

**NAPA -- FACA 2012 Public Comments**  
*(May Comments Only)*  
February 7, 2013

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## MAY 2012 COMMENTS

**DATE:** May 15, 2012

**SUBJECT:** RE: National Plan to Address Alzheimer's Disease Released

I had an opportunity to see the new site. While it may be a good start, you have sugar coated to many things. People need to know it all and the truth. Especially that people die from this disease.

Michael Ellenbogen

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From: NAPA@hhs.gov

Sent: Tuesday, May 15, 2012 2:24 PM

Subject: National Plan to Address Alzheimer's Disease Released

### **Obama Administration Presents National Plan to Fight Alzheimer's Disease**

Health and Human Services Secretary Kathleen Sebelius today released an ambitious national plan to fight Alzheimer's disease. The plan was called for in the National Alzheimer's Project Act (NAPA) [<http://aspe.hhs.gov/daltcp/napa/>], which President Obama signed into law in January 2011. The National Plan to Address Alzheimer's Disease [<http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml>] sets forth five goals, including the development of effective prevention and treatment approaches for Alzheimer's disease and related dementias by 2025.

In February 2012, the administration announced that it would take immediate action to implement parts of the plan, including making additional funding available in fiscal year 2012 to support research, provider education and public awareness. Today, the Secretary announced additional specific actions, including the funding of two major clinical trials, jumpstarted by the National Institutes of Health's (NIH) infusion of additional FY 2012 funds directed at Alzheimer's disease; the development of new high-quality, up-to-date training and information for our nation's clinicians; and a new public education campaign and website to help families and caregivers find the services and support they need.

To help accelerate this urgent work, the President's proposed FY 2013 budget provides a \$100 million increase for efforts to combat Alzheimer's disease. These funds will support additional research (\$80 million), improve public awareness of the disease (\$4.2 million), support provider education programs (\$4.0 million), invest in caregiver support (\$10.5 million), and improve data collection (\$1.3 million).

"These actions are the cornerstones of an historic effort to fight Alzheimer's disease," Secretary Sebelius said. "This is a national plan--not a federal one, because reducing the burden of Alzheimer's will require the active engagement of both the public and private sectors."

The plan, presented today at the Alzheimer's Research Summit 2012: *Path to Treatment and Prevention*, was developed with input from experts in aging and Alzheimer's disease issues and calls for a comprehensive, collaborative approach across federal, state, private and non-profit organizations. More than 3,600 people or organizations submitted comments on the draft plan.

As many as 5.1 million Americans have Alzheimer's disease and that number is likely to double in the coming years. At the same time, millions of American families struggle with the physical, emotional and financial costs of caring for a loved one with Alzheimer's disease.

The initiatives announced today include:

- Research -- The funding of new research projects by the NIH will focus on key areas in which emerging technologies and new approaches in clinical testing now allow for a more comprehensive assessment of the disease. This research holds considerable promise for developing new and targeted approaches to prevention and treatment. Specifically, two major clinical trials are being funded. One is a \$7.9 million effort to test an insulin nasal spray for treating Alzheimer's disease. A second study, toward which NIH is contributing \$16 million, is the first prevention trial in people at the highest risk for the disease.
- Tools for Clinicians -- The Health Resources and Services Administration has awarded \$2 million in funding through its geriatric education centers to provide high-quality training for doctors, nurses, and other health care providers on recognizing the signs and symptoms of Alzheimer's disease and how to manage the disease.
- Easier access to information to support caregivers -- HHS' new website, [www.alzheimers.gov](http://www.alzheimers.gov), offers resources and support to those facing Alzheimer's disease and their friends and family. The site is a gateway to reliable, comprehensive information from federal, state, and private organizations on a range of topics. Visitors to the site will find plain language information and tools to identify local resources that can help with the challenges of daily living, emotional needs, and financial issues related to dementia. Video interviews with real family caregivers explain why information is key to successful caregiving, in their own words.
- Awareness campaign -- The first new television advertisement encouraging caregivers to seek information at the new website was debuted. This media campaign will be launched this summer, reaching family members and patients in need of information on Alzheimer's disease.

Today's announcement demonstrates the Obama administration's continued commitment to taking action in the fight against Alzheimer's disease.

In 2013, the National Family Caregiver Support Program will continue to provide essential services to family caregivers, including those helping loved ones with Alzheimer's disease. This program will enable family caregivers to receive essential respite services, providing them a short break from caregiving duties, along with other essential services, such as counseling, education and support groups.

For more information on the national plan to address Alzheimer's disease, visit: [www.alzheimers.gov](http://www.alzheimers.gov).

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**National Alzheimer's Project Act** <http://aspe.hhs.gov/daltcp/napa/>

**National Plan to Address Alzheimer's Disease**  
<http://aspe.hhs.gov/daltcp/napa/NatPlan.shtml>

**Alzheimers.gov** <http://www.alzheimers.gov>

**DATE:** May 15, 2012

**SUBJECT:** Fwd: Why we need to make educated guesses to solve Alzheimer's disease

I just realized I never sent you the comments I made at the April 17 meeting. Attached please find both Word and PDF files of my comments, which I am providing for the public record.

Thank you,

Caroline Rodgers

**ATTACHMENT:** Why we need to make educated guesses to solve Alzheimer's -- 4-17-2012  
comments by Caroline Rodgers.pdf  
Why we need to make educated guesses to solve Alzheimer's -- 7-17-2012  
comments by Caroline Rodgers.doc

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| <b><i>Available as separate links:</i></b> |   |
| Comments on April 17 Meeting               | <a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach160.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach160.pdf</a> |

**DATE:** May 2, 2012  
**SUBJECT:** We need a bold plan to stop Alzheimer's!

Although the official comment period has closed for the NAPA draft plan, I'm writing today to urge you to go bolder with the final plan to be released by HHS later this month.

Alzheimer's is a cruel disease. It slowly steals one's intellect, ability to communicate, independence, and dignity, even control over basic bodily functions like eating and caring for personal hygiene. It also places an overwhelming burden on caregivers -- emotionally, physically, and financially.

The commitment to a 2025 deadline in the draft NAPA plan represents a major step forward in the fight against Alzheimer's. I am pleased that the plan recognizes the need for increasing enrollment in clinical trials, compressing the drug development process, accelerating targeted research, and better coordinating activities with other countries.

However, I am one of many concerned Alzheimer's advocates who believe that this first draft fails to present a strategy aggressive enough to achieve the goal of preventing and treating Alzheimer's within 13 years. It lacks specificity in terms of timelines and deadlines, provides no path to providing significantly greater resources, and does not hold a single high-level office or individual accountable for the overall plan.

I hope that HHS will address these issues so that the next version of the plan will be bolder.

With the number of Alzheimer's patients expected to triple in the coming decades, we must embrace a plan that eschews a "business-as-usual" approach and tackles Alzheimer's with the urgency and aggressiveness it requires. If not, we stand to lose millions more lives -- and trillions of dollars -- to this disease.

Thank you.

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| <b>Available as separate links:</b>                         |   |
| List of the 14 People Who Sent this Form Letter in May 2012 | <a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach159.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach159.pdf</a> |