

Breakthroughs in Alzheimer's Research: News You Can Use

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Testimony

Good morning Senator Bond and Senator Mikulski. Thank you for inviting me to discuss the Alzheimer's Association's legislative priorities as well as our exciting new "Maintain Your Brain" initiative. I want to acknowledge the outstanding leadership that both of you have provided in the fight against Alzheimer's disease. The Alzheimer's Association especially appreciates your commitment and dedication to improving care and services for individuals with Alzheimer's disease and their caregivers. We thank you for introducing S 566, the Alzheimer's Disease Research, Prevention & Care Act, legislation to renew a highly successful program that is providing federal grants to states to develop innovative models of care for persons with Alzheimer's disease. In addition, we are indebted to Senator Mikulski and other members of this subcommittee who are cosponsoring S 538, the Lifespan Respite Care Act, and S 1214, the Family Caregiver Relief Act, proposals to increase the availability of respite care services and create a tax credit for family caregivers.

Since our founding in 1980, the Alzheimer's Association has provided more than \$150 million to support research into the prevention, treatment and eventual cure for Alzheimer's. Our nationwide network of chapters offer frontline support to individuals affected by Alzheimer's with services that include 24/7 information and referral, safety services, and education and support groups. In addition, we are partnering with over 150 local, state and national organizations representing more than 50 million Americans on our "Coalition of Hope", the largest Coalition ever formed in support of research to find new treatments for individuals with Alzheimer's disease. The Coalition of Hope includes groups well known in the aging field, including AARP, the Older Women's League and the National Association of Retired Federal Employees. It also includes other organizations like the Urban League, the Polish American Congress, the NAACP and the Sons of Italy, who know that Alzheimer's touches so many families and communities, in small towns and big cities all across the country.

The mission of the Alzheimer's Association, working in partnership with government and private industry, is to eradicate this disease and to provide support to improve quality of life for those facing the disease now. Through the combined efforts of the Association, the National Institutes of Health, and the pharmaceutical industry, advances in medical treatment have surged forward in recent years. The Alzheimer's Association's goal of delaying the disabling symptoms of Alzheimer's disease, and eventually preventing the disease now appears possible. For the first time, creating "A World Without Alzheimer's" is within reach. We can go to the

American people now with a new message of hope. We can - we will - have a future where Alzheimer's disease is only a memory.

This hearing comes at a critical time. With the aging of the baby boomers, the number of people with Alzheimer's will grow from 4.5 million today to an astounding 11 to 16 million by the middle of the century. Today's issue of Neurology features a new study estimating state-specific projections of the prevalence of Alzheimer's disease through 2025. Although the study found that the greatest rates of growth in the number of cases of Alzheimer's disease will be seen in the Southern and Western regions of the country, few states will be spared from the impact of Alzheimer's disease. Missouri will see an 18 percent increase in the number of cases of Alzheimer's disease. Maryland faces an even greater rate of growth - 28 percent by 2025. Left unchecked, Alzheimer's will undermine our families, communities, and basic economic security. It will overwhelm our health care system, bankrupt Medicare and Medicaid, drain billions of dollars from American business, and destroy retirement security for tens of millions of families. The cost to Medicare will go up 55 percent to \$50 billion in less than 10 years and the cost to Medicaid will soar by 80 percent to \$33 billion. The costs to families and caregivers will go even higher.

We can treat Alzheimer's and some day we may be able to prevent this disease, but not without more funds for research and greater help from Congress. If the current pace and momentum of research is maintained we may be able to delay the onset and progression of Alzheimer's, saving not only billions of dollars to our health care system but also saving millions of lives. This is not the time to tell the scientists to slow down. But this is exactly what will happen unless we continue to expand the public investment in Alzheimer research.

News You Can Use: The Maintain Your Brain? Campaign

The title of this hearing, "Breakthroughs in Alzheimer's Research: News You Can Use" is particularly relevant to an effort underway to change the way Americans think about Alzheimer's disease. Thanks to the rapid progress being made in understanding, diagnosing and treating Alzheimer's disease, we can share the news that Alzheimer's disease is not an inevitable part of aging. Earlier this year, the Alzheimer's Association launched a new Maintain Your Brain? campaign to let the public know that a world without Alzheimer's disease can be a reality, to encourage Americans to take steps now to take care of their brain and to engage more people in advocacy for research, new treatments and improved care.

