NAPA -- FACA 2011 Public Comments

February 7, 2012

DECEMBER 2011 COMMENTS

NOVEMBER 2011 COMMENTS

OCTOBER 2011 COMMENTS

SEPTEMBER 2011 COMMENTS

AUGUST 2011 COMMENTS

JUNE 2011 COMMENTS

DECEMBER 2011 COMMENTS

DATE: December 30, 2011
SUBJECT: info for Advisory Council-December

I am hopeful that you will see that the attachment is included in the summary of input for the month of December 2011. I look forward to attending the January meeting of the NAPA Advisory Council.

Thank you,

Mary Hogan

ATTACHMENT: NAPA-hhs.docx

Available as separate links:	
Personal Reflection	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach26.pdf

DATE: December 21, 2011
SUBJECT: comments for NAPA Advisory Council

Please advise about the status of on-going comments. Can I assume that you continue to take comments each month and that they are sent to advisory council for review?

Mary Hogan

DATE: December 8, 2011
SUBJECT: NCCDP

We would be interested in being on the Advisory Council for Alzheimer's research Care and Services. Is this possible?

NCCDP ALZHEIMER'S DEMENTIA STAFF EDUCATION WEEK
FEBRUARY 14TH TO 21ST.
Register at the top right of home page and begin downloading Now to March 1st. Free staff in-services includes power point, hand outs, staff pre and post tests. The tool kit includes, Proclamation, Alzheimer's Bill of Rights and Alzheimer's Pledge and so much more. Fantastic in-service on Sexuality and Intimacy and Dementia. See http://www.nccdp.org

Sandra Stimson, CALA, ADC, CDP, CDCM
Executive Director
National Council of Certified Dementia Practitioners
http://www.nccdp.org

DATE: December 5, 2011
SUBJECT: January NAPA Advisory Council meeting

My name is Mary Hogan and I am interested in attending the January 2012 NAPA Advisory Council meeting. I am wondering if this is possible.

I was a guardian/caregiver for my 49 year old brother who had down syndrome and died of complications of Alz. disease. I have a vested interest in the Council activities and national plan and have worked with Matt Janicki on the National Task Group on Intellectual Disabilities and Dementia Practices. Please see the attached article and you will understand my commitment to this important cause.

Hopefully I will have an opportunity to be present for this important meeting.

Thank you for your consideration.

Mary Hogan

ATTACHMENT: Down Syndrome newsletter.pdf

Available as separate links:	
Down Syndrome News, Vol. 34, 2011, #2	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach25.pdf

NOVEMBER 2011 COMMENTS

DATE: November 29, 2011
SUBJECT: FW: Bipartisan letter to Sec. Sebelius regarding Draft National Alzheimer’s Plan

I have attached a letter from Rep. Markey and Rep. Smith, Co-chairs of the Alzheimer's Taskforce and House authors of the National Alzheimer's Project Act (NAPA), with their recommendations for the National Alzheimer's Plan.

Please forward this letter to any any all staff working on NAPA, both at HHS and elsewhere.

We thank you for all of the work you are doing to implement the law and are excited to see the draft plan soon!

Thank you,

MaryAlice Parks
Legislative Correspondent and New Media Specialist
Office of Rep. Ed Markey (MA -07)
Washington, DC

ATTACHMENT: 2011_1129 Letter to Sec Sebelius Re NAPA draft Plan signed.pdf

Available as separate links:	
NAPA Draft Plan Recommendations	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach24.pdf

DATE: November 22, 2011
SUBJECT: Written Comments from SWHR

Please find the attached comments from the Society for Women's Health Research (SWHR). If you have any questions or have problems opening the document, please let me know.

Sincerely,

Leslie Stevens, MA
Senior Government Relations Associate
Society for Women's Health Research (SWHR)
Washington, DC
http://www.swhr.org

ATTACHMENT: NAPA letter 11.22 final.pdf

Available as separate links:	
NAPA Scientific Recommendations	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach23.pdf

DATE: November 20, 2011
SUBJECT: Informed Consent Question

How exactly can these clinical trials be conducted on individuals with cognitive disorders? How do they give informed consent?

