

Testimony of David Hyde Pierce
Finding a Cure: Assessing Progress Toward the Goal of Ending Alzheimer's by 2025

Special Committee on Aging
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Madam Chair, Ranking Member McCaskill and members of the Committee, thank you for the opportunity to testify before the Senate Special Committee on Aging. I would also like to thank the Committee for continuing to focus on Alzheimer's, an escalating national epidemic.

My name is David Hyde Pierce, and like 15 million Americans today, I have a connections to Alzheimer's disease and dementia. I lost my grandfather to Alzheimer's disease in 1992, and my dad died in 1998 with vascular dementia and probable Alzheimer's.

As a family member, I witnessed my grandfather's decline, and saw how the strain of caregiving drastically affected my grandmother's health. Along with my brother and sisters, I was a part-time caregiver for my father after our mom passed away, her own health no doubt compromised by the burden of coping with dad's dementia.

These experiences are all too familiar for many of us in this room and across the country. As you know, there are more than 5 million Americans living with Alzheimer's disease, which is the sixth leading cause of death and the only cause of death in the top 10 without a way to prevent, cure or even slow its progression. Alzheimer's disease is the most costly disease in the United States and is set to increase like no other.

In 2016, the cost of caring for those with Alzheimer's disease will reach \$236 billion, and is expected to grow to \$1.1 trillion by 2050. Without significant breakthroughs in the development of treatments or a cure, it is projected that as many as 16 million Americans will have Alzheimer's by 2050.

When I first testified before the Labor, HHS, Education and Related Agencies Committee on Appropriations in 1998, we were seeking increased funding for Alzheimer's research. And for many years we were spending so much to care for those living with dementia, while investing so little in research.

Since then we have seen the unanimous passage of the *National Alzheimer's Project Act*, the establishment of the first National Plan to Address Alzheimer's, and just last year, an historic increase in research funding for Alzheimer's that has effectively doubled the research investment of just six years ago. These are advances that could not have been done without your leadership here in Congress. Thank you for your steadfast support and for listening to the voices of advocates across the country.

I have had the honor and privilege to serve on the Advisory Council on Alzheimer's Research, Care and Services, which was formed through the *National Alzheimer's Project Act*, as a caregiver representative. In that capacity, I have worked with the federal and nonfederal members to craft a plan to address the needs of those living with Alzheimer's, their caregivers, the research community and other stakeholders.

We have seen considerable progress not only in the focus of the Council, but also in incorporating the priorities of the constituents we serve. Through the *National Plan to Address Alzheimer's Disease* we have developed research milestones that will guide the development of new diagnostics, treatments and interventions. We have learned more about other related dementias and conditions like Down Syndrome, which have a link to Alzheimer's, and examined the state of clinical care and long-term supports and services.

Despite all of this, there remains a considerable amount of work to achieve the goals of the National Plan. We have a roadmap to guide the research community as they work to develop the means to effectively treat and prevent Alzheimer's by 2025, the first goal of the National Plan. However, similar progress has eluded us in the goals to enhance care quality and efficiency and expanding supports for people with Alzheimer's disease and their families.

The investment in research is vital to ultimately achieving an effective treatment for Alzheimer's, but the reality is that we need an equally strong investment in caring for those living with the disease today. We need to prioritize actions within the National Plan that will have the greatest impact on improving the lives of those living with Alzheimer's and their families. The National Plan must find a way to develop action steps with quantifiable metrics that will show progress in meeting those goals.

Thank you for the opportunity to testify today before the committee. This is an issue that affects millions of Americans, as evidenced by the advocates in attendance today. We have taken great steps in providing resources for them and their loved ones, but we must resolve to continue making progress to meet the goals we have set for ourselves. Thank you for being part of this very important work.