

Congress passed NAPA and President Obama signed it into law in January 2011.

By Mary Adam Thomas



# Federal Legislation Puts New Focus on Alzheimer's

The National Alzheimer's Project Act (NAPA) was signed into law by President Obama earlier this year. Here's what it means for you.



In 1937, the United States Congress passed the National Cancer Act, allocating federal funds for cancer research and paving the way for the National Cancer Institute. In 1990, Congress authorized the Ryan White Comprehensive AIDS Resource Emergency Act, which has since been amended and reauthorized four times to continue support for uninsured Americans affected by HIV/AIDS.

Now patients and caregivers dealing with Alzheimer's disease (AD) and other forms of dementia may also claim recognition from the U.S. government. On January 4, 2011, President Barack Obama signed into law the National Alzheimer's Project Act, legislation that passed unanimously through both houses of Congress in December.

The Act—known as NAPA—is a significant victory for the rapidly growing community of Americans touched by AD since it acknowledges the expanding nature of the crisis and the need for federal oversight in the battle against it.

Senator Susan Collins (R-Maine) co-authored the bill with Senator Evan Bayh (D-Indiana), inspired by a combination of personal familiarity and fiscal responsibility. “As someone whose family has experienced the pain of Alzheimer's too many times, I know that there is no more helpless feeling than to watch the progression of this dreadful disease,” says Sen. Collins. “In addition to the suffering it causes, Alzheimer's costs the United States \$172 billion a year, primarily in nursing home and other long-term care costs,” she adds.

According to Sen. Collins, Alzheimer's-related Medicare and Medicaid expenses will grow more than 400 percent by 2050 due to the growing number of diagnosed cases.

## What's in the Bill

NAPA will establish a national strategy and focus the country's efforts to overcome the disease. The U.S. Department of Health and Human Services (HHS) will administer and monitor the program.

According to the text of the Act, the purpose of NAPA is to:

- Create and maintain an integrated national plan to overcome Alzheimer's disease.
- Provide information and coordination of Alzheimer's research and services across all federal agencies.
- Accelerate the development of treatments that would prevent, halt, or reverse the course of Alzheimer's.
- Improve the early diagnosis of Alzheimer's.
- Improve the coordination of the care and treatment of citizens with Alzheimer's.
- Ensure the inclusion of ethnic and racial populations at higher risk for Alzheimer's or least likely to receive care, in clinical, research, and service efforts with the purpose of decreasing health disparities in Alzheimer's.

- Coordinate with international bodies to integrate and inform the fight against Alzheimer's globally.

Department of Health and Human Services Secretary Kathleen Sebelius will be responsible for creating and updating a national Alzheimer's plan and reporting annually to Congress on the state of the plan. Sebelius commended Congress and the President for passing NAPA and says she looked forward to implementing the legislation swiftly and effectively. “The passage of this Act will help to ensure we confront this challenge with an aggressive and coordinated national strategy,” she says.

## The View from the Laboratory

People in the trenches of Alzheimer's research look at NAPA as a crucial first step in a long journey toward improved treatment, early prevention and eventual eradication of the disease. Dr. Barry Reisberg is among the many professionals who believe it will help direct greater attention—which will likely channel necessary funds—toward a disease that touches millions of American families. Dr. Reisberg serves as Director of the Fisher Alzheimer's Disease Education and Resources Program at the New York University Langone Medical Center as well as Director of NYU's Alzheimer's Disease Center, funded by the National Institute on Aging.

“NAPA is potentially very important because it adds direction in terms of research, treatment and care,” he says. “Even though there are no funds currently attached to the legislation, it will help Alzheimer's be seen as the major problem that it is—and has been for several decades.”

Dr. Reisberg identifies three ways in which NAPA has the potential to change the game in the fight against Alzheimer's:

### 1. The Issue of Institutionalization

Even people who recognize the severity of Alzheimer's as a medical condition may be unaware of how many AD sufferers end up institutionalized because of the disease. Furthermore, those outside the world of AD may not understand the toll that institutionalization can take on individuals, families, personal finances and public funds. “The institutional aspect of AD is extraordinarily traumatic,” says Dr. Reisberg. “There are about 1.5 million Americans currently in nursing homes, and an absolute majority of those persons suffer from Alzheimer's or related dementia disorders.” That number, according to Dr. Reisberg, is somewhat greater than the number of people in all hospitals at any particular point in time.

However, the institutional burden of AD is actually even greater. “What's happened with Alzheimer's disease is that

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much of the institutional burden is being hidden because Alzheimer's patients are commonly placed in assisted living facilities where their numbers are not counted. So the true institutional burden of the disease is not seen in the statistics," he explains. A federal plan such as NAPA will improve the likelihood that the problem of AD will be addressed in accordance with the extraordinary burden that the disease places on our society.

