STATEMENT BY
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UPON RECEIPT OF THE HUMANITARIAN AWARD
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Thank you very much. It is a tremendous honor to be the recipient of the Alzheimer's Association's Humanitarian Award.

In preparing my remarks for today's honor, I came across a speech that I gave back in 1984 at a kick-off event for the first program in New England dedicated to the treatment of Alzheimer's Disease in an adult day-care setting. In that speech 17 years ago, I spoke of the ravages of the disease; the need for long-term care solutions; the need for a cure; and the mind-boggling fact that 2 million Americans were afflicted. While great strides are being made every day, in large part because of the work that all of you are doing on an ongoing basis, great challenges remain. The disease continues to ravage – today it's 4 million Americans -- we are still searching for a long-term solution, and despite the remarkable progress in research, a cure continues to elude us.

Little did I know when I spoke of Alzheimer's in 1984 my own mother would become one of the millions who would fall victim to this horrible illness. My family found out just a short time after I delivered that speech long ago.

I know that you all know how difficult it can be to talk about it when there's a person in your family who is living with the disease – it's not an easy thing to do. And so I did not deliver another speech on Alzheimer's for the rest of the 80s and most of the 90s – it was just too painful.

At home, my father cared for my mother for all the years she had the disease. Day in and day out… I view his devotion as heroic… but to my father he saw this burden that he shouldered as an honor. Because you see my mother was the valedictorian of her high school class… she was brilliant…in today's world she would have continued with her education. But in 1926, women didn't go to college, they stayed at home to care for the family. And since my grandmother had passed away while her children were still young, my mother – being the oldest daughter – had to raise her four younger siblings. So she had to stay at home and raise a whole family before she got married at age 39 and had me at 40. My father, who was a graduate of Lawrence Vocational High School, a milkman who married a valedictorian, would always say to me, "Eddie, if the strength of your brain had anything to do with who got Alzheimer's, your mother would have been taking care of *me* for the last fifteen years." That's how insidious Alzheimer's is. And he said, "She's never going to step foot in a nursing home – I'm keeping her at home – I'm keeping her at home the whole time." And he did. He was 81, 83, 85, 87, 88 and she never stepped foot in a nursing home. He said, "It was an honor, Eddie, that she married me. I was a milkman."

My family's story is but one of millions of similar stories across our nation. There are millions of caregivers across this country selflessly shouldering the burden of caring for their loved ones at home… these people are true heroes. But even heroes need help.

My mother passed away from Alzheimer's two years ago. My father and brothers and I were sustained by the love only a family can provide. And, in an interesting twist, it was only at the point in time after which my mother passed away, was it possible for me to return to work on this issue.

In many respects, working on Alzheimer's issues affords me the opportunity to honor my mother who had the disease, and my father who cared for her for all those years.

So, a year after my mother lost her life to Alzheimer's I approached a Republican colleague in the House, Chris Smith of New Jersey to join me in starting the Bipartisan Congressional Task Force on Alzheimer's Disease. Today we are 130 members strong and growing. We formed the Task Force to focus on issues facing Alzheimer's patients and their caregivers and to direct congress to help in the battle that caregivers and patients face every day.

Last year we set out three goals that we wanted to accomplish. One was to dramatically increase the amount of money spent on research for Alzheimer's. Along with your help, we were successful in increasing the NIH budget for Alzheimer's research by $85 million bringing the total federal commitment to $520 million.

The second thing we wanted to do was to create a clinical research program specific to Alzheimer's Disease. During my mother's illness it was brought to my attention that there wasn't enough clinical research going on in the area of Alzheimer's. So we introduced the Alzheimer's Clinical Research and Training Awards Act – to encourage physician-scientists to focus on Alzheimer's clinical research. We were ultimately successful in getting this program into law providing $11.5 million over five years.

And finally, we wanted to clarify the "homebound" definition in the Medicare law so that Alzheimer's patients could attend adult day care and give their caregivers a break in the day, and so that all Medicare beneficiaries could attend Mass or Synagogue or Mosque without losing their home health benefit. We were successful in making these changes. But I know that there's more we need to do to improve this definition – and I am introducing legislation to do this.