A guardians should NEVER be allowed to give consent for testing and for that matter no person other than the subject who will be tested should be allowed to give informed consent for clinical trials.

Can the proxy individual who is giving informed consent feel the physiological consequences? I think not and this practice is in violation of international human research testing laws I believe.

What is being done to protect the incapacitated from being placed involuntarily into clinical trials?

Latifa S. Ring
National Organization To Stop Elder Abuse and Guardianship Abuse (NOTEGA)
http://www.stopelderabuse.net

DATE: November 12, 2011
SUBJECT: National Alzheimer's Project Act [NAPA] - Editorial re: recommendations for action plan

Please find attached the pdf of an editorial concerning NAPA in the current issue of *Alzheimer's & Dementia*: Journal of the Alzheimer's Association. This document includes a set of recommendations for consideration by NAPA's Advisory Council [and/or the Secretary, DHHS] in drafting the National Strategic Plan.

I have also attached the draft of a memorandum concerning PAS2020 effort to formulate a specific recommendation to NAPA concerning a national initiative to establish 'public-private partnership' for discovery-development of treatments for AD.

Let me know your thoughts on these two items

Best regards,

Zaven S. Khachaturian, PhD
President
PAD2020 -- The Campaign to Prevent Alzheimer's Disease by 2020
Potomc, MD

ATTACHMENT: ZK Editorial on NAPA NOV2011 ALZDEM.pdf
Draft Memo re Public-Private partnerships - NAPA - 26OCT11.doc

Available as separate links:	
Prospects for Designating Alzheimer's Disease Research a National Priority	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach21.pdf
Perspective: Public-Private Partnerships to Develop Treatments	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach22.pdf

DATE: November 8, 2011
SUBJECT: Thx for msg

Report's posted at alz.org/napa. I've attached a copy. We'll send out as attachment to AC members later today as well.

Best,
Rob

ATTACHMENT: NAPA_Report_110311.pdf

Available as separate links:	
Alzheimer's from the Frontlines: Challenges a National Alzheimer's Plan Must Address	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach20.pdf

DATE: November 3, 2011
SUBJECT: Report for NAPA Advisory Council: The Path Ahead: A Framework for a Transformative National Plan to Defeat Alzheimer's Disease

Attached please find the report entitled *The Path Ahead: A Framework for a Transformative National Plan to Defeat Alzheimer's Disease.* This report provides a series of recommendations developed by Leaders Engaged on Alzheimer's Disease (LEAD) around research, clinical care, long-term care and support services, and drug discovery and development for consideration by the Advisory Council as it develops a national strategic plan for Alzheimer's disease.

We would greatly appreciate it if you can please distribute the attached report and cover letter to the members of the Advisory Council for their review.

Thank you,

Patrick Fritz

ATTACHMENT: LEAD Recommendations Cover Letter vf.docx
LEAD_ The Path Ahead, A Framework for a Transformative National Plan to Defeat Alzheimer's Disease.pdf

Available as separate links:	
Cover Letter, The Path Ahead: A Framework for a Transformative National Plan to Defeat Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach18.pdf
The Path Ahead: A Framework for a Transformative National Plan to Defeat Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach19.pdf

OCTOBER 2011 COMMENTS

DATE: October 20, 2011
SUBJECT: FROM ERIC HALL/AFA REPORT TO NAPA!

I am extremely pleased to forward a copy of *No Time to Waste*, AFA's recommendations in connection with the National Alzheimer's Project Act. The report will be posted shortly on our website and released on PR Newswire.

Eric J. Hall
President and Chief Executive Officer
Alzheimer's Foundation of America
New York, NY
http://www.alzfdn.org

ATTACHMENT: NoTimetoWasteReport-Final10-11.pdf

Available as separate links:	
No Time to Waste: Recommendations for an Integrated National Plan to Overcome Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach17.pdf

DATE: October 19, 2011
SUBJECT: NAPA National Plan Recommendations

Thank you for the opportunity to submit recommendations for the NAPA National Plan. Attached are our recommendations that focus on the unbefriended elderly. We hope their needs will be addressed in the final plan. Please contact me if you need any additional information.

