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Subcommittee on Africa, Global, Health, Global Human Rights,
And International Organizations

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Chairman Smith and Members of the Committee:

Thank you for the opportunity to address this hearing. I am Dr. Richard Hodes, Director of the National Institute on Aging (NIA), which is one of the 27 Institutes and Centers of the National Institutes of Health (NIH) and the lead Federal Agency supporting research on Alzheimer's disease, a serious public health issue of increasing relevance and urgency to industrialized nations and the developing world alike.

In December, I had the privilege of joining NIH Director Dr. Francis Collins and Department of Health and Human Services (HHS) Acting Assistant Secretary for Planning and Evaluation Dr. Donald Moulds as a member of the American delegation to the G8 Dementia Summit in London. Other members of the U.S. delegation included Erika Elvander from the HHS Office of Global Affairs; Dr. Philip Rubin, Principal Assistant Director for Science at the White House Office of Science and Technology Policy; and Dr. John Wingfield from the National Science Foundation. The goal of the Summit was to develop a coordinated global strategy for addressing the growing issue of Alzheimer's disease and related dementias (ADRD). It is my pleasure to be here today to talk to you about the Summit, its outcomes, and our future plans.

Background: Scope of the Problem

Alzheimer's disease is an irreversible, progressive brain disease that slowly destroys memory and thinking skills and eventually even the ability to carry out the simplest tasks of daily living. In most people with Alzheimer's, symptoms first appear after age 60. Alzheimer's disease is the most common cause of dementia among older people; other forms of dementia include frontotemporal lobar degeneration, Lewy body dementia, and mixed and vascular dementias. Although treatment can help manage symptoms in some people, currently there is no cure for these devastating diseases.

As improvements in modern medicine and care delivery have facilitated a rapid and significant increase in life expectancy in the United States and around the world, we have also seen an accompanying increase in the prevalence of chronic and noncommunicable diseases, including ADRD. In the United States alone, experts estimate that as many as five million people age 65 and older suffer from Alzheimer's disease.[1] An NIH-supported team of economists recently calculated that the costs in 2010 to the U.S. health care and long-term care systems for caring for people with Alzheimer's disease were between $159 billion and $215 billion, depending on how the costs of informal care were assessed, and that those costs could rise dramatically with the increase in the numbers of older people in coming decades. The team estimated direct costs of dementia care purchased in the market in 2010 at $109 billion, exceeding direct health costs for heart disease ($102 billion) and cancer ($77 billion) that same year.[2]

[1] Hebert LE et al. Alzheimer disease in the United States (2010-2050) estimated using 2010 census. *American Academy of Neurology* 80: 1778-1783, (2013).
[2] Hurd MD et al. Monetary Costs of Dementia in the United States. *New England Journal of Medicine* 368: 1321334, 2013. See also http://www.nia.nih.gov/newsroom/2013/04/nih-supported-study-finds-us-dementia-care-costs-high-215-billion-2010

Globally, results of a recent meta-analysis[3] suggest that 35.6 million people lived with dementia worldwide in 2010, with numbers expected to almost double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. In 2010, 58 percent of all people with dementia lived in countries with low or middle incomes, with this proportion anticipated to rise to 63 percent in 2030 and 71 percent in 2050.

The National Alzheimer's Project Act

Recognizing ADRD's devastating impact on patients and families, President Obama signed the National Alzheimer's Project Act (NAPA) into law on January 4, 2011. NAPA established the National Alzheimer's Plan and requires the HHS Secretary to:

- Create and maintain an integrated national plan to overcome Alzheimer's disease
- Coordinate research, both translational and fundamental, and services across all Federal Agencies
- Accelerate the development of treatments that prevent, halt, or reverse the disease
- Improve early diagnosis and coordination of care and treatment of the disease
- Improve outcomes for ethnic and racial minority populations at higher risk
- Create an Advisory Council to review and comment on the national plan and its implementation
- Coordinate with international bodies to fight Alzheimer's disease globally

[3] Prince M et al., The Global Prevalence of Dementia: A Systematic Review and Metaanalysis. Alzheimer's and Dementia 9: 63-75, 2013.

