



Accelerate Cure/Treatments for Alzheimer's Disease

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FIRST MAJOR SURVEY OF BABY BOOMER ATTITUDES ON ALZHEIMER'S SHOWS FEAR ABOUT THEIR OWN FUTURE AND FRUSTRATION OVER PACE OF NEW DRUG APPROVALS

Historic ACT-AD Coalition calls for recognition of Alzheimer's as an urgent national health crisis, activation of Baby Boomers, and acceleration of therapy approvals

National Press Club, Washington, DC – April 27, 2006 – As the first Baby Boomers turn 60 this year, they are beginning to confront the consequences of growing older. A new survey shows the majority of Boomers are anxious about how Alzheimer's disease (AD) will affect their health and quality of life.

At the same time, Boomers are frustrated that the government and the U.S. Food and Drug Administration (FDA) do not address adequately this looming public health crisis. The findings from the first major survey of over 1,000 American Baby Boomers about Alzheimer's disease were announced today by a newly formed coalition of 21 leading advocacy groups known as ACT-AD (Accelerate Cure/Treatments for Alzheimer's Disease).

"These survey findings underscore the fact that when Baby Boomers are asked to address the potential of Alzheimer's in their future, they are clearly not ready emotionally, psychologically or financially," said Daniel Perry, executive director of the Alliance for Aging Research and chair of the ACT-AD Coalition. "Many Boomers are currently more focused on health issues like heart disease or arthritis and mistakenly consider AD a problem of their elders. But when asked to consider themselves at age 70 with Alzheimer's disease, there was a visceral reaction and an awakening to the reality of what could await them. They also have little confidence that policymakers, the US healthcare system, or drug regulators are prepared to help them. As the crisis looms, ACT-AD will press ahead for a solution."

Alzheimer's disease, which is universally fatal, affects 4.5 million Americans and causes millions more to leave the workforce to care for loved ones who eventually need around-the-clock attention. It is a progressive neurodegenerative disorder that results in cognitive deterioration affecting many areas of function. As the disease progresses, people suffer severe cognitive deterioration, confusion, disorientation, personality and

behavior change and eventually death. Estimates suggest that by 2010, Alzheimer's disease will affect one in ten people over age 65, or 5.6 million Americans, and the cost of care will increase 75 percent to about \$160 billion annually in Medicare costs alone.

One hundred years after Bavarian physician and researcher Alois Alzheimer first described the pathology and symptoms that have become the hallmarks of the disease that bears his name, the ACT-AD Coalition is launching a campaign to call attention to the urgency of the Alzheimer's disease crisis, and, at the same time, the lack of a well-defined approach in the U.S. for swift delivery and access to promising transformational therapies that could halt or reverse the disease.

"Alzheimer's is a cruel disease that has been on the back burner of science for 100 years but no one is immune to it and the toll will be staggering unless Baby Boomers wake up to the threat and do something about it," said Meryl Comer, Emmy Award-winning television journalist and full-time caregiver for her husband who was diagnosed with AD over 11 years ago at age 58. "When the onset of the disease is early for a loved one, it is like being a witness to your own future and I am terrified for us all."

Survey Findings

The web-based survey was conducted by Opinion Research Corporation for ACT-AD and sampled 1,009 Americans born between 1946 and 1964. All data were weighted to represent the US general population with respect to age, gender and geographic region. The maximum error range for a sample of 1,000 is ± 3.1 percentage points at a 95 percent confidence level.

In summary, survey results reveal that when provided with basic information on Alzheimer's disease, the vast majority of Baby Boomers are extremely concerned about the potential impact on their health, quality of life and finances as well as on the healthcare system.

Boomers express clear and significant concerns with current treatment options as well as the level of response from the government and the FDA. They place top priority on new drugs that could change the course of the disease, feel that the FDA should give priority review to these drugs, expect the right to decide whether to use them, and are willing to accept a degree of risk with promising drugs.

Key Findings include:

- **Personal Preparedness for Alzheimer's** – 90 to 95 percent of respondents said that they would either be unprepared or would find life "not worth living" if they were forced to face limitations common to the disease by the time they were 70. These limitations included basic abilities (not being able to dress or toilet themselves), social interactions (not being able to recognize family members) and mental abilities (not being able to remember who or where they are).
- **Cost of Alzheimer's** – 80 percent of respondents said that their current savings would not be sufficient to cover the cost of care if they were diagnosed and 81 percent said the same thing about their families' savings. 83 percent said they are also worried that the healthcare system is under-prepared to cover the demands of the coming Alzheimer's crisis.
- **Treatment Options** – Only 8 percent of respondents feel that current treatments are adequate. In fact, most (80 percent) are willing to take experimental

treatments that have the potential for stopping the disease and preserving their quality of life, even if significant health risk was involved. Respondents put the highest priority on drugs that stop the disease/loss of mental abilities (84 percent) or that reverse the disease/loss of mental abilities (82 percent), even though current drugs do none of these things. 90 percent of respondents felt that drugs that have this potential should be given the same priority review and fast track status that the FDA gives to drugs for other life-threatening diseases such as cancer and HIV/AIDS.

