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**“Global Strategies to Combat the Devastating Health and
Economic Impacts of Alzheimer’s Disease”**

*Africa, Global Health and Human Rights Subcommittee
Excerpts of Remarks by Chairman Chris Smith
June 23, 2011*

Good afternoon, and welcome to our witnesses and to everyone who is joining us for this first ever congressional hearing examining the global strategies to combat the devastating health and economic impacts of Alzheimer’s disease.

Alzheimer's disease is the most common form of dementia and is a degenerative, irreversible, and terminal disease. Alzheimer’s disease is most prevalent in people over 65 years of age, but "early-onset" Alzheimer's can occur at a much younger age – even decades earlier. Alzheimer’s progressively destroys remembering, thinking and reasoning skills, and eventually even the ability to carry out the simplest tasks.

While the cause and progression of Alzheimer's disease are not well understood, research indicates that the disease is associated with "plaques" and "tangles" in the brain that begin to develop 10 to 20 years before any problems are evident. As plaques and tangles form, neurons lose their ability to function and eventually die. As more neurons expire, affected brain regions begin to contract. In the final stages of Alzheimer’s, there is widespread brain damage and tissue shrinkage.

Current treatments provide modest symptomatic benefits, but there are no therapies available that can halt or even delay the progress of the disease. The effects and duration of the disease vary from patient to patient, but it is invariably fatal.

According to Alzheimer’s Disease International there were 35.6 million people living with Alzheimer’s and other dementias in 2010, and the number of people living with dementia is expected to nearly double every 20 years to 65.7 million in 2030 and 115.4 million in 2050. However, the increase is greater for low and middle income countries, as 57.7% of all people

with dementia are currently living in low and middle income countries, rising to 63.4% in 2030 and 70.5% in 2050.

Here in the US, up to 5.4 million people have Alzheimer's disease, and the number is expected to increase to up to 16 million by 2050 unless something is done to reverse the trajectory. The elderly population as a whole is growing, but the oldest elderly are the fastest growing age bracket.

According to Alzheimer's Disease International, the total worldwide estimated costs of dementia is \$604 billion, with 89% of the costs occurring in high income countries and about 70% of those costs occurring in just two regions – Western Europe and North America. In low and lower middle income countries, the costs of informal care (unpaid care provided by families and others) accounts for 64% of all care, while in high income countries, informal care accounts for 40% of the costs of care.

Even in counties that have high health care expenditures and that provide government-funded support for long-term care, a vast amount of care occurs informally within families. Not only will the increase in the population with Alzheimer's and other dementias result in skyrocketing costs of healthcare, but changing family dynamics will further exacerbate the economic stress on families, societies and governments.

As an example, on Monday of this week, I chaired a hearing of the U.S. Helsinki Commission on the implications of demographic trends in the OSCE region and elsewhere in the world. Richard Jackson, Director of the Global Aging Initiative at the Center for Strategic and International Studies (CSIS), testified in that hearing that in certain European countries, by 2020, the extended family will essentially be non-existent. Half of young adults don't have any brothers or sisters or uncles or aunts or cousins. Another projection during the same hearing was that Japan potentially could experience an explosion of Alzheimer's prevalence of up to 1 in 25, as a result of the aging of the population, coupled with up to 40% of the Japanese being childless.

When we look more closely at projected demographics for some countries, the pool of family caregivers is shrinking as the number of individuals with Alzheimer's is exploding, which will significantly shift the costs of care model away from unpaid informal care to institutional and direct medical care.

Poor recognition, under-diagnosis, and lack of public awareness are all causes of significant problems for afflicted individuals and their caregivers, especially in low and middle income countries.

In those developed countries, it is often incorrectly assumed that dementia, such as Alzheimer's, is a normal part of aging and that nothing can be done to address it. Because of the lack of recognition of the nature of the problem, there is a lack of pressure on government bodies to respond to the crisis. As a result, there is a lack of effort to devote resources to finding a cure, to help those with Alzheimer's by providing assistance, or to seek a diagnosis and care of those potentially afflicted.

