



Testimony of the Alzheimer's Association
Hearing on The National Plan to Address Alzheimer's Disease:
Are We On Track to 2025?

Special Committee on Aging
United States Senate

May 1, 2013

Mr. Chairman, Ranking Member Collins and members of the Committee, the Alzheimer's Association appreciates the opportunity to submit a statement for the record on the state of the National Alzheimer's Plan. Additionally, the Association would like to thank the Committee for focusing on Alzheimer's, an escalating national epidemic, by holding the first hearing on the progress of implementing the first-ever *National Plan to Address Alzheimer's Disease*. The first year of the *National Plan to Address Alzheimer's Disease (The Plan)* has included significant steps toward changing the trajectory of Alzheimer's disease, but there is still much work to be done. To implement the Plan, it is critical that Congress support the President's FY 2014 budget request for the activities in the Plan, including \$100 million for Alzheimer's research, education, outreach, and caregiver support activities.

State of the Disease

Alzheimer's is a progressive brain disorder that damages and eventually destroys brain cells, leading to a loss of memory, thinking and other brain functions. Ultimately, Alzheimer's is fatal. Currently, Alzheimer's is the sixth leading cause of death in the United States and the only one of the top ten without a means to prevent, cure or slow its progression. Over five million Americans are living with Alzheimer's, with 200,000 under the age of 65. While deaths from other major diseases, including heart disease, stroke and HIV continue to experience significant declines, those from Alzheimer's have increased 68 percent between 2000 and 2010.

In 2013, America is estimated to spend \$203 billion in direct costs for those with Alzheimer's, including \$142 billion in costs to Medicare and Medicaid. Average per person Medicare costs for those with Alzheimer's and other dementias are three times higher than those without these conditions. Average per senior Medicaid spending is 19 times higher. A primary reason for these costs is that Alzheimer's makes treating other diseases more expensive, as most individuals with Alzheimer's have one or more co-morbidity that complicate the management of the condition(s) and increases costs. For example, a senior with diabetes and Alzheimer's costs Medicare 81 percent more than a senior who only has diabetes.

If nothing is done, as many as 16 million Americans will have Alzheimer's disease by 2050 and costs will exceed \$1.2 trillion dollars (not adjusted for inflation), creating an enormous strain on the healthcare system, families and the federal budget. In fact, an NIH-funded study in the *New England Journal of Medicine* confirmed that Alzheimer's is the most costly disease in America, with costs set to skyrocket at unprecedented rates. The expense involved in caring for those with Alzheimer's is not just a long-term problem. As the current generation of baby boomers age, near-term costs for caring for those with Alzheimer's will balloon, as Medicare and Medicaid will cover more than two-thirds of the costs for their care. Smart investments in scientific research have proven to pay big dividends, as demonstrated by recent reductions in mortality rates for conditions such as cancer, HIV/AIDS, cardiovascular disease and diabetes. In sum, Alzheimer's disease is the costliest disease in America, and is set to increase like no other -- but we can change this with the proven policies that have led to progress against other major diseases.

With Alzheimer's, it is not just those with the disease who suffer -- it is also their caregivers and families. In 2012, 15.4 million family members and friends provided unpaid care valued at over \$216 billion. Caring for a person with Alzheimer's takes longer, lasts longer, is more personal and intrusive, and takes a heavy toll on the health of the caregivers themselves. More than 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high, with one-third reporting symptoms of depression. Caregiving also has a negative impact on health, employment, income and finances for countless American families. Due to the physical and emotional toll of caregiving on their own health, Alzheimer's and dementia caregivers had \$9.1 billion in additional health costs in 2011.

Changing the Trajectory

Until recently, there was no federal government strategy to address this looming crisis. Advocates for the Alzheimer's community fought for years to ensure a robust and coordinated federal strategic plan to tackle the problems associated with Alzheimer's and other dementias. In 2010, thanks to bipartisan support in Congress and the tireless work of our dedicated advocates, the National Alzheimer's Project Act (NAPA) (P.L. 111-375) passed unanimously. NAPA mandated the creation of a strategic national plan to address Alzheimer's disease.