- **Satisfaction with Government/FDA** – When provided with an overview of the FDA's current review policy for Alzheimer's drugs, 82 percent of respondents remained unsure about what the government is doing to prioritize Alzheimer's, but most (84 percent) feel that more should be done and over 75 percent feel that Alzheimer's should be made a top priority. 89 percent feel that promising Alzheimer's drugs deserve the same priority status and fast track review that the FDA uses for drugs for other serious diseases.

"What is most striking about these findings is that Americans are no longer accepting the longstanding myth that real treatment breakthroughs for Alzheimer's are still decades off," commented Samuel Gandy, MD, director of the Farber Institute for Neurosciences at Thomas Jefferson University. "The reality is that decades of research have given us a number of investigational and highly promising drugs that could slow or even prevent Alzheimer's. Everyone involved in the discovery, development and approval of these drugs should act with urgency and resolve."

Coalition Declares War on Alzheimer's

As the FDA continues to pursue its Critical Path to modernize the scientific process for developing and evaluating medical products, ACT-AD will begin a comprehensive campaign to work with the agency and legislators involved in health policy to elevate AD as a national health priority. The first goal of the Coalition is to convince the FDA to extend the same rapid approval mechanisms it has developed for other life-threatening diseases, like cancer and HIV-AIDS, to promising drugs for AD.

These initial steps are part of ACT-AD's blueprint for changing the Nation's overall response to the coming Alzheimer's crisis. Planned Coalition initiatives include:

- Partnering with the FDA to identify barriers, evaluate and recommend processes and systems, and create actionable plans to expedite reviews of transformational Alzheimer's therapies
- Meeting with key congressional leaders involved in health policy reform and regulatory reform to assure that promising treatments reach Alzheimer's patients quickly
- Facilitating collaboration among leading research institutions to adopt new strategies to bridge the gap between basic research and clinical research in order to promote innovation while expediting development of transformational therapies
- Educating the public through coalition membership initiatives
- Mobilizing the public to make their voices heard by congressional representatives
- Recruiting corporate America to push for new strategies to address Alzheimer's disease as it will have an impact on employee productivity and spiraling health care costs

- Informing the media in order to focus national attention on the need for a new Alzheimer's disease strategy

"Right now the majority of Alzheimer's victims and their caregivers are our parents. Their plight is our future. We are ticking time bombs without even knowing it," said Meryl Comer, who recently published "From the bedside: A terrified witness to the future – A baby boom generation wake-up call," in the April issue of the scientific journal, *Alzheimer's & Dementia*. "My hope is that ACT-AD will help in the push to get promising AD drugs to patients. As families, we are desperately in need of access to new therapies instead of being left with only agonizing decisions. It is time to borrow a page from HIV activists of the '80s and breast cancer survivors of the '90s. We need to make it clear, as a generation of 75 million strong, that this kind of outcomes to our lives is unacceptable and that we refuse to be robbed of our minds without a fight."

ACT-AD Background

ACT-AD is a growing coalition of organizations representing patients, caregivers, consumers, older Americans, researchers, and women's health advocates. The Coalition, comprised of 21 organizations, is directed by an Advisory Council including the following members: The Alliance for Aging Research, The Alzheimer's Foundation of America, The American Society on Aging, The National Association of Area Agencies on Aging, National Alliance for Caregiving, the National Consumers League, Research!America, and The Society for Women's Health Research. Other members include: The Abigail Alliance, The American Association for Geriatric Psychiatry, The American Medical Women's Association, FasterCures, The Gerontological Society of America, Hadassah, The International Eye Foundation, The Institute for the Study of Aging, The Men's Health Network, The National Council of Patient Information and Education, The American Federation for Aging Research, International Longevity Center and The Older Women's League. The Coalition is supported through an educational grant by Elan and Wyeth.

For more information about the ACT-AD Coalition and campaign against Alzheimer's disease, visit www.ACT-AD.org.

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