The Maintain Your Brain? campaign is targeted to the 77 million American baby boomers to encourage them – I should say “us” – to get involved. To date, baby boomers have largely ignored Alzheimer's disease because they don't think there is anything you can do about it. Our campaign is designed to change that before we enter the age of greatest risk for dementia. If we are successful, we may be able to avoid some of the devastating problems that are looming on the horizon.

Our Maintain Your Brain Campaign is based on the mounting evidence that we can manage certain risk factors and maintain optimal brain functions. Just as we can take steps to preserve a healthy heart, we can manage certain risk factors to maintain a healthy brain. Manage your numbers - blood pressure, cholesterol, blood sugar and body weight - to stay healthy as you age. Feed your brain by taking a multivitamin that includes folic acid, vitamins E and C and eat foods rich in omega-3 fatty acids. Exercise both your body

and brain by working out, taking a class, reading, playing cards or working on crossword puzzles. Know that the joint efforts of government agencies, research centers and pharmaceutical companies have uncovered many of the secrets of Alzheimer's disease and that there are many reasons to be hopeful. And, perhaps most importantly, get involved in advocacy for more research, improved treatments, and better care.

#### The Alzheimer Research Agenda

Most scientists believe that discovering effective methods and treatments that will delay the onset and progression of Alzheimer's as well as prevent the disease are well within reach in the foreseeable future if the current pace and momentum of research is maintained. Research supported by the National Institutes of Health needs \$40 million in additional funding this fiscal year alone to carry out large scale, controlled, clinical trials that will identify therapies and treatments capable of slowing or halting the onset and progression of Alzheimer's. Basic research has produced positive discoveries, but we need to know whether the discoveries will actually work. Clinical trials are the only way to translate—and verify—the findings of basic research into real-world treatments. A single large-scale clinical trial could cost as much as \$25 million and take three to five years. The Alzheimer's Association is asking Congress to increase funding for Alzheimer research by \$40 million for fiscal year 2005 to fund large-scale clinical trials to test the effectiveness of vitamins and other treatments that would slow or delay the progression of Alzheimer's.

While we maintain hope about our ability to slow the progression of and one day prevent Alzheimer's disease, we must also invest in research that will speed the discovery of risk factor genes for late-onset Alzheimer's, the most common form of the disease. Discovery of risk factor genes will help illuminate the underlying disease processes of Alzheimer's disease, open up novel areas of research and identify new targets for drug therapy. The National Institute on Aging (NIA) and the Alzheimer's Association are in the process of recruiting at least 1,000 families over the next three years to create the nation's largest repository of genetic material from families affected by late-onset Alzheimer's disease. The National Institute on Aging, in partnership with the pharmaceutical industry, the Alzheimer's Association and the FDA, is also engaged in a new initiative using imaging technologies to monitor changes in the brain that indicate progression of Alzheimer's disease and to provide accurate, earlier diagnosis. We are hopeful that this initiative will lead to better diagnostic techniques. More importantly, the imaging initiative may help speed up the process of discovering new, more effective treatments and preventive agents for Alzheimer's disease by allowing scientists to detect the effects of interventions on brain function much more quickly than traditional clinical trials without the use of imaging. The full participation of the pharmaceutical industry and the FDA will ensure that we gain maximum effect from this important initiative.

#### Supporting A Public/Private Partnership

The Alzheimer's Association is the largest private funder of Alzheimer research, next to the pharmaceutical industry. As our commitment to research has grown, we have expanded the program to support Alzheimer researchers at every stage in their career. Projects supported by the Alzheimer's Association research program now explore the broadest possible spectrum of biological approaches to understanding, preventing, and treating Alzheimer's. In addition to our support of medical research, the Association also invests in improving care, with research grants supporting efforts to develop innovative

social and behavioral strategies for managing the symptoms of the disease and improving quality of life, approaches to caregiving and improved understanding of caregiver issues. Our goal is to support research that complements the programs of the National Institute on Aging (NIA) and other centers of the National Institutes of Health (NIH). Our research program is designed to serve as an incubator for innovative ideas that can be further enhanced by the tremendous resources only available through NIH and its national network of Alzheimer's Disease Centers.

