HARRY JOHNS, PRESIDENT & CEO ALZHEIMER'S ASSOCIATION CHICAGO, IL SUMMARY

Alzheimer's is the most under-embraced, serious health crisis our nation faces today. It is undermining efforts to control health care costs, assure access to quality care, and protect the retirement security of generations to come. That is the undeniable conclusion of the report the Alzheimer's Association report on *Facts and Figures about Alzheimer's disease* in the United States. Summarizes key findings:

- 5 million people have the disease now (10% more than previous estimates.) By midcentury, as many as 16 million will have Alzheimer's.
- Half a million new cases will develop this year one every 72 seconds.
- Alzheimer's is now the 5th leading cause of death in older Americans. Death rates from the disease have risen 33% in four years, at the same time that rates for other diseases common in the elderly are going down every year.
- Alzheimer's is costing the nation \$148 billion a year. Medicare spend \$91 billion; Medicaid another \$21 billion.
- By 2015, Medicare and Medicaid will be spending \$210 billion on beneficiaries with Alzheimer's.
- Alzheimer's is overwhelming the health and long term care system. 25% of elderly hospital patients, at least 47% of nursing home residents and half of people in assisted living and adult day care have dementia.
- Yet 70% of people with Alzheimer's live at home where at least 10 million family members provide unpaid care. The annual value of the unpaid work Alzheimer caregivers do is valued at nearly \$83 billion.

These statistics are a call to action. For the first time in history there is real hope that we can get this disease under control. With sufficient resources, we will find ways to prevent this disease in millions of Americans and, for those who still get it, change it from a death sentence to a manageable chronic illness. A modest investment in total federal budget terms has the potential for enormous returns. Within five years of the start of a breakthrough treatment, projected annual Medicare and Medicaid spending on Alzheimer's could decline by more than \$60 billion, with even larger savings every year thereafter.

Describes current collaborations of Alzheimer's Association with key federal agencies – NIH, CDC, AOA, FDA. Presents key Alzheimer's Association legislative priorities for the 110 Congress:

- 1. To provide *access* to effective treatments, increase funding for Alzheimer research at NIH by \$125 million and provide adequate resources to FDA to expedite review of new drugs.
- 2. To ensure *quality* health care for people with Alzheimer's, add a targeted chronic care management benefit to Medicare and continue support for proven programs serving Alzheimer families the Call Center, the Brain Health Initiative, Safe Return, and the State Matching Grants Program.

3. To protect *retirement security* of American families enact long term care financing legislation to help insure against the economic risk of Alzheimer's and increase funds for caregiver support programs.

STATEMENT OF HARRY JOHNS, PRESIDENT & CEO ALZHEIMER'S ASSOCIATION CHICAGO, IL

to

AGING SUBCOMMITTEE, SENATE HEALTH, EDUCATION, LABOR & PENSIONS COMMITTE MARCH 20, 2007

Chairman Mikulski, Senator Burr, and Members of the Subcommittee. Thank you for holding this hearing, and for your persistent leadership in the fight against Alzheimer's disease.

It is an honor to appear before you, on behalf of people with Alzheimer's and their families — hundreds of whom are behind me here this morning. They have come to Washington at their own expense, from 48 states, to tell their Members of Congress about their own struggles with Alzheimer's, and to enlist them in an all-out war against this horrible affliction.

I especially want to thank you, Senator Mikulski, for introducing with Senator Bond the Alzheimer's Breakthrough Act and the Alzheimer's Family Assistance Act. Your legislation will help millions of families and caregivers and will speed the day that we have a world without Alzheimer's. We appreciate your commitment to act quickly on these important measures. I assure you that all of us in the Alzheimer's Association will do everything we can to help you.

Today, the Alzheimer's Association is releasing a comprehensive report on the latest Facts and Figures about Alzheimer's in the United States. We are issuing a wake up call to Congress and the nation. Alzheimer's disease is exploding into an epidemic that will undermine all of our best efforts to control health care costs, assure access to quality care, and protect the retirement security of generations to come. Despite its devastating consequences, which you know all too well, it remains the most under-embraced, serious health crisis our nation's faces. I do not have time here to go over all of the data. I ask that the report be made a part of the record and will just note a few of its findings.