Thanks again,

Kathy Cubit
Director of Advocacy Initiatives
Center for Advocacy for the Rights and Interests of the Elderly (CARIE)
Director of Advocacy Initiatives
Philadelphia, PA
http://www.carie.org, http://www.caregivergps.org

ATTACHMENT: NAPA National Plan Recommendations

Available as separate links:	
NAPA National Plan Recommendations	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach16.pdf

SEPTEMBER 2011 COMMENTS

DATE: September 30, 2011
SUBJECT: Comments for the Council

The single most staggering dilemma facing our Nation today is the upcoming tsunami of “boomers” barreling down upon us that will become victims of Alzheimer’s!

At this time, Right Now, visionary leadership is absolutely essential in order to effectively direct action that will lessen the hardship that will be experienced by millions so stricken as well as their loved ones. Decisive action towards implementing screening that will diagnose severity with appropriate treatment being scheduled at the time of screening.

While the emphasis remains on “The Cure” we cannot afford to lose sight of the here and now and the fact that today there are meds available that will lessen the impact of this mind-robbing malady and provide relief for friends and loved one of these individuals in the way of quality of life extensions. Early detection must be recognized as a priority concern.

Florida, with its huge Elder population, leads the Nation in this devastating and incurable disease. It is projected that in just a few years this amount may increase three fold. Now s the time for action/Further delays will be a reflection of an abdication of responsibility.

As a caregiver who has experienced first hand the horrific loss of individuality by those who have no control of this I stand firmly for immediate priority action to alleviate the suffering associated with Alzheimer’s. As a civilized society we can do no less to insure the respect and dignity of these souls.

Austin R Curry
Executive Director
Elder Care Advocacy of Florida

DATE: September 29, 2011
SUBJECT: National Alzheimers Plan

Dear Advisory Council, for the past 7 years my siblings and I have been assisting my mother manage the challenges of Alzheimers disease. I am a veteran of the nursing/psychiatric field with training in Geriatric Mental Health. When our mother began to show signs of the disease I urged her doctor to do a mini mental exam. At the time she scored below 20 and I believe this was due in part to the fact that she is Spanish speaking only and the test was designed for the English speaker. And I don't believe she comprehended its purpose and mostly joked around with the questions and answers. The fact remained that she missed all the critical orientation questions and her recent memory was severely impaired. Today she remains coherent, jovial and she converses easily. She has some difficulty with remote and recent memory, and item recognition, but she still recognizes familiar faces and is able to do most familiar tasks. She can still prepare simple meals, make coffee, and perform all ADLs. Recently, she has shown signs of new memory formation. These memories are based on new information obtained a month or two prior. The new memories are usually linked to an emotional response, eg; something she enjoys or wants to do. The new memories are formed after she has asked the same question repeatedly and it has been answered each time as though it was being asked for the first time. She has been on a combination of drugs called Namenda and Aricept, as well as the chewable version of Melatonin that only Trader Joes sells. She does not experience sundowning and sleeps 8 or 9 hours per night. She experiences one waking about 4 am when she takes another Melatonin and sleeps until 8 or 9 am. The geriatric mental health training I participated in was offered by the University Of Washington School of Social Work, it featured a wonderful section on a program called the Beyond Love Project. The project workbook was written by Moyra Jones and it is a community based model that can be adopted by any community. The Beyond Love Project utilizes the collaborative effort of various medical and legal professionals, as well a community volunteers to teach caregivers to care for themselves and their loved ones with compassion. It provides tools to assist caregivers in recognizing the stages of dementing disorders, as well as the limitations and challenges of each stage. I have been working on distribution of pamphlets that are produced by the Dept of Health and Human Services to encourage education and early detection. But I am one person and it is not enough. Our Medical professionals are the first line of defense and often they are not aware of the early signs. My mother's own doctor said to me in horror "how did I not see this? I've known this woman for 10 years." I responded "she presents well doesn't she?" The truth is, like any other disease, the only way for a medical professional to detect this disease is by testing for it. My point here is that a Mini Mental Exam should be as standard as a colonoscopy or prostate exam at 55. Thank you for your time and I look forward to hearing about the new plan and I hope to be a part of bringing much needed services to my community. In the meantime, I will continue my efforts to bring awareness, education and support and advocacy to my community.

