

U.S. House Foreign Affairs Committee
Subcommittee on Africa, Global Health, and Human Rights
Global Strategies to Combat the Devastating Health and Economic Impacts of Alzheimer's Disease

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Good afternoon Chairman Smith, Ranking Member Payne and members of the Subcommittee. Thank you for the opportunity to join you in this discussion about the global impacts of Alzheimer's disease.

I am Bill Thies, Chief Medical and Scientific Officer for the Alzheimer's Association.

About Alzheimer's Disease

Since its inception in 1980, the Alzheimer's Association has led the Alzheimer's movement: promoting and funding innovative research; speaking out for greater public awareness and the need for increased research, prevention, and care; and working on a global, national and local level to enhance care and support for all those affected by Alzheimer's and related dementias.

The urgency of the Alzheimer's Association's work is driven by the millions now affected by Alzheimer's. Today, an estimated 5.4 million people suffer from Alzheimer's in the United States¹ and approximately 36 million are affected worldwide.² By 2050, there will be as many as 16 million Americans suffering from Alzheimer's, with a projected global total of more than 115 million. Alzheimer's disease is an escalating global epidemic. In almost every country, the proportion of people aged over 60 years is growing faster than any other age group as a result of both longer life expectancy and declining fertility rates.

Alzheimer's is the most common type of dementia that causes problems with memory, thinking and behavior. While research has revealed a great deal about Alzheimer's, with the exception of certain inherited forms of the disease, the cause or causes of Alzheimer's disease remain unknown. The greatest risk factor for Alzheimer's disease is advancing age, but scientists have come to understand that Alzheimer's is not a normal part of aging. In its early stages, memory loss is mild, but with late-stage Alzheimer's, individuals lose the ability to carry on a conversation and respond to their environment, requiring caretakers to provide constant supervision and attentive care.

No treatment is available today to slow or stop the deterioration of brain cells in Alzheimer's disease. Approximately 75 to 100 experimental therapies aimed at slowing or stopping the progression of Alzheimer's are in clinical testing in human volunteers. The Alzheimer's Association applauds the Chairman's leadership on Alzheimer's issues by authoring the Alzheimer's Breakthrough Act, a bill that requires the Director of NIH to accelerate the development of treatments that prevent, cure, or slow the progression of Alzheimer's disease.

¹ Alzheimer's Association, *2011 Alzheimer's Disease Facts and Figures*.

² Alzheimer's Disease International, *World Alzheimer Report 2010*

The Global Cost of Alzheimer's

Alzheimer's disease is a global crisis. Current estimates indicate that about 36 million people worldwide are living with dementia, and that is expected to more than triple by 2050.

Last year on World Alzheimer's Day, the Alzheimer's Disease International (ADI) released the *World Alzheimer Report 2010: The Global Economic Impact of Dementia*, which explores the cost of dementia to our societies. ADI is a London-based, nonprofit, international federation of 73 national Alzheimer's organizations, including the Alzheimer's Association (U.S. member), which was a founding member.

According to the 2010 Report, the global cost of dementia consumes one percent of global Gross Domestic Product (GDP) and is estimated to cost \$604 billion by 2010. About 70% of the costs occur in Western Europe and North America. The Report finds that costs in low and middle income countries are likely to rise much faster than in high income countries, because, with economic development, costs will increase towards levels seen in high income countries, and because increases in numbers of people with dementia will be much sharper in those regions. In the United States, the aging of the population will result in the direct costs to American society of an estimated \$183 billion this year to \$1.1 trillion in 2050. This does not include the \$202 billion in unpaid care provided by nearly 15 million family and friends.

Costs were attributed to the direct costs of medical care (the costs of treating dementia and other conditions in primary and secondary care), direct costs of social care (provided in residential care settings and by community care professionals), and informal care (unpaid care provided by family caregivers and others).

