



Testimony
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Statement of

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Mr. Chairman and Members of the Committee, I am Donald B. Moulds, Ph.D., Acting Assistant Secretary for Planning and Evaluation (ASPE) in the Office of the Secretary of the Department of Health and Human Services (HHS). I am honored to come before you today to talk about the implementation of the National Alzheimer's Project Act (NAPA) and the National Plan to Address Alzheimer's Disease. We have an historic opportunity to engage in an open collaborative discussion focused on reducing the burden of this disease with the active engagement of government and the private sector. I will provide a brief overview of Alzheimer's disease and related dementias in the United States, offer a brief history of the development of the National Alzheimer's Plan and its implementation, discuss our work on each goal of the plan, and preview upcoming work on Alzheimer's disease.

The Administration and the Congress are partnering in this unprecedented opportunity to influence the way we address Alzheimer's disease, its impact on those who have it and their families, and, perhaps, reduce the incidence – and devastation it causes – in the future. In January 2011, President Obama signed the NAPA, calling for an aggressive and coordinated national Alzheimer's disease plan to be updated annually. In 2012, President Obama directed that HHS make available \$56 million for initiatives in cutting edge research, increased public awareness, and provider education on the disease. Increasing the momentum, the Administration is seeking to direct \$100 million to such initiatives in 2014. President Obama and Secretary Sebelius have made it abundantly clear: we cannot wait to act on this urgent national priority.

In my testimony, I refer to Alzheimer's disease; under this term I include related dementias consistent with the approach the Congress used in the law. It can be difficult to distinguish between

Alzheimer's disease and other dementias in clinical presentation and diagnosis. People with dementia and their families face similar challenges finding appropriate and necessary medical and supportive care.

Burden of Alzheimer's Disease

As many as five million people in the United States have Alzheimer's disease¹. While estimates of the number of people vary, few dispute the urgent need to find ways to prevent, delay, and treat this disease—especially in light of America's aging population. The effects of Alzheimer's can be devastating, both for individuals with the disease and their families. People with Alzheimer's may require significant health care and intensive long-term services and supports including, but not limited to, management of chronic conditions, help taking medications, round-the-clock supervision and care, or assistance with personal care activities, such as eating, bathing, and dressing. As Dr. Hurd will testify, the cost of care for people with AD was estimated to be in the range of \$159 billion to \$215 billion in 2010². There is no treatment for AD and eventually it is fatal. It is the fifth leading cause of death among people age 65 and older. As we have made progress fighting other diseases and the population has aged, mortality from Alzheimer's has risen.³

National Alzheimer's Project Act Implementation

The Act establishes an Advisory Council on Alzheimer's Research, Care, and Services, which brings together some of the Nation's foremost experts on Alzheimer's disease. Ron Petersen, the chair of the Advisory Council, will speak about their work in a few moments.

¹ Hebert LE, Weuve J, Scherr PA, Evans DA (2013). Alzheimer's disease in the United States (2010-2050) estimated using the 2010 census. *Neurology*, March 2013.

² Hurd MD, et al. (2013). Monetary costs of dementia in the United States. *N Engl J Med*; 368: 1326-34.

³Tejada-Vera B (2013). Mortality from Alzheimer's disease in the United States: Data for 2000 and 2010. *NCHS Data Brief* No. 116.

Soon after enactment, we began work on the National Plan. In April 2011, HHS established an Interagency Group on Alzheimer's Disease and Related Dementias to begin carrying out the National Alzheimer's Project Act. This Interagency Group includes the Departments of Veterans Affairs and Defense, the National Science Foundation, and over a dozen HHS agencies. The Interagency Group inventoried all Federal programs including research, clinical care, and services and supports. It then identified areas of overlap, opportunities for collaboration, and gaps. The inventory and gap analysis formed the basis for initial work on the National Plan.

In early 2012, we shared a framework and draft of the National Plan to Address Alzheimer's Disease with the Advisory Council and the public and solicited feedback. We incorporated the input received from the Advisory Council and thousands of stakeholders – program providers, health professionals, policy makers, researchers and others – and most important, the experts who see the issues up close every day and every night - people who experience the disease personally and their caregivers. We built off the President's historic investments and identified concrete steps to address the disease. The final first National Plan was released on May 15, 2012. As Secretary Sebelius said, it provides “the cornerstones of an historic effort to fight Alzheimer's.”