Laura Villegas

DATE: September 29, 2011
SUBJECT: Alzheimer's National Advisory Council / participation

I am writing because I would like to become involved in advocacy work on behalf of U.S. citizens suffering from Alzheimer's. I was the sole caretaker for my mother, who passed away in February 2010; I began my long, sometimes difficult, but very rewarding journey with her in 1999. She was housed for several years in assisted living facilities, and my experience clearly showed me that Alzheimer's patients are not receiving the specialized care they deserve. Further, I also learned about traumatic housing transfer issues, and the need for the Alzheimer's patient to have one-on-one care daily with someone they are familiar with, whether or not recognition is still available.

I attended the Alzheimer's Association International Research Conference in Paris this July, learning about the disease process and lifestyle factors that may aide in prevention. My prior education included a B.S. in Psychology and graduate classes in Adult Education and Counseling. Prior to my care taking journey, I was (and still am) a Certified Alcohol and Drug Counselor. I have had a few brief classes in Pharmacology and Neurology, but nothing that fully addresses the mechanisms of Alzheimer's and other dementia diseases.

When I heard that a national advisory council was forming, I relayed feedback via e-mail. However, it seemed so little with such a huge problem / concern looming for the nation. I wish to be involved and helpful in other ways. I am willing to go back to school, move from my current residence -- anything to really make a solid difference in this complex, multi-faceted issue.

Do you have any advice as to a course of action that I can take? Does the National Advisory Council or any other organization involved with Alzheimer's need help that I am qualified to do? I sincerely wish to make a difference.

Thank you,

Annette Guidry, B.S., CADC

DATE: September 29, 2011
SUBJECT: Compulsory national service to all students in USA

I am a retired primary care physician who worked in Long Term Care for over 35 years.

With aging society and growing rate of Dementia, we need the entire society to involve.

Specially we need the our young people to involve and to participate for the care of this enormous medical and global problems.

Even for the few weeks of special human service by the students, probably will make a big difference in national awareness of this problems.

Jhin J. Cynn MD, CMD, FAAFP

DATE: September 27, 2011
SUBJECT: A National Strategy on Alzheimer's

I read the article in the New York Times today about the upcoming committee that will tackle the job of Alzheimer's and our governments role and responsibility. I am a daughter of my 82 year old mother who has been living with this disease for the past seven years. My father, who is 88 years, has been amazing through this entire journey. In February, my mother fell down and broke her hip and my father finally agreed to let me bring someone in to help them 24/7.

This is not an easy task nor an inexpensive one. We are able to manage to have them home right now but the financial and emotional burden that is put upon us by this disease is difficult to describe in words. It is a shame that our government and our health care system does not allow for this type of help to be covered under medical plans. Yes, you can purchase long term care, but really, how many people really ever think about this type of insurance at an early age, before any disease kicks in and you don't qualify. My hope and dream is that this task force can develop a plan that will tackle not only government's role in funding medical research to wipe out this horrific disease, but also will look at the financial burden caregiving places on individual families and our nation. If we could find a cure for Alzheimer's, our nation would flourish. I know I am one small voice in a very big, big picture. I do my part to help every day. I actively fundraise for the Alzheimer's Association and support all causes that can lead to a cure. I am scared not only for my mom, but also for myself and my children. I don't want to go through what my mom is going through now and I certainly can't imagine passing this on to my children. It truly breaks my heart.

But I hope you will listen to my voice and if you ever need information from a person deep in the trenches, I would be happy to share my knowledge on to the committee. As I tell my friends and love ones, I fight for my mom's present and for all of our future!

Thank you.

Diane Kounalakis
Hillsborough, CA

DATE: September 27, 2011
SUBJECT: Suggestion

I have been conducting training for health care professionals for over 20 years, including physicians on Alzheimer's disease. It is a fact the the physicians are not prepared to assess for symptoms of the disease nor able to cooperate with the community health and social agencies on coordinating services that are needed. There needs to be much more education at the basic level through the tele-health programs, especially in the rural areas, on basic skills in assessing for Alzheimer's

The other issue is the importance in establishing a base line for possible early signs of dementia -- i.e. MCI. About 80% of early assessments of MCI usually end up within 10 years or so being "diagnosed" as Alzheimer's.

