

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

**JUNE 2012 COMMENTS**

We Need a Bold Plan to Stop Alzheimer's.....	2
Down Syndrome Comment .....	3
Very Important to Me.....	4
Advisory Council on Alzheimer's Research, Care, and Services .....	5

## **JUNE 2012 COMMENTS**

**DATE:** June 27, 2012

**SUBJECT:** We need a gold 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.

Sister Clare Joseph Farabaugh  
Dallas, PA

**DATE:** June 19, 2012  
**SUBJECT:** Down Syndrome Comment

Attached, please find a letter to Secretary Sebelius from the Congressional Down Syndrome Caucus co-chairs. A hard copied was mailed today.

Thank you,

Karen L. Summar, MD, MS  
Joseph P. Kennedy Foundation Public Policy Fellow  
Office of Congresswoman Cathy McMorris Rodgers  
Washington, DC

ATTACHMENT: 20120618 LTR Sec. Sebelius NAPA DS.pdf

<b><i>Available as separate links:</i></b>	
Comments from the Bipartisan Congressional Down Syndrome Caucus	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach161.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach161.pdf</a>

**DATE:** June 13, 2012  
**SUBJECT:** Very important to me

Thanks again for all of your help in the past. This is the most important work, I have ever completed. Please help me make this link below go viral. Please add it to twitter, Facebook, your web site and place it on other websites in comments sections. If this can become viral, this will definitely have a huge impact on Alzheimer's perception.

<http://youtu.be/oXKO1Qr5qf0>

Thanks for your support,

Michael Ellenbogen  
Author of "The Insider's Guide To Saving Money"  
<http://www.michaelellenbogen.com>  
<http://www.michaelellenbogenmovement.com/>

P.S. If you should receive this message more than once I do apologies. My skills are not as good as they use to be.

**DATE:** June 9, 2012

**SUBJECT:** Advisory Council on Alzheimer's Research, Care, and Services

I am a retired public school principal (age 64) and a caregiver for my wife (age 65), who has Alzheimer's Disease (AD). I have written two articles that have recently been published in *American Journal of Alzheimer's Disease & Other Dementias*. "Alzheimer's and Baby Boomers" was published in their September, 2010 issue, and "Ten Things You Should Do When the Diagnosis is Alzheimer's" appeared in their March, 2011 issue. I also had a third article published, "Forget the Mental Status Test and Learn to Listen," as a lengthy Letter to the Editor in the May issue of *Journal of Family Practice*. These three articles were written to help doctors improve their process of diagnosis and treatment of AD patients ... and their caregivers ... based upon my experience to date. I am now writing a fourth article to educate the public on the urgent need to increase federal funding through NIH for research. I have appended a draft of that piece to the end of this email.

I respectfully request that your Advisory Council address the issues raised in my three articles, as well as in the attached draft. Aside from the need to increase AD research funding,

Thank you for your time and consideration.

### **Alzheimer's ... Our New Cancer?**

Allan Vann

Cancer is the second leading cause of death in this country. Earlier this year, the Centers for Disease Control reported that between 1971-2007, the number of cancer survivors in the United States grew tremendously due to "earlier detection, improved diagnostic methods, and more effective treatment," among other reasons. Furthermore, according to CDC, "about 1.1 million of the (cancer) survivors had lived with the diagnosis for more than 25 years."

Alzheimer's Disease (AD) is the sixth leading *and fastest growing* cause of death in this country, and the *only* one of the top ten causes with *no means of prevention or cure*. Unlike with cancer, CDC cannot report *any* AD survivors. *None*. Most people only live for 8-10 years after an AD diagnosis, and between 5-10% of those with Alzheimer's are still in their thirties, forties, and fifties when diagnosed.

Our country faces a huge AD crisis in the years ahead. More than 5 million Americans have already been diagnosed with AD, and with so many baby boomers now turning 65 each day this number is expected to triple in the next 30-40 years.

One politician seeking greater funding for AD research is Maine Senator Susan Collins. She noted that, "We spend one penny on research for every dollar the federal government spends on care for patients with Alzheimer's. That just doesn't make any sense." Care for Alzheimer's patients already costs this country nearly \$200 billion a year and, according to Senator Collins, "If nothing is done to slow or stop the disease, Alzheimer's will cost the United States \$20 trillion over the next 40 years."

This year, our National Institutes of Health (NIH) will allocate *more than \$6 billion* for cancer research ... but *less than \$500 million* for AD research ... just as was true last year. This doesn't make any sense. Despite the need to reduce overall federal spending, we must increase NIH funding for AD research. Aside from the human cost to AD patients, caregivers, and their families, current research spending is penny wise and dollar foolish. As Senator

Collins suggested, without major breakthroughs in treating AD, let alone finding a cure, future long term costs to our Medicare system will be astronomical.

My wife was diagnosed with AD at age 63. No treatment or cure will arrive in time for her. But if our country begins to devote funding for AD research as we have for cancer, then perhaps one day some people will be able to say that they are AD survivors. And perhaps our health care system will be that much further away from bankruptcy.

Allan Vann, Ed.D.  
Commack, NY