

Testimony for the 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 Plan to Address Alzheimer's Disease. I am also a Professor of Neurology and Director of the Mayo Clinic Alzheimer's Disease Research Center at the Mayo Clinic in Rochester, Minnesota and am a member of the World Demential Council.

As you know, the National Alzheimer's Project Act was signed into law by the President in 2011. The law required the Secretary of Health and Human

Services to develop the first United States Plan to Address Alzheimer's Disease. This was accomplished in May of 2012, and the Plan has been updated annually since that time. The Advisory Council meets quarterly and advises the Secretary and her staff on revisions of the Plan and directions for the future. The law also required that the Advisory Council generate a separate list of recommendations that go directly to the Secretary and to Congress, reflecting our opinions regarding the necessary steps to be taken to treat Alzheimer's disease and related dementias.

The National Plan refers to Alzheimer's disease, but is meant to include related disorders such as frontotemporal degeneration, Lewy body disorders and vascular cognitive impairment and dementia.

So, have we made progress since 2012? I think the short answer is a definite "yes," but we are far from finished.

While the primary goal of the Plan is to prevent and effectively treat Alzheimer's disease by 2025, in reality, we are attempting to delay the onset and/or slow the progression of the disease. That is an achievable goal, and

significant progress has been made toward that end. I will focus my testimony on the research elements of the Plan, and others will address the care and services.

The National Plan has five goals: 1) Prevent and effectively treat Alzheimer's disease by 2025, 2) Enhance care quality and efficiency, 3) Expand supports for people with Alzheimer's disease and families, 4) Enhance public awareness and engagement, and 5) Improve data to track the progress of the disease. In the parallel set of recommendations generated by the Advisory Council, a goal for research funding for Alzheimer's disease and related dementias of \$2B has been enthusiastically supported.

In the difficult funding climate in Washington, increasing attention is being paid to Alzheimer's disease and related dementias, and the Director of the National Institutes of Health, Dr. Francis Collins, has responded in a very proactive fashion. At the onset of the period covered by the National Plan, the federal budget was approximately \$448M. In FY 2012, Dr. Collins repurposed the \$50M from his budget toward Alzheimer's disease research. In 2013, we were faced with sequestration, and Dr. Collins and Dr. Richard

Hodes from the National Institute on Aging were able to use their discretionary funds to offset the negative effects of sequestration. In FY 2014 and FY 2015, Congress provided additional support for Alzheimer's disease research in very austere times.

Most notably, in December of 2015, Congress passed the FY 16 budget which authorized an additional \$350M for Alzheimer's disease and related disorders' research. This constituted a major step toward the goal of the National Plan and raised the overall funding level to approximately \$991M per year. This was a tremendous expression of confidence made by Congress and the Administration for which we are genuinely grateful.

The National Institutes of Health, in particular, the National Institute on Aging and the National Institute on Neurologic Disorders and Stroke, have responded in anticipation of these increased funding authorizations. These institutes have surveyed the entire field of research on Alzheimer's disease and related disorders and have developed new funding opportunities to address the gaps. As such, the number and quality of research projects in this area have increased dramatically.

In addition, in 2014, Congress passed the Alzheimer's Accountability Act which asked the National Institutes of Health to develop a Professional Judgment Budget, also known as a Bypass Budget, which required NIH to provide Congress with the amount of funding that would be necessary on an annual basis to allow the research community to achieve the goals of the Plan by 2025. As such, Dr. Collins working with Dr. Hodes and Dr. Walter Koroshetz of NINDS were able to generate the Bypass Budget for FY 17 of \$323M. These Directors are currently working on the Bypass Budget for FY 18. We strongly encourage Congress to endorse these thoughtfully generated recommended funding levels for the upcoming years.

These positive steps ultimately provided by the Administration and Congress have buoyed up the field of Alzheimer's disease dementia research and have led to numerous research projects designed to characterize persons with these disorders at the earliest stage in the disease spectrum possible and to focus randomized control trials aimed at the various components of the disease process.

To achieve the best and most effective utilization of these funds, four research summits have been held over the past several years, bringing the international research community together to address the field, its current status, gaps in knowledge and recommendations for further research opportunities. These recommendations have been translated into milestones, and with the Alzheimer's Accountability Act, these milestones now have been transformed into funding opportunities. The momentum in the field has been remarkable, and we are confident that this accelerated research toward our goal will allow us to achieve significant progress by 2025.

However, to be honest, our job is not done. The 2025 goal of the Plan is fewer than ten years away. While the almost \$1B in research currently being allocated by the federal government for Alzheimer's disease and related dementias is commendable, the Advisory Council believes that this number, based on input from the scientific community, should be \$2B or more. Again, this is in comparison to other major chronic diseases such as cancer, heart disease, HIV/AIDS and diabetes that receive considerably greater funding, but investigators in these fields have made substantial progress. Among these disorders, Alzheimer's disease is the only one with an annual increasing death

rate, no effective treatments and no cure. As we have indicated previously, Alzheimer's disease and related dementias may very well be the single disease to bankrupt the healthcare system going forward. At previous hearings of this committee, it has been documented that Alzheimer's disease is the costliest of all chronic diseases facing this country today, outstripping the costs of cancer and heart disease, and consequently, we believe that these investments are absolutely necessary.

Alzheimer's disease is a complex disorder of the brain that represents the failure of multiple systems. It is not a simple condition representing the failure of one type of brain cell. Rather, it involves numerous interacting networks of brain regions that have been compromised by the underlying disease process. Currently, investigators are identifying numerous potential drug targets for exploration and possible treatment.

At a research summit last week at NIH, Alzheimer's and related conditions were characterized as multi-factorial such that ultimately we will likely need combination therapy to attack various components of the disease process. Toward that end, biomarkers reflecting each of these components are being

developed that will allow us to determine which components are present and which therapies should be employed. This strategy is already in place in other conditions such as hypertension, cancer and HIV/AIDS. Numerous clinical trials are currently underway using biomarkers to guide the therapies toward their intended targets.

While this is an exciting time to be involved in research for Alzheimer's disease and related disorders, and patients and families cannot wait. It is incumbent upon all of us from the scientific, clinical, advocacy and legislative perspectives to not disappoint our constituents. The disease is not slowing or diminishing, and we need to act aggressively now.

I would like to commend both the federal and nonfederal members of the Advisory Council for Research, Care and Services for the National Alzheimer's Plan as well as the federal officials in the Department of Health and Human Services, particularly in the Office of the Assistant Secretary for Planning and Evaluation, who have worked diligently at carrying out these activities. Advocacy organizations, most notably the Alzheimer's Association, have been fundamentally involved at all levels of this process.



However, I must implore Congress to continue to focus on additional funding for Alzheimer's disease and related dementias going forward. The need cannot be any greater than it is today. Thank you.