Many of this country's premier Alzheimer researchers got their start with funds from the Alzheimer's Association. Alzheimer researchers funded by the Association have gone on to acquire major federal funding, originate and advocate for important areas of research, train the next generation of scientists, establish many of the Alzheimer's Disease Research Centers and direct key programs at NIA. These researchers include brilliant scientists such as Dennis Selkoe, whose early work on amyloid proteins helped define our current understanding of Alzheimer's disease, Caleb Finch, who is the director of the Alzheimer's Disease Research Center at the University of Southern California, Gary Small, a leader in the imaging field and Marcelle Morrison Bogorad, who as an integral part of Dr. Hodes' team, directs the Neuroscience and Neuropsychology of Aging Program at NIA.

In addition to partnering with NIA and other centers at NIH, the Alzheimer's Association also plays a major role in bringing the Alzheimer research community together for scientific meetings. In July we will present the ninth annual International Conference on Alzheimer's Disease and Related Disorders, the world's leading forum on dementia research. The International Conference serves as a catalyst for generating new knowledge about dementia and fostering a vital, collegial research community. Approximately 4,500 researchers, double the number who attended the July 2000 meeting in Washington, will gather in Philadelphia to share groundbreaking information and resources on the etiology, pathology and treatment of Alzheimer's disease and related disorders. The program will include 135 invited speakers, who are respected leaders and new voices in their disciplines, and more than 2,000 oral and poster presentations on current research. The conference also provides a significant opportunity to educate the public about breakthroughs in Alzheimer treatment and care.

#### A Roadblock to Progress

All of the hope we have for a future without Alzheimer's disease will come to a crashing halt if we cannot maintain the current pace and momentum of funding for Alzheimer research. Only Congress and the President, through a significant addition of new funding, can assure that we realize the unprecedented opportunities in Alzheimer research.

Minimal increases in funding for the NIH are not enough to support additional clinical trials and maintain the pipeline of basic scientific discovery. Failure to provide the funding increases that will help keep pace with inflation will destroy the momentum gained over the past five years. Inadequate funding increases mean that less money will be available to support new research grants and clinical trials, delaying scientific discoveries and resulting in lost opportunities.

Although I am not a scientist, I have spent a lot of time talking with scientists. Let me give you just a few examples of the opportunities we will miss if we stick with current and proposed funding levels:

- Thanks to Congress' investment in NIH, the best scientists in the world are chomping at the Alzheimer bit – and that means NIA is receiving record numbers of applications. But at current budgets, they will be able to fund only about 15 percent of those proposals – far less than the 20 – 25% of past years. And they can only do that much by cutting one of every five dollars out of the successful grants. Think about how many scientific opportunities we are missing.

- What about the large scale clinical trials in which Congress has invested billions of dollars? After all, research doesn't mean a lot in the real world until we are successful in getting science from the bench to the bedside.

- o Scientists at the University of California in San Diego are poised to start the next big trial of combinations of anti-oxidants. This offers one of the most exciting possibilities for a safe and relatively inexpensive way to protect against Alzheimer's. But NIA does not have the money to get it started.

- o Even trials that are well underway – like the ginkgo biloba trial being conducted through a collaborative effort between NIA and NCCAM – will have to be slowed down. There may be no money to analyze the data that has already been collected on the hundreds of volunteers who have participated in this trial.

- NIA currently funds 29 Alzheimer's Disease Research Centers, a program that has created the infrastructure for multidisciplinary collaborative research on the disease. NIA has seen an increasing number of applications from academic institutions seeking to create such centers and there are still parts of the country where Centers do not exist. Limited funding will make the competition for center grants especially tough this year. At the same time, we have heard that existing centers are increasingly strapped for funds to carry out their broad mission.