Under NAPA, the National Plan to Address Alzheimer's Disease was released on May 15, 2012, was subsequently updated in June 2013,[4] and will continue to be updated annually. The five primary goals of the Plan are to:

1. Prevent and Effectively Treat Alzheimer's Disease by 2025
2. Optimize Care Quality and Efficiency
3. Expand Supports for People with Alzheimer's Disease and Their Families
4. Enhance Public Awareness and Engagement
5. Track Progress and Drive Improvement

To begin to implement the Plan, the Administration supported NIH investments in clinical trials and other research, enhanced training efforts focused on educating health care providers about Alzheimer's disease, and new tools to increase public education and awareness of Alzheimer's disease and the supports available.

Since the Plan was established, NIH has made significant progress on a number of fronts.

- Recommendations resulting from the NIH-hosted Alzheimer's Disease Research Summit held in 2012—which drew some 500 participants, including speakers and researchers from the world over—set overarching goals for the field. A subsequent meeting on AD-Related Dementias, similar in reach and scope, was held in 2013.
- The NIH research program has helped to support new technologies that have stepped up the pace for identifying genes associated with AD; notably, in November 2013, the International Genomic Alzheimer's Project, which is supported in part by the NIH, announced identification of 11 new genes, offering important new insights into the disease pathways. Under an intensifying research effort, we have initiated major new

[4] See http://aspe.hhs.gov/daltcp/napa/NatlPlan2013.shtml.

clinical trials, including the first primary prevention trial in people at highest genetic risk for the disease; supported intensive genetics sequencing; and initiated development of innovative new cellular models.

Other HHS components are actively working under NAPA as well to enhance care and services:

- Through its network of Geriatric Education Centers, the Health Resources and Services Administration has provided resources that have facilitated reaching 34,000 trainees – including primary care physicians – on topics from dementia diagnosis to effective management.
- HHS has also launched www.alzheimers.gov, a one-stop portal to information about Alzheimer's care and services. The site links to both public and private resources for the public and health professionals.
- An HHS Specific Populations Task Force has identified the unique challenges faced by groups unequally affected by Alzheimer's disease.[5]

International Activities and the G8 Dementia Summit

We recognize the staggering international scope of the problem of ADRD, but also the tremendous opportunity for progress if nations work together to leverage knowledge and coordinate efforts. We at NIH are particularly interested in improving coordination of research so that investments are maximized, but we are also interested in learning from other countries' successes, particularly in areas such as improving care and support, including for ADRD caregivers.

[5] The Task Force's report is available at http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.pdf.

The G8 Dementia Summit represented an exciting opportunity to confer with global leaders in science policy on development of a coordinated approach to ADRD. Summit participants included United Kingdom Prime Minister David Cameron, World Health Organization (WHO) Director General Dr. Margaret Chan, and Organisation for Economic Co-operation and Development (OECD) Deputy Secretary General Yves Leterme, among many others. We discussed a number of topics, including improving life and care for people affected by dementia and their caregivers; preventing and delaying dementia; and social adaptation to global aging and dementia.

The Summit concluded with the publication of a declaration and communique[6] recording the joint activities decided on during the meeting. In the declaration, the participating countries stated their intention to:

- Set a shared goal to identify a cure or disease-modifying therapy for dementia by 2025
- Collectively increase the amount spent on dementia research
- Increase the number of people involved in clinical trials and studies on dementia
- Support the United Kingdom's establishment of a new global envoy for dementia innovation
- Develop an international action plan for research
- Share information and data from dementia research studies across the G8 countries to work together and get the best return on investment in research
- Encourage open access to all publicly-funded dementia research to make data and results available for further research as quickly as possible

These joint activities are fully consistent with NIH's priorities for ADRD research, and we look forward to working closely with other G8 nations to achieve mutual goals. In particular we

[6] https://www.gov.uk/government/publications/g8-dementia-summit-agreements

are delighted that our G8 partners share in our primary objective set forth under the 2012 National Plan—to find effective interventions to prevent or treat Alzheimer's by 2025. In addition, it is worth noting that NIH has already significantly boosted spending on ADRD research by redirecting existing funds within NIH toward this investment; and we will continue to support this high-priority area of research to the extent possible, striving as always to balance this and other compelling areas of scientific opportunity within our available resources.