Recently, the Alzheimer's Association called on the World Health Organization (WHO) to make Alzheimer's disease and other dementias a Non-Communicable Disease (NCD) priority. As the costs and prevalence show, the global Alzheimer's crisis demands the attention of the WHO, who can assist in implementing programs to increase the early detection and diagnosis of Alzheimer's; ensure access to medical and non-medical care and support services; promote comprehensive and coordinate care approach to treatment and disease management of those with NDCs; and support the unpaid Alzheimer's caregivers.

This crisis is placing – and will increasingly place – an enormous strain on the health care system, families, and government budgets of nations around the world.

Global Research Efforts

The Alzheimer's Association is committed to accelerating the global effort to eliminate Alzheimer's disease. No single organization can surmount a challenge as great as Alzheimer's. To help achieve our vision of a world without Alzheimer's, the Association partners with key government, industry and academic stakeholders in the global race to end Alzheimer's. We believe in the value of collaboration and are a catalyst toward the time when we will have disease-modifying treatments, preventive strategies and gold-standard care for all people affected by Alzheimer's disease.

The Association formula for progress rests on four pillars. Funding, increasing collaborations with investigators, sharing data, and overcoming barriers to progress. The first pillar is the Alzheimer's Association International Grant Program. Typically 10 to 15 % of our grant funds are expended outside the US. Currently, we fund grants in 24 countries. We fund across the total spectrum of Alzheimer's research from molecular biology to medical systems investigation. Our funding is peer

reviewed by a vast international network of volunteer scientists and quality-assured by our Medical and Scientific Advisory Council, a group of distinguished professionals who represent a range of dementia research, including bench research, clinical care, community health and support services. In addition to funding research directly, we work to ensure the Federal investment in Alzheimer's research is comparable with the public threat of the disease.

The second pillar of the Alzheimer's Association program is encouraging increased cooperation between scientists. The Association is responsible for the largest meeting of Alzheimer's scientists every year. This meeting, The Alzheimer's Association International Conference (AAIC), will attract 5,000 scientists to Paris in July to compare, reveal progress, and develop new working collaborations to advance the disease. AAIC provides a platform for presentation and discussion of all aspects of Alzheimer's research from genetics to animal models, pathology, biomarkers, interventions, and social and behavioral issues. By encouraging the attendance of researchers from around the world, the Alzheimer's Association is able to bring new innovations in Alzheimer's research to a single thought forum designed to accelerate the understanding of Alzheimer's and related dementias. The Association is also the home of the International Society for the Advancement of Alzheimer's Research and Treatment, a collegial society that encourages focus groups for increased cooperation.

The third pillar of our program is sharing of information. We publish *Alzheimer's & Dementia*, the official journal of the Alzheimer's Association. This journal allows important progress to be collected in one place to increase efficiency of Alzheimer's research. Recently, the latest criteria defining Alzheimer's disease were published in *Alzheimer's & Dementia*. We partnered closely with the National Institute on Aging (NIA) of the National Institutes of Health to develop the first new criteria and guidelines to diagnose Alzheimer's disease in 27 years. The new criteria and guidelines are the result of work that began two years ago, when three expert workgroups consisting of a total of more than 40 Alzheimer's researchers and clinicians from around the globe began the in-depth process of reviewing the original criteria and deciding how they might be improved by incorporating research advances from the last three decades. These criteria are in the process of reshaping our approach to Alzheimer's research and treatment.

The fourth and final pillar of our program is selectively investing in projects to overcome common barriers in the field of Alzheimer's. Projects included in this effort, that I will discuss in detail, include TrialMatch™, World Wide Alzheimer's Disease Neuroimaging Initiative (WW-ADNI), and the Cerebrospinal Fluid (CSF) Quality Control Program.

Last year, the Association launched TrialMatch™, a confidential, free, and interactive tool that provides comprehensive clinical trial information and an individualized trial matching service for people with Alzheimer's disease and related dementias. Recruiting and retaining trial participants is now the greatest obstacle, other than funding, to developing the next generation of Alzheimer's treatments.