It was no easy task getting the homebound definition broadened to allow beneficiaries to attend adult day care for therapeutic purposes and religious services. To be honest with you, I ran into a brick wall for most of the year… but I kept talking to as many Republicans as I could, to find those who were sympathetic to the needs of the homebound and their caregivers. And so finally, with about two weeks left in the session, I found the person on the Republican side who would partner with me, who would ensure that as a condition of the budget act passing in October, that this provision would actually remain in. And I won't tell you who was opposed to having it included – because we'll all have to work with him again in this Congress. But this was a mighty -- a titanic battle -- that included me calling Maureen Reagan and trying to ensure that I was creating a campaign that would make this work. I called in every chit I had in those final two weeks to put it in, and it was basically this little personal operation calling upon the good will and power of some Republicans who had family members who had been in a long-term care situation.

I share that story with you just to illustrate the challenge of making even a small change in these important programs notwithstanding the obvious need for a sea change in how we approach long-term care. The trends are ominous. Our nation is aging. The health of <u>older Americans</u> is a critical priority. We have a moral obligation to take care of the generation of Americans who gave so much to all of us and whose work and sacrifices have made America great. Today's seniors are the greatest generation.

In 1900, the average life expectancy was 48. In 1999, life expectancy at birth reached an all-time high of 77 years. In 1900 about 1 in 25 Americans were over the age of 65. In 1990, the proportion rose to 1 in 8 -- a 10-fold increase. It is estimated that by the year 2040. 1 in 5 Americans will be over the age of 65 and there will be almost four times as many very old people over the age of 85 as there are today.

As America ages, the number of people with chronic conditions such as heart disease, cancer, diabetes and Alzheimer's disease is increasing dramatically. By the year 2030, nearly 150 million Americans will have a chronic condition.

We have a chronic care crisis in our country today. Without a coherent and comprehensive approach to care for people with disabling chronic conditions, this situation will only worsen. People with chronic diseases and disabilities -- patients and families affected by conditions like Alzheimer's, Parkinson's, Congestive Heart Failure, Multiple Sclerosis, Cerebral Palsy, Spinal Cord Injury, Muscular Dystrophy, and Stroke to name a few -- will continue to suffer the consequences of deteriorating health if a strategy is not implemented to meet their long-term care needs.

The rising rate of chronic disease in America has significant implications not only for quality of life but also for escalating health care costs in the United States. We currently spend $470 billion dollars annually on medical costs for people with chronic conditions. By the year 2050, this number is estimated to double. We need a strategy for the future that addresses not only inpatient and outpatient care, but also at-home care, and adult day care.

As a society we must also develop a more enlightened and compassionate approach to end of life issues and provide support for hospice care.

The poet Robert Browning once wrote, "Grow old with me, the best is yet to be." We must ensure that we increase not only the lifespan but also the health span of Americans so that the 30 bonus years of life we have gained in this century and hopefully will continue to gain in the new millenium are truly be be1ter years of life.

But where is long-term care on the President's agenda?

Each and every one of us in this room has an obligation to do everything in our power to reshape the debate over national spending priorities. I view this year as perhaps the most critical year in a generation in terms of the long-term repercussions of the budget decisions that will be made. Just a quick recap. As most of you know, the Congressional Budget Office has estimated that over the next decade, we can expect to accumulate a surplus of $5.6 TRILLION. Right off the top, we should put the tax revenues dedicated to the Social Security and Medicare Trust Funds in a lockbox and take $3.1 trillion off the table. $2.6 trillion for the Social Security Trust Fund, and $500 billion for the Medicare Trust Fund. That leaves $2.5 trillion for all spending and tax relief for the next ten years. That sounds like a pretty big number right – we should be able to set some important public policy goals and fully fund them with that much revenue – we could for instance, come pretty close to solving the long-term care crisis in our country with $2.5 trillion. But wait, there's more to the story.

