

U.S. Senate Appropriations Committee  
Subcommittee on Labor, Health and Human Services, Education and Related Services

Testimony of The Honorable Dennis Moore

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Good afternoon Chairman Harkin, Ranking Member Moran and members of the Subcommittee. As an individual living with Alzheimer's disease, thank you for the opportunity to testify before the Subcommittee.

Alzheimer's is a devastating, progressive and ultimately fatal disease. It currently impacts more than 5 million Americans living with the disease and their 15.4 million caregivers. These men and women are husbands and wives, mothers and fathers, sisters and brothers, business leaders, medical professionals, Republicans and Democrats. I should know. I, a former member of the U.S. House of Representatives, am one of them.

I was diagnosed with Alzheimer's disease just two years ago on June 1, 2011. I had become concerned when I noticed I was having some difficulty remembering random events and difficulty managing our household finances. Since then, I have learned coping skills but still recognize the issue I have with my short-term memory loss. I am now an Alzheimer's advocate for the Alzheimer's Association and serve on the Advisory Council on Alzheimer's Research, Care, and Services because I know personally how this disease affects an individual and family. There is a great need for educating the general public and funding research for a cure.

**Alzheimer's Impact on the American People and the Economy**

In addition to Alzheimer's stealing our memories, independence and eventually our ability to function, it demands increasing amounts of care. Beyond the exhaustion and stress, there is the financial burden. Alzheimer's is creating an enormous strain on the health care system, families and the federal budget. 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.

A federal commitment can lower costs and improve health outcomes for people living with Alzheimer's today and in the future. By making Alzheimer's a national priority, we can create the same successes that we have been able to achieve in other diseases that have been prioritized by the federal government. Leadership from the federal government has helped to lower the number of deaths from other major diseases like heart disease, HIV/AIDS, many cancers, heart disease and stroke. While those deaths have declined, deaths from Alzheimer's have increased 68 percent between 2000 and 2010.

Alzheimer's is the most expensive disease in America. 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. In 2013, America is estimated to have spent \$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

high costs is that Alzheimer's makes treating other diseases more expensive, as most individuals with Alzheimer's have one or more co-morbidities 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 (not adjusted for inflation), creating an enormous strain on the healthcare system, families and the federal budget. 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.

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 2012.

### **Changing the Trajectory of Alzheimer's**

Until recently, there was no federal government strategy to address this looming crisis. In 2010, thanks to bipartisan support in Congress, the National Alzheimer's Project Act (NAPA) (P.L. 111-375) passed unanimously, requiring the creation of an annually-updated strategic National Alzheimer's Plan (Plan) to help those with the disease and their families today and to change the trajectory of the disease for the future. 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.

As mandated by NAPA, the Secretary of Health and Human Services, in collaboration with the Advisory Council on Alzheimer's Research, Care and Services, developed the first-ever *National Plan to Address Alzheimer's Disease* in May of 2012. The Advisory Council, of which I am a member, is composed of both federal members and expert non-federal members. It is an integral part of the planning process as it advises the Secretary in developing and evaluating the annual Plan, makes recommendations to the Secretary and Congress, and assists in coordinating the work of federal agencies involved in Alzheimer's research, care, and services.

NAPA, and the Plan it has yielded, finally provides a framework for Congress to assess whether the nation is meeting the challenges of this disease for families, communities and the economy. The Plan sets important goals. The first of these aims squarely at changing the trajectory of Alzheimer's by setting the goal to, "[p]revent and effectively treat Alzheimer's disease by 2025." Further, to the great credit of the National Institutes of Health and the National Institute on Aging, our nation's leading scientists have specified the annual research milestones they have concluded they must achieve to remain on track to accomplish this transformative goal. With these milestones in hand, a direct product of NAPA, this Subcommittee now has a tool to constructively assess whether we remain on track toward 2025, whether congress is providing the necessary resources, and whether available resources are yielding the anticipated progress from year to year. Until this past year, such engagement between congress and the

National Institutes of Health simply was not possible for lack of this framework. We ought to recognize what a significant achievement this is in the service of disciplined, priority-driven science, and I urge you to take full advantage of it.

Having this Plan with measurable milestones and outcomes is important. But unless there are resources to implement the Plan and the will to abide by it, we cannot hope to make sufficient progress. If we are going to succeed in the fight against Alzheimer's, Congress must provide the resources the scientists need. These funds are critically needed for research and services for Alzheimer's patients and their families.

