

**Statement of  
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Retired Associate Justice  
U.S. Supreme Court**

**Before the  
Special Committee on Aging  
United States Senate**

**May 14, 2008**

Chairman Kohl, Ranking Member Smith and members of the Committee. I appreciate the invitation to testify before you today. I commend you for delving into a subject that is very dear to my heart and to the hearts of the millions of American families who love and provide care to relatives who have Alzheimer's disease.

As you know, I became one of these caregivers in 1990 when my husband, John, was diagnosed with Alzheimer's. Living with this disease has been sad and difficult for my entire family. But it has also given us a first-hand understanding and a profound empathy for caregiving families around the nation. These caregivers are continually called upon to make fundamental sacrifices and adjustments in their lives in order to nurture and support the people they love.

You may remember that in the early days of my husband's illness, I often took him to court with me because he could not be left alone. And, as you know, I retired from the U.S. Supreme Court in 2006 to find a care center for John in Phoenix, where two of our children live. Many caregivers make similarly difficult decisions each and every day. Sadly, these life-changing decisions are simply part of caring for someone with Alzheimer's.

Clearly, Alzheimer's disease is a family disease. It may directly attack only one member of a family. But every member of that family feels the effects. Every member loses something.

Alzheimer's ruthlessly robs families of husbands and wives, mothers and fathers, grandmothers and grandfathers, aunts and uncles, brothers and sisters. Researchers are now telling us that the disease can also rob caregivers of their health. According to a recent study in the *Journal of Immunology*, people who care for relatives with Alzheimer's are twice as likely as non-caregivers to suffer from depression. They are also more likely to develop a compromised immune system that could shorten their lives.<sup>1</sup>

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<sup>1</sup> Damjanovic, A.K., Yang, Y., Glaser, R., Kiecolt-Glaser, J.K., Nguyen, H., Laskowski, B., Zou, Y., Beversdorf, D.Q., Weng, N.P. 2007. "Accelerated telomere erosion is associated with declining immune function in caregivers of Alzheimer's disease patients." *Journal of Immunology*, 179: 4249 - 424.

Researchers have not yet determined why some of us develop Alzheimer's and others do not. We do not yet fully understand the biological processes that cause such dramatic degeneration. But families with Alzheimer's know all too well the devastating effects.

From even the earliest stages, the symptoms of Alzheimer's disease are very difficult to handle. As the disease progresses—often over the course of decades—its symptoms become cruel and punishing. This disease begins quietly, with memory difficulties that gradually become more serious and much more frightening with each passing year. Then, what follows is confusion ... impaired judgment ... trouble expressing even the simplest thoughts ... disorientation ... and socially inappropriate behavior.

Eventually, formerly self-reliant, articulate and loving family members lose the ability to bathe, dress or eat without help ... lose the ability to communicate ... and fail to recognize the spouse or the children for whom they have cared so deeply for so many years. I submit to you that until you have actually stared Alzheimer's in the face, as millions of Americans and their families have done, you cannot truly understand the deep sense of frustration, fear, helplessness and grief that accompany it.

While Alzheimer's takes a staggering toll on families, it is not *just* a family disease. Indeed, Alzheimer's is fast becoming a national disease – a national health crisis.

The Alzheimer's Association estimates that 5.2 million Americans now have Alzheimer's disease—a figure about equal to the population of Wisconsin. More than eight million Americans over the age of 65 could have the disease by 2030—that's roughly the combined populations of Wisconsin and Oregon.

Alzheimer's also brings with it a staggering cost. The nation now spends an estimated \$150 billion each year to care for people with Alzheimer's. The disease's enormous budget impact will only grow larger by 2050, when as many as 16 million Americans could find themselves in its grip.<sup>2</sup>

Is this rapid growth in Alzheimer's cases inevitable? I do not believe it is. That is why I am here today and why I chose to join the Alzheimer's Study Group. As you know, the Alzheimer's Study Group is a taskforce of national leaders charged with creating a National Strategic Plan to overcome the mounting Alzheimer's crisis. This group has received bipartisan support here on Capitol Hill, and rightly so. It represents an important step in helping the United States establish and carry out a bold national goal – one that seeks nothing less than to eradicate Alzheimer's disease.

