, if we do not prioritize Alzheimer's, Alzheimer's will not only devour our memories, but it will cripple our families, devastate our healthcare system and decimate the legacy of our generation. Well, you and other members of Congress from both sides of the aisle listened. Since 2009, we have seen great progress in the fight to end Alzheimer's - but our work is not done.

At the end of the 111th Congress, both the House and Senate unanimously passed bipartisan legislation, which requires the creation of an annually-updated strategic plan to address Alzheimer's. First released in May 2012 by the Secretary of Health and Human Services (HHS), the *National Plan to Address Alzheimer's Disease* (the National Plan) is structured to help those with the disease and their families today and to change the trajectory of the disease for the future. The National Plan outlines priority actions to reduce the financial impact of Alzheimer's; improve health outcomes for all Americans living with Alzheimer's; and improve prevention,

diagnosis, treatment, and care, of individuals living with Alzheimer's and their caregivers. The National Plan's primary research goal is to effectively treat and prevent Alzheimer's by 2025. Unless there are resources to implement the plan and the will to abide by it, however, we cannot hope to make adequate progress.

Recognizing this challenge, Congress passed another bipartisan bill requiring the NIH to develop a professional judgment budget focused on achieving the milestones established by the National Plan, providing Congress with an account of the resources that NIH believes are needed to reach that primary research goal of treating and preventing Alzheimer's by 2025.

Having a National Plan and a clear path for the researchers working on promising breakthroughs to tell Congress what they need to make progress on Alzheimer's has led to great progress in increasing the federal commitment to Alzheimer's research. When I last testified before this Committee, Alzheimer's research was funded at less than \$450 million per year at the NIH. Today, Alzheimer's research receives \$991 million annually and is poised to grow even further. Congress has more than doubled its commitment to fight this disease, laying the foundation for more meaningful progress.

I want to thank Chairman Collins for introducing a bipartisan resolution declaring that achieving the primary goal of the National Plan to prevent and effectively treat Alzheimer's disease by 2025 is an urgent national priority. I strongly agree with that statement and with the resolution's call for robust investments in Alzheimer's research funding. I know millions of families around the country feel the same way.

In order to achieve this urgent national priority, we need to ensure the scientists have the funding they requested in the professional judgment budget -- we cannot afford to stall research and delay this important lifesaving work. 1,300 Alzheimer's Association advocates are in Washington today to urge their members of Congress to support a \$414 million increase for Alzheimer's research funding for Fiscal Year 2018. This request echoes your call for increasing research funding and directly matches the professional judgment budget released by the scientists at NIH. I urge Congress to listen to these experts and fully fund that request -- because doing so will empower the brilliant scientists like the ones I've met in laboratories around the country to discover the treatments to slow the progression of Alzheimer's and even prevent it from happening in the first place.

Funding research is critical to ending the Alzheimer's crisis, but we also need to ensure that the more than 5 million Americans living with Alzheimer's today have access to high-quality care and that their nearly 16 million unpaid caregivers have the support they need. That means we need to have an adequate, well-trained workforce and programs like respite, home health, and palliative and hospice care, to address the wide range of needs that come with the disease.

Finally, I have dedicated so much of my work to educating women about Alzheimer's because women are disproportionately impacted by this disease. The Women's Alzheimer's Movement believes that by answering the question of why women are more affected by Alzheimer's, we will unlock the other mysteries surrounding this mind-blowing disease and that will lead to a cure for all.

There is also growing body of evidence that a healthy lifestyle can delay, slow, or even prevent Alzheimer's and other dementias. We need to educate people on the connection between brain health and a healthy diet, physical activity, stress reduction, and how to expand brain power with life-long learning and social connection. The Women's Alzheimer's Movement is working to help women understand this connection. By promoting the positive effects of a variety of healthy lifestyle choices can have on brain health and overall well-being, we are empowering a new generation to combat this disease.

Nearly everyone knows someone or has been personally impacted by Alzheimer's. That is why I choose to speak up about this -- for my father and for the millions of Americans currently struggling through this disease. I call on you to continue to make Alzheimer's the national priority it needs to be. Together, I am confident that we can make progress to one day end Alzheimer's.