National Plan to Address Alzheimer's Disease

The National Plan addresses five ambitious goals:

- 1. Prevent and Effectively Treat Alzheimer's Disease by 2025* – We will accelerate the pace of scientific research and ensure that evidence-based interventions are identified and quickly translated into clinical practice. In May 2012, the National Institute on Aging convened an international summit of scientists to assess research goals and suggest priorities. As you

know, we do not have effective ways to prevent AD today. However, under this goal we are funding studies of risk and protective factors to fill that gap. Clinical studies based on these findings will be directed at the earliest diagnosis and treatment of Alzheimer's, with a special emphasis on rapidly reporting research results to practitioners and the public who can use them.

2. ***Optimize Care Quality and Efficiency*** – This goal will provide people with Alzheimer's disease the highest quality of care, in all settings, from the earliest stages of the disease. Early diagnosis is essential. We have made progress in linking the latest research findings, such as new assessment technologies coming out of NIH, with the Administration on Community Living's information and referral sources in local communities and with the Medicare Annual Wellness Visit created by the Affordable Care Act. The Health Resources and Service Administration (HRSA) invested \$2 million in 2012 to educate health providers to help them detect Alzheimer's disease and care for people who have it. Further, because people with AD use a lot of services from multiple providers, the plan focuses on care coordination, information sharing among providers, and easing individuals' transitions between providers and settings. We are paying particular attention to the unique needs of different age and racial and ethnic groups affected by dementia.

3. ***Expand Supports for People with Alzheimer's Disease and Their Families*** – We are supporting care, which in the case of Alzheimer's disease is a 24/7 family endeavor, well beyond interactions with doctors, hospitals, or nursing homes. Families and caregivers frequently provide care to loved ones at home over many years, sometimes decades. The work is demanding physically, financially and emotionally. In the course of this work, I have had the opportunity to hear from many dedicated caregivers who cope with behavioral

changes, sleep disturbances, wandering, and a myriad of other challenges related to cognitive impairment as well as the physical demands of hands-on care. We are working to provide culturally sensitive resources, to help family caregivers with their own health and well-being, and to assist families in preparing for future long-term care needs. I have heard their testimony to the Advisory Council and in national listening sessions, and read comments they submitted to the NAPA website. People like Judy Roth – both of her parents were diagnosed with Alzheimer’s disease in 2009. She told the Advisory Council: “It breaks my heart to see them slowly slip away. And there is no respite from this horrible disease. So many around me are suffering from it or caring for those who have it. As Olga Molinari told us, “it takes a village to handle an aggressive, geriatric Alzheimer’s family member.”

4. *Enhance Public Awareness and Engagement* – We are educating and engaging the public in the fight against Alzheimer’s disease. Greater public awareness encourages families to seek assessments, reduces their sense of isolation, and provides them with accurate information, resources and services. As the Advisory Council heard last year, “Alzheimer’s is a quiet disease. People who have it don’t want to talk about it.” Engaging in a public dialogue can help remove the shame associated with the disease and ensure people with concerns about their memory or a diagnosis get the care and supports they need.

5. *Track Progress and Drive Improvement* – We need more and better information on people with Alzheimer’s, their caregivers and the care and support they receive, to improve programs, support policy initiatives, and evaluate the impact of the National Plan. We are investing in data collection on Alzheimer’s disease, to improve our understanding of who has Alzheimer’s disease and what caregivers do to help them. I am proud of the cutting edge

web-based planning tool developed by my office that enables policy makers, Advisory Council members, and the public to follow plan implementation and actions in real time.

Progress Since The Plan's Release

In the 11 short months since the National Plan was released, we have already made great progress. In May 2012, the National Institutes of Health (NIH) and HHS convened the [Alzheimer's Disease Research Summit 2012: Path to Treatment and Prevention](#) which brought together national and international researchers and advocacy groups to develop recommendations on how to best advance Alzheimer's research. The Summit recommendations, which are designed to capitalize on current scientific opportunities, will inform Alzheimer's research for years to come.

