Testimony for the Senate Committee on Finance
Subcommittee on Healthcare

"Alzheimer's Disease: The Struggle for Families, a Looming Crisis for Medicare"

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Ronald C. Petersen, Ph.D., M.D.
Director, Mayo Clinic Alzheimer's Disease Research Center
Mayo Clinic, Rochester, Minnesota

Good afternoon, Chairman Toomey and Ranking Member Stabenow. My name is Ronald C. 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 a Professor of Neurology and Director of the Mayo Alzheimer's Disease Research Center at the Mayo Clinic in Rochester, Minnesota. Recently, I was appointed to the World Dementia Council by United Kingdom Prime Minister David Cameron.

Alzheimer's disease is the most devastating disorder of our generation. We are all familiar with persons who suffer from the disease, as well as families and caregivers of those individuals who are keenly aware of the urgency in addressing this disease now.

It is estimated that there are over 5.1million people currently in the United States with Alzheimer's disease, and that number is projected to exceed 13 million by 2050. A recent research project from the RAND Corporation published in the *New England Journal of Medicine* based on data from 2010 indicated that the cost to the US healthcare and long-term care systems for Alzheimer's disease was between $159B and $215B. This is in comparison to similar 2010 data for heart disease estimated at $102B and cancer at $77B. As such, this was the first documentation that Alzheimer's disease is, in fact, the *most costly disease* to the US health economy.

In 2011, President Obama signed the National Alzheimer's Project Act into law. This law required the Secretary of Health and Human Services to develop the first United States Plan to Address Alzheimer's Disease. The first Plan was published in May of 2012, and it has been revised annually. The law also required the appointment of an advisory council to advise the Secretary on the development and revision of the Plan, and the Advisory Council, which I chair, has been meeting quarterly since 2011. The law also required that the Advisory Council generate a separate set of recommendations that would go directly to the Secretary and to Congress outlining our opinions and necessary

steps for treating Alzheimer's disease and related dementias. These recommendations are not constrained by any current fiscal considerations.

The primary goal of the National Plan is to effectively treat and prevent Alzheimer's disease by 2025. One of the corresponding recommendations that the Advisory Council has put forth to the Secretary and Congress urges the federal government to allocate at least $2B a year for research in Alzheimer's disease. Currently, with the recent increase in the FY2016 budget, the federal allocation is $991M. We are making progress, but we have a long way to go.

According to a report from the Alzheimer's Association, caring for persons with Alzheimer's disease in 2015 cost the United States $226B, 70% of which came from Medicare and Medicaid. This means that approximately one in five Medicare/Medicaid dollars was spent on Alzheimer's disease. By 2050, that annual cost is estimated to be greater than $1.1T. This represents a 420% increase over that timeframe and indicates that, by 2050, we will be spending one in three Medicare and Medicaid dollars on Alzheimer's disease. The cumulative costs from now until 2050 will over $20T, again 70% of which will be covered by federal and state governments. Therefore, if we were to be successful at addressing the primary goal of the Plan, to develop an effective treatment by 2025, these figures may become modifiable. We need to act now to avert this untenable scenario for our country.

Putting this in the context of the primary goal of the National Plan, if we were to develop by 2025 a disease-modifying therapy that delayed onset of the disease by five years, this would reduce the number of individuals with Alzheimer's disease over the succeeding five years, from 8.2M to 5.8M. This would result in a savings of $83B from $451B to $368B. If you project these numbers out to 2050, at which time we indicated that we would be spending $1.1T without a disease-modifying therapy, that number would be reduced to $734B.

Without an effective treatment, cumulatively over the ten year period from 2025 to 2035, federal and state governments would pay an estimated $3.2T. Again, assuming a disease-modifying therapy by 2025 over the ensuing ten years, federal and state governments would appreciate a cumulative savings of $535B. Even in the first year following a disease-modifying therapy, we would be saving $3B. I do not mean to inundate you with statistics, but the numbers are impressive that, for as little of an investment of $2B a year for federal research, the impact in savings to the federal healthcare system would be enormous.

So, are we there? As I mentioned, the current federal budget for Alzheimer's disease research is approximately $991M. In 2014, Congress passed the Alzheimer's Accountability Act which required the National Institutes of Health to generate an annual

Professional Judgment Budget, also called a bypass budget, to estimate what the annual costs would be to reach the goal of the plan by 2025. Last year, Dr. Francis Collins, Director of the National Institutes of Health, announced the first bypass budget for FY17 at the Advisory Council's summer meeting. He estimated that the recommended increase in the budget for FY17 would be $323M. He and his staff are currently working on the 2018 bypass budget.

The research community is poised to make the necessary progress to make these treatment projections a reality with the disease-modifying therapy by 2025. The academic field is working on the notion of prevention of Alzheimer's disease. By prevention, we mean a delay in the onset or the slowing of progression of the disease, which is entirely realistic. Through recent research advances funded largely by NIH, such as the Alzheimer's Disease Neuroimaging Initiative and our Mayo Clinic Study of Aging, we have become able to identify the underlying disease process causing Alzheimer's disease in cognitively normal individuals. This research opens the door for designing more efficient and effective clinical trials.

As we move toward earlier and earlier identification of the disease through the use of clinical tools and biomarkers, we are developing better techniques to assess individuals. The Patient Centered Outcome Research Institute (PCORI) has focused a recent dementia initiative on evaluating clinical measures from the patients and, and very importantly, from caregivers, to assist in the development of these new therapies.

In closing, I would like to thank Congress for its proactive stance in addressing these issues. The time is now to act at continuing to increase the budget for federal funding of research for Alzheimer's disease because the consequences of these projections are otherwise unsustainable. Alzheimer's disease is the most costly disease in this country and will become increasingly so unless we develop these effective therapies.

I would like to commend both my federal and nonfederal colleagues on the Advisory Council for Research, Care and Services for the National Alzheimer's Plan as well as our colleagues in the Department of Health and Human Services, most notably in the office of the Assistant Secretary for Planning and Evaluation and the National Institutes of Health. Our work is just beginning. I appreciate the opportunity to share these thoughts with you this afternoon and would be happy to entertain questions. Thank you.