- More than 5 million people in the United States are living with Alzheimer's disease today. That is a 10% increase from previous estimates, but it is only the tip of the iceberg. By mid-century, as many as 16 million will have the disease. That is more than every man, woman and child currently living in Maryland and North Carolina combined.
- We will see half a million new cases of Alzheimer's this year alone. That means someone in America is developing Alzheimer's disease every 72 seconds!
- A diagnosis of Alzheimer's is a death sentence. It is now the fifth leading cause of death in older Americans. Death rates from many diseases common in the elderly —

like heart disease, breast and prostate cancer, and stroke — are declining every year. But the death rates for Alzheimer's disease went up 33% in just four years. The absence of effective disease modifying drugs, coupled with the aging of the baby boomers, makes Alzheimer's *the* health care crisis of the 21st century.

- Alzheimer's already costs the nation \$148 billion a year. Medicare alone spent \$91 billion on beneficiaries with the disease in 2005 and Medicaid spent another \$21 billion. By 2015 those two programs will be spending \$210 billion just on people with Alzheimer's. And, by 2025, the cost of today's entire Medicare program will be consumed by Alzheimer's alone.
- The disease is overwhelming health and long term care systems: 25% of elderly hospital patients, 47% of nursing home residents, and at least 50% of people in assisted living and adult day care have Alzheimer's or another dementia.
- This is true, even though 70% of people with Alzheimer's live at home, where at least 10 million family members provide unpaid care. In Maryland, these caregivers are providing over 145 million hours of care a year; in North Carolina, almost 270 million hours. Nationwide, the work Alzheimer caregivers are doing is valued at nearly \$83 billion.

These caregivers are the lifeblood of long term care in the United States today. Our report documents the huge toll this is taking on families – in lost work, physical illness and injury, depression, even premature death. The term "help with activities of daily living" doesn't sound so bad, until you stop to think about what that means, day in and day out, for families struggling with Alzheimer's disease. It is a 70-year old woman getting her husband in and out of bed every day, an 80-year old man who never gets a decent night's sleep because his wife wanders the house all night and he has to keep her from harm, a daughter changing her father's diapers and cleaning up after him, a son bathing and dressing his mother who no longer knows who he is.

This is the reality of Alzheimer's disease. It is not a pretty picture. But it is a picture that we can change. Today, there is real hope that we can get Alzheimer's under control, that we will find the ways to prevent millions from ever getting the disease, and that for those who do get it, we can change it from a death sentence to a manageable chronic illness. Other witnesses this morning will tell you about effective drug treatments on the horizon, new information on how to maintain our brains, and proven interventions that can reduce the burden of the disease.

We cannot win this fight against Alzheimer's without an all-out commitment from Congress and from every relevant part of the federal government – especially NIH, FDA, CMS, CDC, and AOA. The Association is working closely with all of these agencies to maximize our mutual efforts within the limits imposed by existing law and resources. We are proud of our longstanding partnership with the National Institute on Aging. We are gratified by the response of the Food and Drug Administration to our Effective Treatments Initiative, to increase its focus on Alzheimer's and to bring patients and caregivers into the drug review process. Our joint projects with the Administration on Aging are serving hundreds of thousands of Alzheimer families. We are excited about our new collaboration with the Centers

for Disease Control to expand public understanding of Alzheimer's and ways to reduce personal risk and improve diagnosis and treatment.

We need your help as well. We are here on Capitol Hill to enlist the support of the 110th Congress on our three Key Legislative Priorities:

- 1. Provide access to effective treatments to prevent or slow the onset and progression of Alzheimer's, by increasing funding for Alzheimer research at the National Institutes of Health by \$125 million and by providing adequate resources to the Food and Drug Administration to expedite review of new drugs.
- 2. Ensure quality health care for people with Alzheimer's disease, by adding a targeted chronic care management benefit to Medicare and by continuing support for proven programs that are serving Alzheimer families the Call Center, the CDC Brain Health Initiative, Safe Return, and the State Matching Grants Program.
- 3. Protect the retirement security of American families, by enacting long term care financing legislation to insure against the economic risk of Alzheimer's disease, and by increasing funds for caregiver support programs.

These proposals require a modest investment in total federal budget terms but, as the other witnesses in this panel will explain to you, they have the potential for enormous returns – in reduced health and long term care costs to federal and state budgets and in improved quality of life for millions of American families.

I would like to close on a personal note. We cannot forget the human faces behind all of the statistics. They are the faces of spouses, parents, children and grandchildren whose lives are being disrupted by Alzheimer's disease. I am now one of those faces. This past year, my mother was diagnosed with Alzheimer's. Each of us now lives with a new realization that, unless we deliver on the promise of research, our nation's children and grandchildren may be facing a similar fate.

Please, help us make sure that does not happen. Thank you.