

# Testimony for House Health and Human Services Finance Committee

January 21, 2015

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Good afternoon, Mr. Chairman and Members of the Committee:

I am Dr. Ron Petersen, the Director of the Alzheimer's disease Research Center at the Mayo Clinic and Director of the Mayo Clinic Study of Aging in Rochester, Minnesota. Both of these are funded by the National Institutes of Health to conduct research on aging, Alzheimer's disease and other dementias.

This is an exciting time to be involved in research and the care for patients with Alzheimer's disease and related dementias, and I am thrilled that Minnesota will be taking on the challenge of addressing these issues in a proactive fashion. The time is now. Currently, there are approximately 100,000 individuals in Minnesota diagnosed with Alzheimer's disease, and this translates to over 5M individuals nationally. It is a global phenomenon with over 30M people being affected worldwide. The toll that dementia takes on individuals and families is incalculable. The impact on society is enormous. We have been proactive here in Minnesota to address these issues in many ways, and I will return to that topic.

From a national perspective, Congress unanimously passed the National Alzheimer's Project Act in 2010, and the President signed it into law in 2011. That law required the Secretary of Health and Human Services, then Kathleen Sebelius, to develop a national plan to address Alzheimer's disease since this had never been done previously. As part of that charge, Secretary Sebelius appointed an Advisory Council on Research, Care and Services, and I was honored to be chosen as the Chair. The Council oversees the Plan, gives recommendations to the Secretary and directly to Congress on how to deal with Alzheimer's disease now and in the future. The Plan outlines an ambitious goal of preventing and effectively treating the disease by 2025, just ten short years away. The Plan is divided into five

goals covering research, clinical care, caregiver support, education and awareness and metrics of progress. The law required that the Plan be revised annually, and the Council is busily preparing its recommendations for the 2015 Plan. While it is difficult to be certain if the Plan has had a definite impact thus far, funding for Alzheimer's disease by the National Institutes of Health has risen over 20 percent in the last few years, and it is likely that the attention given to Alzheimer's disease by the National Plan has played a role.

There has been increased interest in dementia globally, as well. In December of 2013, United Kingdom Prime Minister David Cameron used the last Summit of his G8 Presidency to highlight the topic of dementia. As a follow up to that meeting, several legacy events have occurred in 2014, and a couple more will continue in 2015 designed to carry out the recommendations that ensued from the G8 Summit. Prime Minister Cameron also established the World Dementia Council to coordinate issues among the G7 countries following the Summit in London. I was honored to be appointed to that Council, as well, and we will be meeting in Washington in February and in Geneva in March to discuss the progress that has been made since the original Summit. The overall impact of this is to emphasize the point that dementia, and in particular Alzheimer's disease, is a global issue that impacts millions of individuals, families and the economic picture of all countries.

I am proud to say that Minnesota has been a leader among states in addressing the Alzheimer's crisis. There are approximately 35 states that have State plans for Alzheimer's disease, but only about six or seven have supplied funding to address issues raised in their plans. In 2011, Minnesota published a comprehensive plan to prepare for the developing epidemic of dementia. This plan led to the creation of ACT on Alzheimer's, a collaborative effort in which people from community sectors throughout Minnesota work together to accomplish transformative work on Alzheimer's disease. This effort includes work to build dementia-capable communities throughout the state. I can say that the impact of

ACT on Alzheimer's in Minnesota has been far reaching. The Director of that program, Olivia Mastry, was invited to address the Advisory Council on Research, Care and Services for the National Alzheimer's Project Act, and she impressed the entire Council with the forethought and accomplishments of ACT on Alzheimer's thus far. The program has received recognition with national awards and is being considered for broader adoption throughout the country and internationally. Minnesota should be proud of this effort since it is leading the way in developing dementia-capable communities.

I would like to say a few words about the disease process itself. Dementia refers to a change in the brain that results in difficulties in thinking and in one's ability to carry out daily functions. Alzheimer's disease is just one form of dementia but is, by far, the most common. However, other forms such as frontotemporal lobar degeneration and dementia with Lewy bodies are equally devastating.

Currently, a great deal of research is focused on early identification of the disease process with the hope of early intervention. Many studies are underway, some in Minnesota, dealing with typical aging populations trying to identify early features of the disease, perhaps through biomarkers which can be detected in blood, cerebrospinal fluid or imaging measures of the brain designed to detect early risk conditions. Work is being done on genetic predisposition since sometimes dementia runs in families, and the genetic characteristics of the disease can give us potential targets for therapy. With regard to Alzheimer's disease, we know a great deal about the underlying biology and are now able to detect the proteins that cause the disease in the brain even when a person is still cognitively normal. Our anticipation is that, by identifying these hallmarks, we will be able to intervene with therapies.

Some of the pioneering and trend-setting work being done on Alzheimer's disease and dementia is being conducted in Minnesota. In a moment, you will hear from my colleague, Dr. Karen Ashe from the

University of Minnesota, who has done landmark work on the earliest pathologic features of the disease, trying to identify these markers in the blood and cerebrospinal fluid. Again, this vital understanding of the early stages of the disease will likely provide opportunities for early intervention.

The Minnesota State Plan suggested the development of techniques for the early identification of individuals who might be experiencing cognitive impairment. HealthPartners has developed an algorithm to identify possible cognitive impairment in the primary care physician's office. The Affordable Care Act required that the Medicare Annual Wellness Visit now contain an assessment of cognitive function. However, the law did not specify how this should be conducted. Clinicians and investigators at HealthPartners have taken it upon themselves to clarify this for primary care physicians to enable them to identify potential problems as early as possible in the pathological cascade. While it is important to identify these illnesses as early as possible to be able to intervene therapeutically, in addition, knowledge about them impacts a person's general medical care, and consequently, there can be a strong interaction between one's cognitive function and management of a patient's overall medical condition.

In Duluth, the Essentia Institute of Rural Health is carrying out a project (state funded) to implement decision support tools to improve dementia diagnosis, treatment, and management in primary care, leveraging the concept of the dementia capable health care home and dementia as an organizing principle of care. Dr. Steve Waring will expand on this in a few moments.

At the Mayo Clinic, we have extensive research programs on the development of biomarkers in aging and disease. We have had a project underway in Olmsted County for over ten years looking at individuals who are randomly sampled from the population and evaluated longitudinally. This project has provided enormous information for the field, and several of my colleagues lead the way in

describing models of the disease progression which help us understand the temporal progression of various disease processes. We have seen over 5,000 people in Olmsted County and are following many of them on an annual basis to allow us to understand the natural profile of people developing Alzheimer's disease and dementia. This is truly a unique study in the country and perhaps the world because of the unique characteristics of Olmsted County, Minnesota. Mayo has been in collaboration with the University of Minnesota in the development of biotechnologies, and many grant opportunities have been shared between the two institutions. We enjoy a very collegial and mutually beneficial relationship.

In addition to the groundbreaking research done in Minnesota, Minnesota has also been attendant to the needs of the caregivers. The Minnesota Board on Aging has been very active in dealing with issues pertaining to the needs of the caregivers and maximizing the quality of life for all persons involved.

In conclusion, I cannot think of a more timely opportunity for Minnesota to continue to expand its leading role in fighting dementia and Alzheimer's disease. The proposed legislation will augment the resources of an already active community of investigators and provide support for agencies charged with the provision of services. The proposed legislation has been thoughtfully composed to include rigorous scientific review of a competitive grant process which will guarantee the absolute highest level of academic excellence. I am proud to support the state of Minnesota through these activities and look forward to greater progress in combatting these dreadful diseases.