WW-ADNI, which the Alzheimer's Association is a major sponsor, is a collaborative effort of scientists from around the world and is the umbrella organization for neuroimaging initiatives being carried out through the North American ADNI, European ADNI (E-ADNI), Japanese ADNI, Australian ADNI (AIBL), and Taiwan ADNI. The Initiative unites leading international investigators in a common effort to:

- Help predict and monitor the onset and progression of Alzheimer's disease
- Establish globally recognized standards to identify and diagnose Alzheimer's disease

- Document cognitive changes linked to physical changes
- Share data across the international research community

Ultimately, we aim to better understand the physical changes that occur in healthy individuals compared with individuals with mild cognitive impairment (MCI) and Alzheimer's disease. WW-ADNI focuses both on changes in the brain that can be identified with tools such as positron emission tomography (PET) and magnetic resonance imaging (MRI) and changes in fluids such as blood and cerebrospinal fluid (CSF). As its name suggests, another area of focus is to involve individuals from multiple sites around the world and to follow their progress over several years to gain a worldwide picture of the physical changes that lead to Alzheimer's disease.

Data from WW-ADNI are expected to play a key role in identifying effective treatments for Alzheimer's, as well as methods that may prevent the disease or slow its progression. Each WW-ADNI site collects participant data from MRI and PET scans. Other data on physical changes related to the onset and progression of MCI and Alzheimer's (called biomarkers) are also gathered. WW-ADNI is unique in that most of the clinical, neuropsychological, imaging, and biological data gathered is quickly made available to the scientific community at no cost so researchers can use the information when designing or evaluating their own research.

The Alzheimer's Association Cerebrospinal Fluid (CSF) Quality Control Program, which brings together laboratories across the globe with the aim of standardizing the measurement of potential Alzheimer's biomarkers. Several studies, including studies involving data from the ADNI have shown that levels of biomarkers in CSF are often accurate predictors of which individuals will go on to develop Alzheimer's disease. CSF biomarkers may be useful not only in aiding early detection of Alzheimer's and improving diagnostic accuracy, but also in identifying and monitoring the effects of drugs in clinical trials, understanding the molecular changes that lead to Alzheimer's, and helping to ensure that individuals recruited into Alzheimer's clinical trials are on a path toward developing the disease. More than 60 labs in North and South America, Asia, Australia and Europe are participating in the program.

A Plan for the Alzheimer's Crisis

The *World Alzheimer Report 2010* contained seven recommendations, one of which called on governments to make dementia a health priority and develop national plans to deal with the disease. Thanks to your support, this year the United States joined the growing list of countries across the world taking an important step towards tackling Alzheimer's disease — the creation of a national plan.

The National Alzheimer's Project Act (NAPA) passed unanimously in both the U.S. House and Senate last December and was signed into law by President Obama in January 2011. The National Alzheimer's Project requires creation of an annually-updated national strategic plan to address the rapidly escalating Alzheimer's disease crisis and will ensure the coordination and evaluation of all national efforts in Alzheimer's research, clinical care, institutional, and home- and community-based programs and their outcomes.

By requiring the government to make Alzheimer's a national priority, create a strategic plan for Alzheimer's, and coordinate its activities, the National Alzheimer's Project has the potential to create the same success that has been demonstrated in the fights against other diseases. Leadership by the Federal government has helped lower the number of deaths from other major diseases such as HIV/AIDS, Influenza and Pneumonia, and stroke. We can and must do the same for the millions of Americans living with Alzheimer's disease.

In addition to improving health outcomes for people living with Alzheimer's and for reducing the financial impact of Alzheimer's on families and our Federally funded programs, NAPA requires the Secretary of Health and Human Services to coordinate with international bodies to integrate and inform the fight against Alzheimer's globally. We hope that the Secretary will work with her global partners to improve the treatment and care of the millions of people living with Alzheimer's.

The Alzheimer's Association is working with the Administration to ensure swift implementation of the National Alzheimer's Project and looks forward to working with Congress once the first annual plan is reported early next year.

Conclusion

Thank you for inviting me to participate in this important discussion about the global impact of Alzheimer's disease. The Alzheimer's Association commends the committee for today's hearing and looks forward to continued work together to do all we can to improve the lives of those contending with Alzheimer's, as well as for those who care for them.