## 2. The Impact on Communities

Communities bear a significant burden when it comes to Alzheimer's and other forms of dementia (including Mild Cognitive Impairment, a phrase coined by Dr. Reisberg and his associates after studying and defining its effects and clarifying how the condition differs from full-blown Alzheimer's disease). "The dimensions of cognitive disorders are enormous and comparable to those of cancer or heart disease in many ways," he says. "Yet Alzheimer's hasn't gotten the attention and necessary financial research support that other major illnesses of similar magnitude receive."

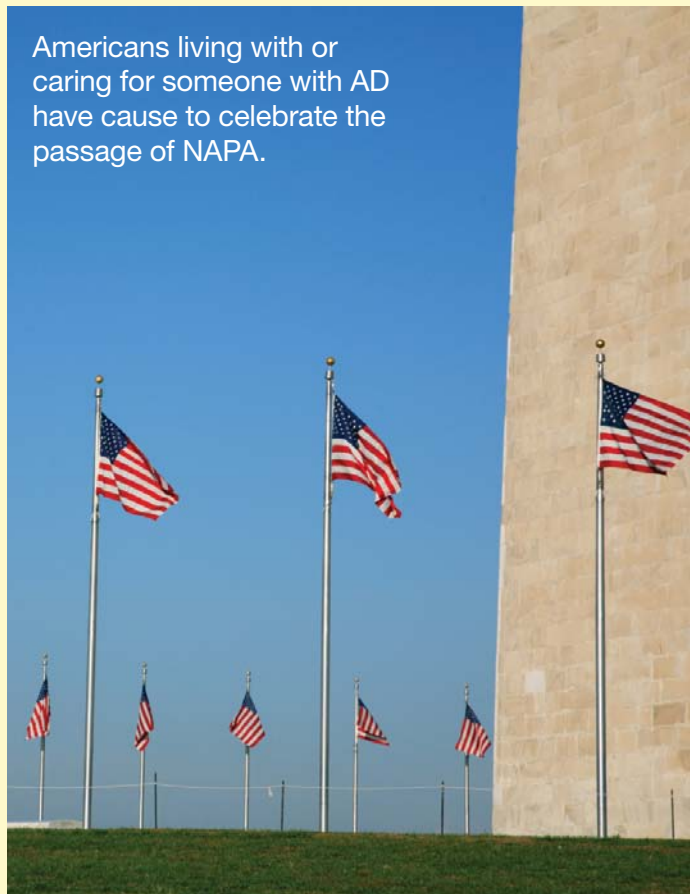
According to Dr. Reisberg, NAPA could begin to make a real difference in recognizing the care needs of AD patients in *communities* as well as—or perhaps instead of—in institutions. "The kind of structured assistance that's often needed for persons with Alzheimer's—everything from physical therapy to social support—can be difficult for them to get within communities," he says. "We need comprehensive solutions." NAPA will shine a broader spotlight on the ways in which this far-reaching disease affects neighborhoods, towns, cities and states and the various ways we can meet the needs of AD patients closer to and in the home.

## 3. Expanding Research Efforts

Dr. Reisberg believes it is noteworthy that AD is garnering national political attention through the NAPA legislation. Such attention might pave the way for better funded research in the future. Significantly, it could also help strengthen the financial foundations of research efforts supporting the broad spectrum of age-related health concerns. "The pay line for investigator-initiated research grants—the bread and butter of research—for the National Institute on Aging [the primary agency at the NIH responsible for AD research] is the lowest of any of the national institutes at this time," he points out. "So NAPA could be a tremendous advance in terms of AD research funding if the sentiment in the legislation is concretized in terms of necessary funds."

With time and what Dr. Reisberg refers to as "additional substance and sentiment" he hopes NAPA will eventually yield

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research funding and an integrated approach to Alzheimer's disease. "I'd like to see unified centers for research, treatment and care," he says. "Perhaps even outreach to help the many persons in the community who don't know how to properly manage this devastating condition."

## Something to Celebrate

Every American living with or caring for someone with AD has cause to celebrate the passage of the National Alzheimer's Project Act. It recognizes the patients. It validates the caregivers. It expands awareness among segments of the population not directly touched by the disease. It provides new hope that Alzheimer's and other forms of dementia will be addressed with increasingly available treatment strategies and, eventually, with prevention strategies.

"Persons with Alzheimer's disease are forced by their condition to bear their losses in silence. Their caregivers are forced to take on a tremendous burden," acknowledges Dr. Reisberg. "For those of us who are concerned about Alzheimer's—which is an increasing proportion of the community—we hope and want to believe that this legislation is the beginning of a truly comprehensive approach to this enormous problem." ■