The potential in reach could scarcely be greater. A disease-modifying or preventive therapy would not only save millions of lives but would save billions of dollars in health care costs. Specifically, a treatment that delayed the onset of Alzheimer's by five years (a treatment similar to anti-cholesterol drugs), would reduce Medicare and Medicaid spending nearly in half in 2050.

Today, despite the federal investment in Alzheimer's research, we still must do much more to understand what causes the disease and to capitalize on it. Americans are growing increasingly concerned that we still lack effective treatments that will slow, stop, or cure the disease, and that the pace of progress in developing breakthrough discoveries is much too slow to significantly impact this growing crisis. For every \$27,000 Medicare and Medicaid spend caring for individuals with Alzheimer's, the National Institutes of Health (NIH) spends only \$100 on Alzheimer's research. Scientists fundamentally believe that we have the ideas, the technology and the will to develop new Alzheimer's interventions. But that progress depends on implementing NIH's prioritized Alzheimer's research agenda, and on having the resources necessary to carry out the scientific strategy for both discovery and translation for therapeutic development.

Additional funding has been requested in the NIH budget over the past several years because their scientists have determined that additional research on Alzheimer's is a priority. These budget requests reflect the changing needs of the Alzheimer's community, the scientific opportunity, and the results of disciplined analysis and planning. It is vital that Congress support the research projects the scientists at NIH deem necessary.

However, Congress does have a responsibility to direct resources to solve the most serious problems. By every objective standard (whether cost to Medicare/Medicaid, families caring for individuals with Alzheimer's, or mortality rate), Alzheimer's is one of our most serious health problems – and it will only get worse as the Baby Boomer generation ages.

**While pursuing effective treatments for tomorrow, deliver better care and support today**  
Alzheimer's is the most expensive disease in the country not just because of the lack of adequate treatments, but also because our care systems do not effectively address dementia and its consequences. For too many individuals with Alzheimer's and their families, the system has failed them, and today we are unnecessarily losing the battle against this devastating disease. Despite the fact that an early and documented formal diagnosis allows individuals to participate in their own care planning, manage other chronic conditions, participate in clinical trials, and ultimately alleviate the burden on themselves and their loved ones, as many as half of the more than five million Americans with Alzheimer's have never received a formal diagnosis.

Unless we create an effective, dementia-capable system that finds new solutions to providing high quality care, provides community support services and programs, and addresses Alzheimer's health disparities, Alzheimer's will overwhelm the health care system in the coming years. For example, people with Alzheimer's and other dementias have more than three times as many hospital stays as other older people.

Furthermore, one out of seven individuals with Alzheimer's or another dementia lives alone and up to half of them do not have an identifiable caregiver. These individuals are more likely to need emergency medical services because of self-neglect or injury, and are found to be placed into nursing homes earlier, on average, than others with dementia. Ultimately, supporting individuals with Alzheimer's disease and their families and caregivers requires giving them the tools they need to plan for the future and ensuring the best quality of life for individuals and families affected by the disease.

Recognizing this, President Obama's budget request for fiscal year 2014 included an increase of \$80 million for Alzheimer's research at NIA and an increase of \$20 million for education, outreach and support services. Congress, through the leadership of Chairman Harkin and Ranking Member Moran, provided much needed resources in the Consolidated Appropriations Act of 2014 that are allowing the pursuit of the goal of effectively treating and preventing Alzheimer's by 2025 to continue into the next immediate steps without faltering.

The funding provided in the omnibus will allow scientists to pursue innovative research that will lead to new treatments, interventions and diagnostics. Continued funding of these programs will encourage a greater investment in the academic and private sector and ultimately lead to a game-changing diagnostic or treatment. For all these reasons, it is vital that we continue to make investments in Alzheimer's disease research, education, outreach and support activities to implement the National Alzheimer's Plan as we look to FY15.

### **Conclusion**

Thank you again for the opportunity to testify today. I appreciate the steadfast support of the Subcommittee and its priority setting activities. I look forward to continuing to work with Congress in order to address the Alzheimer's crisis. Alzheimer's is the costliest disease in the country and these costs are set to increase like for none other. I ask Congress to address Alzheimer's with the same bipartisan collaboration demonstrated in the passage of the National Alzheimer's Project Act (P.L. 111-375) and this Subcommittee's deliberations on Alzheimer's, and with a commitment equal to the scale of the crisis. An epidemic is well upon us, and too many families are in situations like mine – facing a fatal disease that currently has no way to prevent, cure or even slow its progression. As a nation, we cannot afford to wait until Alzheimer's bankrupts the nation, just as it already has so many hardworking families in Iowa, Kansas, and all across this country. We must make the smart investment now to realize a better, healthier future for our families and our nation. Thank you.