This is a travesty. We cannot let it happen. We know that Congress faces many competing priorities, with very little discretionary money in the budget. We understand that, after doubling the NIH budget, there are those who are ready to say, "we've done enough." But if we slow down now, we will be throwing away much of the investment the American taxpayers have already made in Alzheimer research. We must continue, and build on, the progress of the last twenty years. That is why we are asking you to increase funding for Alzheimer research by \$40 million for fiscal year 2005. This is a modest request, given the urgency of the Alzheimer crisis and the enormity of the scientific opportunities. But it would be enough to sustain the momentum in tough budget times. The Neurology study on the growth in the prevalence of Alzheimer's disease by state that I cited earlier provides further evidence of the need to invest in the research that will help prevent or delay the onset of Alzheimer's disease. The study found that five states (Utah, Alaska, Colorado, Wyoming and Nevada) will see their total number of cases of Alzheimer's disease more than double between 2000 and 2025. The three largest states will also experience big increases in the number of cases of Alzheimer's disease - California faces a 50 percent increase, Florida a 64 percent increase and Texas a 74 percent increase. The best way to ensure that these estimates do not come true is to find an effective method of preventing Alzheimer's disease.

Taking Care of People With Alzheimer's & Their Caregivers: Social & Behavioral Research

One of the greatest challenges in Alzheimer's disease research is the translation of knowledge and technology from laboratory and research settings into everyday practical

care situations with the goal of improving the quality of life for affected people, their families and care providers. Often, lack of knowledge about what constitutes the most important or "active" ingredient in a successful intervention hinders transporting the technique to usual care settings. There is a huge range of questions in the social and behavioral arenas that are ripe for research. The answers to these questions, if broadly applied, would improve the daily lives of millions of people with Alzheimer's disease and their families.

The Alzheimer's Association has made improving the quality of care for persons with Alzheimer's disease and expanding access to home and community based services top priorities. In addition, we must find ways to support family caregivers who continue to be the backbone of the long term care system in this country. Seven in ten people with Alzheimer's disease live at home. The estimated annual value of the informal caregiving system is \$257 billion, far more than the \$32 billion cost of paid home health care and the \$92 billion cost of nursing home care. The Association has endorsed several pieces of pending legislation that will help us achieve these goals including:

- S 566, the Alzheimer's Disease Research, Prevention, and Care Act of 2003 - cosponsored by the Chair and Ranking Member as well as several members of this subcommittee, this bill would reauthorize the highly successful Administration on Aging Alzheimer's Disease Demonstration Grants to the States Program. 39 states, including both Maryland and Missouri are participating in this unique program that is fostering the development of innovative models of care for persons with Alzheimer's disease and their caregivers, especially those in rural and low-income communities.
- S 1214, the Family Caregiver Relief Act of 2003 - sponsored by Senator Mikulski, as well as other members of this subcommittee, this bill would provide a \$3,000 tax credit to help family caregivers with long term care expenses such as adult day care and respite care.
- S 538, the Lifespan Respite Care Act of 2003 - introduced by Senator Clinton of this subcommittee and co-sponsored by Senators Mikulski, Warner and Murray, this bill would increase the availability of respite care services and provide training for respite care workers and volunteers.

#### Conclusion

There is now real hope for a future without Alzheimer's disease. Greater understanding of the disease, improved care and treatment, and unprecedented scientific opportunities for delaying onset and preventing the disease can all lead to a future where Alzheimer's is just a memory. Imagine the billions in savings to Medicare and Medicaid if scientists were able to develop a presymptomatic diagnostic technique and a preventive therapy that did not allow the disease to occur. But none of this will happen if we do not take action. Research supported by the National Institutes of Health needs \$40 million in additional funding in this fiscal year alone to carry out large scale, controlled, clinical trials that will identify therapies and treatments capable of slowing or halting the onset and progression of Alzheimer's. Basic research has produced breakthroughs in our understanding of Alzheimer's disease, but we need to know whether the discoveries will actually work. Clinical trials are the only way to translate—and verify—the findings of basic research into real-world treatments.