Through the International Alzheimer's Disease Research Portfolio, NIA has created a mechanism that enables funders of Alzheimer's disease research to coordinate efforts. The Administration's Alzheimer's commitment of \$50 million in 2012 supported some exciting research projects that enable us to "roll up our sleeves to see where we can go," as Francis Collins says. Among them:

- Whole-genome sequencing to identify new genetic variants that increase or reduce risk for AD.
- A clinical trial of an insulin nasal spray that could prevent memory impairment and improve cognition during the initial period of the disease.
- Testing the potential of a new treatment that targets amyloid, a brain hallmark of AD, with a unique and large family in Colombia whose members are otherwise healthy but share a genetic mutation that causes early onset Alzheimer's disease. This is the first clinical trial of a drug aimed at preventing the disease.
- Use of new stem cell methods to obtain insights into the cellular processes of Alzheimer's.

- Support to the Atherosclerosis Risk in Communities (ARIC) Neurocognitive study (ARIC-NCS) focused on mid-life vascular risk factors and markers that might predict cognitive impairment later.

While this important scientific work is underway, we have taken steps to improve the care received by people with AD. The network of Geriatric Education Centers funded by HRSA have provided training to over 10,000 doctors, nurses and direct care workers better recognize the symptoms of AD and provide screening and help for consumers and families who are living with the disease

The Centers for Medicare & Medicaid Services (CMS) and NIH identified tools that physicians can use to assess for cognitive impairment during the Medicare Annual Wellness Visit. These recently validated and free tools take 5 minutes or less to administer. They will help providers determine when someone needs further testing for dementia and speed up diagnoses.

CMS's Center for Medicare & Medicaid Innovation (CMMI) awarded grants to test four models of improved care for people with dementia. The grants test various models to assess individuals, develop and implement individualized treatment plans and support people in care transitions.

While there is still much we do not understand, there are concerns that using certain medications, including atypical antipsychotics, to treat the behavioral symptoms of Alzheimer's or other dementias may not be appropriate. CMS has taken important steps to address inappropriate use of these drugs to manage behavior in nursing homes. CMS and public and private partners have made major presentations, educated providers, and completed 200 nursing home case studies on how decisions are

made to use antipsychotic medication. Nursing home surveyors are specifically trained on how to look for inappropriate antipsychotic use. HHS has set a goal of reducing antipsychotic drug usage by 15 percent.

Family members and other informal, unpaid caregivers play an essential role in helping people with AD live with the disease. Karen Lowe told the Advisory Council about her 89 year old mother who once spoke four languages: “She thinks I’m an overly friendly nursing home staffer who kisses her and tells her how much I still love her. She has disappeared so slowly, I’m not even sure when I said goodbye to the mother I once knew. I am saddened and scared. I am scared now that I, too, will suffer this fate. And that my children will one day wonder where I went and who is this apparition is who looks like me but seems lost at sea.”

The Administration on Community Living has partnered with the National Family Caregiver Alliance to publish *Selected Caregiver Assessment Measures (2nd Edition): A Resource Inventory for Practitioners*. This resource provides assessment measures that providers can use to help identify the caregiver’s needs and build upon their strengths to create a care plan that addresses the individualized needs of the care recipient and the caregiver.

HHS launched www.alzheimers.gov as a one-stop resource for families and caregivers. It also fielded an awareness campaign to enhance public awareness of Alzheimer’s disease and link caregivers and people with a diagnosis to the resources they need. The campaign included an award winning commercial and print and web advertisements. There were over 200,000 visits to Alzheimers.gov in the first 10 months.

Upcoming Work

Despite all of the progress, we still have a long way to go in our fight against Alzheimer's disease. We are finalizing the 2013 Update to National Plan, which will add additional steps we will take to beat this disease. The President's FY 2014 budget includes a \$100 million initiative to fight this disorder through expanded research, improved supports for caregivers, and enhanced provider education and public awareness. In addition, the President recently announced his BRAIN initiative, which will create a dynamic picture of the interactions between cells and neural circuits. This effort will complement our research by giving us insight into healthy brain functioning and the impact of Alzheimer's disease, to help pinpoint interventions to treat this disease.

With many partners, the Administration has done a lot of work on Alzheimer's over the past year, but much work remains. I look forward to working with you to improve the care received by the millions of people with the disease, better support their families and caregivers, and prevent and effectively treat AD by 2025. Secretary Sebelius said it best: "We can't wait to act. Reducing the burden of Alzheimer's disease on patients and their families is an urgent national priority."