When President Bush sent Congress the blueprint for his tax plan, he said it would cost $1.6 trillion. A number of other analyses indicate that when the cumulative effect of the proposal is calculated, including making it retroactive and reducing the amount of debt repayment, that the tax cut will actually cost closer to $2.5 trillion. That's the entire surplus. No money for education. No money for prescription drugs. No money for defense. No money to privatize Social Security. And those are just the programs the President has promised he will spend money on. What about our nation's other pressing problems that the President has set no money aside for at all. No money for health insurance to cover 44 million uninsured Americans. No money for school construction. And no money for long-term care – no tax credits, no low-cost insurance offerings, no chronic care benefit through Medicare – nothing for long-term care. This must not stand.

Some people say to me, "Well, we have got to get the surplus out of Washington." And I say, "Well, you can't solve the problem of long-term care or Alzheimer's unless you create it as a *national* campaign." And then I say, "By the way, who's surplus is this anyway?" It's not *my* surplus. Sure, my father worked for the Hood Milk Company, but I went to BC and BC Law School; any failures I have, have to be strictly attributed to me because I didn't measure up to my mother's standards. I don't need anything; I'm doing great! I don't need a tax break. I think the surplus belongs to my mother and father- it's *their* surplus. They built the country. They're the greatest generation. They lived through the Depression, they didn't get to go to school, they had to fight World War II, they had to build the country almost in its entirety after that, and they're all in retirement or heading towards retirement. It's *their* surplus. It's *their* country! So how can we not then say, we're not going to cut Medicare, we're not going to cut Medicaid, we're not going to cut Social Security, we're not going to just nickel and dime the research programs at NIH. And by that I mean, sure we have a bipartisan consensus to increase them, but I mean we should *massively* increase them. This should be a *massive* program.

Research is medicine's field of dreams from which we harvest new findings about the causes, treatment, and prevention of disease. Did you know that since 1950, we have learned more about health and disease than in the entire history of medicine? In fact, we've eliminated some of the major scourges that killed us at the turn of the century like smallpox and diptheria.

That's why we must make sure that research not only survives but thrives.

One of the goals of the Task Force – and I know that you share this goal – is to increase research funding to $1 billion. ONE BILLION DOLLARS FOR ALZHEIMER'S. We are asking for a down payment of $200 million towards a full increase by 2003.

In addition, I want to build on the successes of last year and see to it that more is done with respect to translating the good research that's been done into real and practical benefits for those afflicted with Alzheimer's. I plan to work with the CDC to create an initiative to translate research results in to public health practice.

I recently shared a podium with Walter Cunningham, the astronaut, and we got to talking about the man on the moon project. An individual can't decide to go to the moon. An individual can't decide to cure Alzheimer's. One company can't do it. A medical school can't do it. They need federal funding. They need the National Institute of Health. That's the life's blood of what this entire effort is all about.

And I was thinking as I came over- remember the movie *Apollo 13*, when something has gone wrong with the mission? After studying the problem, the mission control instructed Jim Lovell to make an *adapter*. "Make an adapter." The flight director sent the message: **Failure is not an option**. The message is sent to us**: Failure is not an option**. We must adapt. We must find a way to make sure that the next generation is not beset by this crisis in chronic care.

Pasteur once observed that "Chance favors the prepared mind." The CBO surplus projections are fiction – they may or may not materialize. The aging of Americans is reality. The first wave of baby boomers will retire beginning in 2011. We can choose to prepare for that eventuality by locking away the Social Security and Medicare Trust Fund dollars and reducing the size of President Bush's tax cut or we can turn a blind eye to this reality and leave the fate of chronic care patients to chance. We need you to make that case for Congressman and Senators this year – it's now or never.

So, as we leave here this afternoon, let us all continue to work together to soon reach that day when children will have to turn to their history books to find out what Alzheimer's Disease was. I am grateful for this high honor and I look forward to working with all of you toward that goal in the future.