We anticipate that several ongoing NIH initiatives on ADRD will serve as resources or models for new or expanded global initiatives. These include:

The Alzheimer's Disease Neuroimaging Initiative (ADNI). NIA launched ADNI in 2004. The largest public-private partnership to date in Alzheimer's disease research, it receives generous support from private-sector companies and foundations. ADNI's goal is to find neuroimaging and other biological markers that can detect disease progression and measure the effectiveness of potential therapies. The study expanded over the years and now involves over one thousand volunteers, a mix of cognitively healthy people and those with Alzheimer's disease or mild cognitive impairment, which is frequently a precursor condition to Alzheimer's disease. To speed the pace of analysis and findings, magnetic resonance imaging and positron emission tomography brain images as well as clinical, genetic, and fluid biomarker data are available to qualified researchers worldwide through a Web-based database. Findings from this initiative have generated excitement about using brain and fluid biomarkers to identify people at risk for developing Alzheimer's or to characterize the pace of deterioration.

ADNI has been remarkably fruitful. To date, more than 430 papers using ADNI data have been published from investigators around the world, and many more will come as more data are collected and analyzed. Accomplishments include new findings about how changes in the

structure of the hippocampus may help gauge disease progression and the effectiveness of potential treatments, and the establishment of biomarker and imaging measures that predict risk for cognitive decline and conversion to dementia. The success of ADNI has also inspired similar efforts, supported by the Alzheimer's Association, in Europe, Japan, Argentina, Australia, Taiwan, Republic of Korea, and China.

The International Alzheimer's Disease Research Portfolio (IADRP). To enhance coordination and collaboration among Alzheimer's research funders internationally, NIA, in partnership with the Alzheimer's Association, developed a public database for tracking Alzheimer's disease research and funding. Launched in 2012, the International Alzheimer's Disease Research Portfolio enables funding organizations and researchers to assess the changing landscape of Alzheimer's research, coordinate strategies, leverage resources, avoid duplication, and identify promising areas of growth. Today, 13 major Alzheimer's disease research funders in the United States, United Kingdom, Canada, and Australia have provided funding data, and many others use the IADRP database.[7]

The Health and Retirement Study. NIA has pioneered cross-national research, sponsoring collaborative international projects, and disseminating findings in aging-related conditions, including Alzheimer's Disease, and concerns affecting people worldwide. Significantly, NIA's Health and Retirement Study has served as the model for similar large-scale longitudinal studies in other countries. These include the English Longitudinal Study of Ageing; the Study of Health, Ageing, and Retirement in Europe; the Mexican Health and Aging Study; the Korean Longitudinal Study of Aging; and the Chinese Health and Retirement Survey.

Future Directions

[7] See http://iadrp.nia.nih.gov/cadro-web/.

A particularly promising area for the G8 to approach first involves the rapid and extensive sharing of data, disease models, and biological specimens, with appropriate consent and privacy protections. Alzheimer's disease is a complex disorder, and collaboration and sharing of data and samples on an international scale is crucial, especially in light of constrained budgets. Over the past few years, international collaboration and data sharing have resulted in unprecedented advances in identifying Alzheimer' s disease gene risk factors. These discoveries offer new therapeutic targets for researchers world-wide. The more we encourage collaboration and the breaking down of barriers, the more we advance our understanding of Alzheimer's disease.

In 2014, the G8 countries plan to hold a series of high-level "legacy events" in partnership with the OECD, WHO, the European Commission, the EU Joint Programme on Neurodegenerative Disease, and private partners, to develop cross sector partnerships and innovation focused on social impact investment, new care and prevention models, and partnerships between academia and industry. We look forward to participating in these important meetings, as they will represent useful opportunities to learn from other countries about what is working in each of these critical areas. The U.S. will lead one of these efforts, hosting a follow-up meeting of G8 health ministers and global experts (including WHO and OECD) in early February 2015 as part of the next NIH-hosted Alzheimer's Research Summit. Participants will review the progress that has been made on our research agenda and help provide updated direction for the way forward.

Thank you. I welcome your questions.