The Plan is required to include an evaluation of all federally-funded efforts in Alzheimer's research, care and services -- along with their outcomes. In addition, the Plan must outline priority actions to reduce the financial impact of Alzheimer's on federal programs and on families; improve health outcomes for all Americans living with Alzheimer's; and improve the prevention, diagnosis, treatment, care, institutional-, home-, and community-based Alzheimer's programs for individuals with Alzheimer's and their caregivers. NAPA will allow Congress to assess whether the nation is meeting the challenges of this disease for families, communities and the economy. Through its annual review process, NAPA will, for the first time, enable Congress and the American people to answer this simple question: *Did we make satisfactory progress this past year in the fight against Alzheimer's?*

On May 15, 2012, the U.S. Department of Health and Human Services (HHS) released the first-ever *National Plan to Address Alzheimer's Disease*. The Plan established goals and action steps in the areas of research, care, support and public awareness in order to prevent and effectively treat Alzheimer's disease by 2025. We are pleased that the Plan includes such a specific and important goal that, when successfully achieved, will deliver critically needed progress in the fight against Alzheimer's disease.

Prior to the release of the Plan, the Alzheimer's Association convened public input sessions across the country to allow affected individuals to share their insights, concerns and hardships in facing Alzheimer's disease. The result of those sessions was a report, *Alzheimer's from the Frontlines: Challenges a National Alzheimer's Plan Must Address*, which included input from more than 43,000 individuals from across the country. We were pleased to see many of these concerns addressed in the first iteration of the Plan.

Over the past year, the Plan has made progress in the fight against Alzheimer's including:

- Creating a blueprint for Alzheimer's research at the National Institutes of Health (NIH), a much needed first step in setting priorities for Alzheimer's research.
- Expediting Food and Drug Administration (FDA) approval of drugs for early-stage Alzheimer's.
- Developing quality measures for dementia care in nursing homes.
- Enhancing dementia training for healthcare professionals.
- Promoting resources for caregivers through the creation of www.alzheimers.gov.

Yet, despite this progress, there are still things that have yet to be accomplished. Immediately following the release of the Plan, we applauded actions taken by the President and NIH to shift an additional \$50 million in existing funds toward new Alzheimer's research. We were also grateful for the inclusion of an additional \$100 million in funding for Alzheimer's research as well as education, outreach and support in the FY 2013 budget request. However, because of challenges experienced during last year's appropriations process, Congress was unable to provide this additional funding that is so desperately needed. For two years, the Advisory Council on Alzheimer's Research, Care and Support has recommended a rapid ramp-up in Alzheimer's research to at least \$2 billion a year. In Fiscal Year 2013, NIH is expected to spend only \$484 million on this research. This means that for every \$29,000 Medicare and Medicaid spends caring for individuals with Alzheimer's, the NIH spends only \$100 on research to find treatments for Alzheimer's.

Quality care is dependent on an individual being diagnosed and receiving care planning. The Plan has not done enough to ensure that Medicare is addressing these needs, nor has it led to the creation of a more comprehensive and effective strategy to train healthcare professionals to provide this service. Additionally, the Plan has not begun to address the home- and community-care needs of individuals with the disease and their caregivers. Recommendations made in January by the Advisory Council on Alzheimer's Research, Care and Services would take steps to address these shortcomings, and we support their inclusion in the next version of the Plan as HHS prepares its release in the coming weeks.

Understanding current gaps in research and provider training, the President's FY 2014 budget requests funds to implement the Plan, including \$80 million for Alzheimer's research and \$20 million for education, outreach and support. These funds are a critically needed down payment for research and services for Alzheimer's patients and their families.

With these funds, states will be able to improve dementia care services and supports, create greater public awareness campaigns to connect caregivers to community resources and provide better provider education and training. These steps will better prepare individuals with the disease and their caregivers while lengthening the ability to provide care in the home and community setting.

Research funding is the key to unlocking a means for earlier diagnosis, preventive treatments or even a life-saving cure. We have seen the smart investments in research yield treatments that have saved individuals and the health care system millions while creating research and clinical jobs. If a treatment were developed that delayed the onset of Alzheimer's by just five years, it would cut government spending on care for people with Alzheimer's nearly in half. But to do so, we must give the scientists funds to do the job.

That is why Congress must provide the resources necessary to implement the Plan, and should support the President's budget request for \$100 million for implementation.

Conclusion

The Association would like to thank the Committee again for the opportunity to share our support for the work being done to address Alzheimer's disease. We would also like to express our gratitude to the Committee for holding last week's important hearing on the implementation of the Plan and for inviting our advocates, including Glen Campbell and his family, to participate. We strongly believe in the Plan and the goal of preventing and effectively treating Alzheimer's disease by 2025. The Association strongly supports the President's budget request of \$100 million to ensure implementation of the Plan. We urge Congress to move quickly to pass legislation which implements this request.