

The National Alzheimer's Project Act... Missed Opportunities from a Caregiver's Perspective

Alzheimer's disease (AD) is the sixth leading cause of death in this country and the only cause of death among the top 10 killers with no effective means of prevention, treatment, or cure. AD has a mortality rate of 100%. An estimated 5.2 million people are already struggling with AD in this country, and deaths due to AD have increased 68% during the past decade,¹ yet the National Institutes of Health (NIH) continues to underfund research on AD. For each of the past 5 years, NIH funding for research on the human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS) was six times as great as the funding for AD.² These funding differences are particularly glaring when one considers that HIV/AIDS is not even among the top 10 causes of death in this country and that there are five times as many people living with AD as living with HIV/AIDS.³ HIV/AIDS is not the only disease receiving more funding than AD. Eye disease research, for example, receives three times as much funding as that for AD.

In 2010, Congress unanimously passed the federal National Alzheimer's Project Act (NAPA), with aspirations of ending AD by 2025. As reported in the *New York Times*, NAPA's goal was to "accelerate the development of treatments that would prevent, halt or reverse the course of Alzheimer's" and "improve the early diagnosis of Alzheimer's disease and coordination of the care and treatment of citizens with Alzheimer's." The article referred to NAPA as "a national plan to combat Alzheimer's disease with the same intensity as the attacks on AIDS and cancer."⁴

We are now in our fourth year of NAPA, but I have yet to see the "same intensity," with NIH funding AIDS research at six times and cancer research at 12 times AD funding. At the time of its creation, one of the cosponsors of the NAPA bill, Rep. Edward Markey (D-MA), said that NAPA was created "to create a sense of urgency," but since NAPA's creation, Congress still has not authorized increased AD funding, nor has the NIH reallocated its research priorities.

In April 2013, Harry Johns, president of the Alzheimer's Association and a member of the NAPA Advisory Council, said, "The Alzheimer's epidemic is gaining momentum. And with Alzheimer's recently identified as the nation's most expensive disease, it is now clear to everyone that we can no longer afford to ignore it."⁵ Another year has passed, and our nation continues to

largely ignore AD. In June 2013, Johns noted that "caring for people with Alzheimer's, the country's most expensive condition, currently costs the nation \$203 billion annually with projections to reach \$1.2 trillion by 2050."⁶ But... still no sense of urgency to address AD. The federal budget for 2014 proposes an additional \$100 million for AD research. Although such money would be helpful, it is a proverbial drop in the bucket. AD research and programs need billions, not millions, of federal dollars.

Without power to authorize new federal spending or redirect current federal spending by NIH, NAPA cannot realistically hope to accomplish its goals. Congress did not authorize NAPA to have "power of the purse strings," and that was a missed opportunity. Another missed opportunity is NAPA's Advisory Council membership. NAPA legislation mandated an Advisory Council with all the "politically correct" federal agencies and non-federal organizations represented. Two caregivers are also mandated, but only one is a 24/7 caregiver. Its second caregiver member provided some caregiving for his father but cannot be a voice for what it is like to be a 24/7 caregiver.⁷

NAPA needs to have multiple 24/7 caregiver voices on its Advisory Council so that Council members hear those voices at every meeting when they come together to set priorities. Council members need to hear about how many doctors fail to inform people with AD and their caregivers about the existence of support groups and resources available to educate them about the disease, or how doctors often continue recommending costly medications for their loved ones long after such medications are no longer effective. The Council needs to hear caregivers speak about the lack of available day care services and support groups and the severe economic consequences to caregivers without long-term care insurance when they need to place loved ones in assisted living facilities or nursing homes or hire full-time help at home.

I was pleased to note that former Congressman Dennis Moore (D-KS) was appointed to NAPA's Advisory Council in November 2013. Moore publicly announced his own AD diagnosis in 2011. The president of the Alzheimer's Association said about Moore, "As a member of the Advisory Council, his perspective will contribute significantly to the conversations about the human and economic threats of the Alzheimer's epidemic."⁸ For that same reason, NAPA needs more 24/7 caregiver voices on its Advisory Council... to gain caregivers' perspectives firsthand about the human and economic threats they face each day.

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In his vision statement for the 2013 update to the NAPA goal statement, President Obama wrote, “For millions of Americans, the heartbreak of watching a loved one struggling with Alzheimer’s disease is a pain they know all too well. Alzheimer’s disease burdens an increasing number of our nation’s elders and their families, and it is essential that we confront the challenge it poses to our public health.”⁹ Were the President and NAPA members listening to more caregiver voices, they would be more aware that AD is not just a disease affecting our “nation’s elders.” More than 200,000 people with AD are younger than 65, some still in their 30s and 40s. People younger than 65 diagnosed with AD are referred to as having early-onset AD. I know about this firsthand, because my wife, Clare, was demonstrating clear symptoms of early-stage AD at age 60 and was later diagnosed as having early-onset AD.

In 1983, fewer than 2 million Americans had AD, but that year President Reagan signed a proclamation declaring November as National Alzheimer’s Disease Awareness Month. He cited the need for more research, noting “the emotional, financial and social consequences of Alzheimer’s are so devastating that it deserves special attention.”¹⁰ In the 30 years since President Reagan’s proclamation, the number of people with AD in this country has gone from just under 2 million to more than 5 million and is expected to rise to approximately 15 million people by 2050, but our country has yet to reflect that “special attention.” President Obama has now echoed President Reagan’s warning. In another 30 years, will we hear yet another U.S. president say that AD “deserves special attention” or that “it is essential that we confront the challenge.”

Adding billions of dollars for federal funding of AD research and programs when our nation is mired in \$17 trillion of debt is not an easy task, but we must do it anyway. The president knows this, and Congress knows this. We must advance beyond “talking the talk” and start “walking the walk.” We need to vastly increase funding for AD research and programs for those with AD and their caregivers, we must listen carefully to the voices of caregivers when establishing goals and priorities for how to proceed, and we must do this now.

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