Our collective experience with Alzheimer's to date – as family members, scientists, medical professionals and policymakers – has convinced group members of three critical facts.

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<sup>2</sup> Alzheimer's Association. 2008. *Alzheimer's Disease Facts and Figures 2008*. Retrieved from Alzheimer's Association, May 7, 2008. Web site: [http://www.alz.org/national/documents/report\\_alzfactsfigures2008.pdf](http://www.alz.org/national/documents/report_alzfactsfigures2008.pdf)

- **First**, Alzheimer's is a complicated disease that requires a coordinated, multidisciplinary response. We need to fight this killer not only in the research lab, but also at the treatment site, in the halls of government, and in the communities that people with Alzheimer's call home.
- **Second**, we will never succeed in tackling Alzheimer's by tweaking our existing systems or being satisfied with piecemeal, incremental changes. Instead, we must transform our thinking about Alzheimer's. We need to create new research, treatment, care and support systems. And we need to make sure that those systems work together toward common goals.
- **Third**, we need to move quickly. I cannot over-emphasize the need for urgency. The families of people with Alzheimer's disease are impatient for new treatment options that can offer new hope to them and their loved ones. We must resolve, by our swift action, that the current generation of people with Alzheimer's will be the last generation that we lose to this miserable disease.

A forward-thinking nation, led by a forward-thinking Congress, can take steps now to transform our approach to Alzheimer's. Specifically:

- We must expand clinical and research efforts that improve the diagnosis and treatment of Alzheimer's disease. In particular, we must aggressively emphasize prevention and early diagnosis. Researchers increasingly agree that, just as with heart disease, early intervention offers the best opportunity to stop Alzheimer's in its tracks. By taking swift action we can spare millions of Americans from the indignities of Alzheimer's.
- We must encourage researchers to share their insights with one another in real time—rather than waiting many months, or even years, until patents are filed or study results are published. As a nation, we are depending on these gifted experts to deliver the breakthroughs we need so desperately. In return, we need to support their work fully by offering them new opportunities and incentives to work together on a much broader and more collaborative scale.
- We must renew our commitment to strong public investment in developing new treatments. We have been far too lax on this front. Despite the growing number of Alzheimer's cases, public funding for Alzheimer's has grown very little in the past 5 years. In fact, when biomedical inflation is taken into account, funding levels have actually declined.
- We must also encourage the sustained private investment that will help translate research breakthroughs into new treatments. Disturbingly, we see signs that the private sector is losing interest in funding Alzheimer's programs because of the scientific challenges, the regulatory uncertainties and delays, the reduction in effective patent life for preventive therapies, and unclear reimbursement policies.

- Finally, we must improve formal and informal supports for those who currently have Alzheimer's and for their caregivers. It is time to ensure that *best* practices in Alzheimer's care become *standard* practices in communities across the country.

The Alzheimer's Study Group is working closely with experts from around the country to develop strategies that address these and other issues. Our group includes leading experts in the fields of medicine, research, policy, education, communications, business and law. This multidisciplinary approach makes the Alzheimer's Study Group unique and, I believe, gives it a much greater chance of success.

Thank you for allowing me the opportunity to speak as one of the millions of family members around the country who are caring for people with Alzheimer's disease. I suspect that you will not hear from many of my fellow caregivers directly ... not because they are uninterested in the topics I've raised, but simply because they do not have the resources to take time away from their loved ones in order to come before you. I am truly honored to represent these courageous Americans here today.

In closing, let me challenge you, as representatives of these same Americans, to address this growing national Alzheimer's crisis with the urgency it demands. When the Alzheimer's Study Group releases its final report early next year, I ask you to carefully consider our recommendations. Keep these families in mind when you choose how to act on those recommendations. The stakes are high. Without a doubt, the future health and well-being of these families – indeed, the health and financial well-being of our entire nation – depends on how swiftly and decisively we act to address this terrible disease.