

Testimony for Senate Special Committee on Aging
The National Plan to Address Alzheimer's Disease

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Good afternoon, Chairman Collins, Ranking Member McCaskill and distinguished members of the Senate Special Committee on Aging. My name is Ronald Petersen, Ph.D., M.D., and I serve as the Chair of the Advisory Council on Research, Care and Services for the National Alzheimer's Project Act. I am also Professor of Neurology and Director of the Alzheimer's Disease Research Center at the Mayo Clinic in Rochester, Minnesota. In 2014, I was appointed to the World Dementia Council by United Kingdom Prime Minister David Cameron.

I would like to thank the Committee for your attention to this issue and for the opportunity to discuss the importance of Alzheimer's. I would also like to commend Senators Collins and Klobuchar for introducing their resolution to double the funding for Alzheimer's disease research in 2016 and to achieve the goal of increasing the annual research budget to two billion dollars in five years.

As you know, in 2010 Congress unanimously passed and the President signed into law in 2011 the National Alzheimer's Project Act requiring the Secretary of Health and Human Services to develop the first United States Plan to Address Alzheimer's Disease ("Plan"). The Advisory Council has just completed its recommendations for the 2015 edition of the Plan.

The primary goal of the Plan is to “effectively treat and prevent Alzheimer’s disease by 2025.” This goal is but a short ten years away. An essential feature of the recommendations submitted to the Secretary and Congress includes the recommendation that the federal government spend at least two billion dollars a year on research for Alzheimer’s disease. This figure is in comparison with other major diseases such as cancer that receives almost six billion dollars a year; HIV/AIDS, three billion dollars a year; and cardiovascular diseases, two billion dollars a year. We currently spend under 600 million dollars (less than half a billion) for Alzheimer’s disease research annually. These investments in cancer, HIV/AIDS and cardiovascular disease have likely contributed to the reduction in annual deaths in many of these diseases while the annual death rate for Alzheimer’s disease continues to climb. Alzheimer’s disease is an incurable disorder with no survivors.

Please allow me to clarify my terminology: By dementia, I am referring to a condition that affects one’s memory and thinking to the degree that the person’s daily activities are impaired. Alzheimer’s disease is one form of dementia but by far the leading cause in an aging society. When I refer to Alzheimer’s disease in my remarks, I am also including other forms of dementia such as frontotemporal lobar degeneration, dementia with Lewy bodies and vascular cognitive impairment. All of these disorders constitute a form of dementia, and all are incurable.

In 2013, United Kingdom Prime Minister David Cameron used the final event of his G8 Presidency to host a Summit on Dementia. In preparation for that meeting, Professor Nick Fox of University College London and I wrote a commentary in *The Lancet* suggesting that the member countries consider spending one percent of their current care budgets on research. The US spent \$214 billion in 2014 caring for persons with dementia, and if we were to spend one percent of that figure on research, we would reach the two billion dollar figure recommended by the National Plan Advisory Council and Senators Collins and Klobuchar.

Last week in Geneva, Switzerland, the World Health Organization sponsored the *First WHO Ministerial Conference on Global Action Against Dementia*, and I presented figures regarding the projected numbers of individuals with dementia, if untreated, by the middle of the century. These figures demonstrate the impact of delaying the onset of dementia by five years or slowing the progression of the disease or both on the numbers of persons affected by the disease. These figures can be translated into cost savings as well.

In a recent report from the Alzheimer's Association, it is projected that, if a treatment were to be introduced by 2025 that would delay the onset of Alzheimer's disease by five years, that treatment would reduce the number of individuals affected by the disease by 5.7 million by 2050 and save all payers, including Medicare, Medicaid and families, more than \$220 billion within the first five years. As recommended by the Advisory Council, if the federal government were to invest two billion dollars per year, the country would recoup this investment within the first three years after a treatment became available. All of the economic models converge and indicate that the savings to the federal government would more than capture the increased investment in research in a relatively short period of time.

It should be noted that the Advisory Council's recommendation of increasing the federal budget for research to two billion dollars a year needs to take place as soon as possible. This is not a goal for 2025; rather, the Council recommends that the federal government ramp up its funding rapidly since this degree of investment is necessary immediately to be able to accomplish the goals of the Plan by 2025.

The Advisory Council ("Council") has also made several other recommendations to effectively deal with the disease. The Council has recommended that the Department of Health and Human Services should encourage efforts to foster Dementia Friendly Communities. Early results from this program

implemented in Minnesota suggest that there is an increased awareness of dementia throughout all sectors of the community including law enforcement, business, transportation and faith communities as well as increased options for care partner support and engagement within the community. The Council has also recommended measures to improve the clinical care for persons living with dementia and to ensure the quality of life and quality of care for persons living with advanced dementia and their families across care settings. A panel convened by the Institute of Medicine addressed the issues facing individuals with advanced dementia. From the perspective of long term services and support, the Council recommended that the Department of Health and Human Services support state initiatives to provide robust dementia-capable long-term services and supports through providing coordinated Alzheimer's disease-related activities across state agencies and identifying a lead entity in each state with adequate funding from Congress.

I would like to commend my colleagues at the Department of Health and Human Services for their work toward enacting the National Alzheimer's Plan thus far. Great strides have been accomplished in coordinating federal agencies and improving federal capabilities with respect to Alzheimer's disease. However, a great deal of work needs to be accomplished since we are not close to our goal of effectively treating or preventing Alzheimer's disease by 2025.

I can say with confidence that the research community is poised to make significant contributions toward the goal if adequate funding were available. As outlined by my colleague, Dr. Richard Hodes, of the National Institute on Aging, he and his staff have established milestones for the execution of the Plan and now with the passage of the Alzheimer's Accountability Act are working diligently to prepare a professional judgment budget to submit to Congress outlining the expenditures necessary to accomplish the goals set forth in the Plan.

Research is currently underway to identify the earliest features of developing Alzheimer's disease with the idea of prevention. From a public health perspective, we cannot wait until individuals become symptomatic; we must address the earliest biologic underpinnings of the disease. Toward that end, the field is making great strides toward identifying the earliest biological features, so-called biomarkers, of the developing disease. Numerous therapies are currently under investigation to address the disease at the earliest possible point in an effort to prevent further damage from being done to the central nervous system. This does not mean that we will abandon individuals who are already symptomatic; rather, numerous treatments to have an impact on the symptoms are currently underway, as well.

We cannot wait until there is a more convenient time to increase funding for this disease. Projections indicate that Alzheimer's disease will bankrupt the healthcare system as we know it today. We simply cannot afford to spend more than a trillion dollars a year, as is projected by 2050, to care for individuals with Alzheimer's disease. The impact on individuals and families is enormous, and the cost to society is unsustainable. We appreciate the difficult constraints under which the federal government is currently operating, but our patients and families cannot wait. With 10,000 baby boomers turning age 65 on a daily basis, this problem is not going to be resolved by itself. We are all poised to make a difference given the opportunity considering a new potential treatment was announced at an international meeting just last week in Nice. Ultimately, it will be up to individuals such as those on this committee to make very difficult decisions regarding funding for Alzheimer's disease and related disorders going forward. We call upon Congress to make the bold decisions to alter the course of this disease now so as not to burden the next generation with an intractable situation. The National Plan to Address Alzheimer's Disease has established a blueprint to make this possible, and we need your support. I thank you for the opportunity to represent the Advisory Council.