International cooperation and collaboration to find solutions for Alzheimer's is not new, as clearly demonstrated by the fact that the Alzheimer's Disease International began in 1984 – 27 years ago – with four members and has grown through the years to over 75 members. Similarly, I look forward to receiving testimony outlining past, present and future international research collaborations.

However, we seem to be at a precipice now of making great strides on several different fronts. First, there is a greater recognition, including in low and middle income countries of the need to address Alzheimer's as a major public health crisis. I agree with many of you that we need to pressure international institutions responsible for health issues to recognize dementia as a global health problem. That is why Congressman Markey and I coordinated a letter signed by 28 Members of Congress, to U.N. General Assembly President Deiss, to include Alzheimer's disease in the September U.N. Summit on Non-Communicable Diseases. Involvement of international organizations, such as the U.N. and WHO, are necessary to make substantial inroads toward raising awareness of dementia and beginning to address it in national health care policies. I plan on sending today's hearing record to all relevant U.N. officials and heads of country delegations.

Second, there is a significant momentum toward broader sharing and an increasing number of proposals for major intergovernmental research projects that will take advantage of emerging research opportunities and new computing platforms and communications technologies. Also, in direct response to two of our witnesses, Eric Hall and George Vradenburg, who made recommendations for a government-sponsored international conference, I will introduce legislation to convene in the first quarter of calendar year 2012 or at a date thought to be more appropriate an international conference to include at a minimum countries that have or are in the process of developing National Alzheimer's Plans.

Third, it is significant that that NIH funded the first intensive caregiver support intervention proven to be effective, through rigorous testing, in an ethnically diverse population, and that they are beginning to export the program. I look forward to Dr. Hodes' testimony on this and other initiatives.

Finally, since 2005, several countries have developed national Alzheimer's plans or strategies, which have already become to accelerate changes in health care systems.

I was honored to have introduced with Congressman Markey legislation to create a national strategic Alzheimer's plan for the US. The National Alzheimer's Project Act (S 3036), which was passed by the Senate and House in December and signed by the President on January 4, 2011, was a large legislative victory for the cause of Alzheimer's in the US. The National Alzheimer's Project Act (or NAPA) is designed to help turn the tide by creating a national strategic plan to address the rapidly growing crisis of Alzheimer's disease. NAPA provides for the coordination of all Alzheimer's disease efforts across the federal government. It also establishes an Advisory Council on Alzheimer's Research, Care, and Services that will allow participation by patient advocates, health care providers, researchers, and State health departments in the evaluation of federal Alzheimer's plans and in the formulation of the strategic plan to reduce costs and improve health outcomes. Recognizing the importance of international

collaboration, the law requires coordination with international bodies to make the US government a committed partner in the global fight against Alzheimer's.

Like many of you, I will be closely following the implementation of NAPA, and, if Dr. Hodes would like to share any information on HHS' activities in implementing NAPA, that would certainly be appreciated.

While the National Alzheimer's Strategic Plan is being developed, Congressman Markey and I have introduced additional legislation designed to bolster programs for Alzheimer's research and diagnosis.

Introduced in May of this year, the Alzheimer's Breakthrough Act (HR 1897) is designed to accelerate treatments that prevent, cure, or slow the progression of Alzheimer's disease and reduce the financial burden of Alzheimer's on federally funded programs and families. The Director of NIH will develop a strategic research plan, including budget estimates, for Alzheimer's disease—focused on targeting scientific opportunities and priorities; developing public/private partnerships; and improving coordination of Alzheimer's research across the 27 Institutes and Centers at NIH.

Instead of prescribing a funding level for Alzheimer's research at NIH, the bill requires the experts at NIH to tell Congress and the Administration what Alzheimer's research is needed to develop treatment breakthroughs and what level of funding is needed to accomplish that goal.

In addition, I joined Congressman Markey in introducing in April 2011, the Health Outcomes, Planning and Education (H.O.P.E.) for Alzheimer's Act (HR 1386), which will provide Medicare coverage for comprehensive diagnoses of Alzheimer's disease and help improve care and reduce costs by providing information and resources to newly diagnosed patients and their families.

I am looking forward to hearing the valuable perspectives that each of our witnesses brings to this hearing.