Suggestion is that a baseline, as one does for blood pressure, using a modified mini mental status test be made for the population starting at 50.

Redo it every year when visiting the doctors office -- and compare the changes. If there are changes then further investigation is needed with possibly early intervention using Aricept or Memantine. These have been shown to be effective together the earlier they are administered.

Thank you for the link to express my ideas and concerns

Ron Lucchino, PhD

DATE: September 27, 2011
SUBJECT: Help, Direction for Alzheimer's Caregivers

As you undertake this crucial work, please consider the nearly 14.9 million unpaid Alzheimer's caregivers, many of whom are overwhelmed by their caregiving role. This number will grow year by year as will the number of those diagnosed with Alzheimer's.

In more than 20 readings and discussions which I have conducted this year, I inevitably find a thirst among caregivers for honest, lived, true stories of caregiving. Tonight I will address this issue at a meeting in St. Louis. The issue was framed for me this way: What happens when you have to parent your parents? How do the parents react who are now in the role of care recipient? The FAQs from my meetings represent a document of the profound and thoughtful concerns of audiences from Michigan to Washington state to Missouri. I urge you to consider this aspect of the Alzheimer's "dilemma."

The literature of lived Alzheimer's experiences is invaluable as a tool for caregivers. It complements the excellent medical and advice literature in its human and humane perspective. Please consider its role as part of an outreach to the millions of caregivers who feel as if they are swimming solo in their duties.

Sincerely,

Susan Rava, Ph.D.
Author of *SWIMMING SOLO: A Daughter's Memoir of Her Parents, His Parents, and Alzheimer's Disease* (Sewanee, TN: Plateau Books, 2011).

DATE: September 27, 2011
SUBJECT: National Plan for Alzheimer's Disease

I am a practicing geriatric medicine specialist who devotes a large amount of my practice to diagnosing and treating persons with Alzheimer’s disease. I would very much like to discuss some recommendations with a staff member of the Advisory Committee.

While a large number of researchers are focused on using new imaging techniques to diagnose this disease earlier, I find in my practice that many people who have had this disease for years are going undiagnosed. I believe that this is because primary care physicians are intimidated by this diagnosis and many psychiatrist and neurologists just not interested in making this diagnosis. I lecture frequently to professional groups on just this topic and in that talk I try to demystify the diagnosis.

I would be very happy to discuss my views with a staff member if you are interested.

Thank you for your time.

James P. Richardson, M.D., M.P.H.
Chief, Geriatric Medicine
St. Agnes Hospital
Baltimore, MD

DATE: September 26, 2011
SUBJECT: Comments for NAPA advisory council meeting on Sept 27th.

Attached is a copy of my testimony/comments for tomorrow's Council meeting. Would appreciate if copies could be made for each Council member.

Thanks.

Matthew P. Janicki, Ph.D.
Associate Research Professor and Director for Technical Assistance
Rehabilitation Research and Training Center in Aging and Developmental Disabilities --
Lifespan Health and Function
Department of Disability and Human Development
University of Illinois at Chicago
Chicago, IL

ATTACHMENT: Testimony-Sept 27 2011-b.pdf

Available as separate links:	
National Task Group on Intellectual Disabilities and Dementia Practices: Comments to the Advisory Council on Alzheimer's Research, Care, and Services	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach15.pdf

DATE: September 23, 2011
SUBJECT: Latino Alzheimer's Alliance

Thank you so much for returning my call. As I mentioned to you during the last 4 years the Latino Alzheimer's and Memory Disorders Alliance is working very hard on the Alzheimer's Awareness in the Latino community in the most important cities of the US as is Los Angeles, New York, Chicago and now DC.

Bilingual and Bi-cultural programs has being offering to more than 15,000 Latino families in the last 2 years, not only by support groups, encourage them to participate in clinical studies, provided the follow up to the individuals who required. The Latino ALzheimer's Alliance train more than 700 healthcare providers a year on how to be sensitive to cultural and social barriers in the Hispanic community. Sinai Health System, Loyola, Rush Alzheimer's Disease Center, Alivio Clinics, Sinai Health System, Psychology School of Chicago and LA, UCLA, are some of the institutions that received our trainings.

The Chicago Tribune, LA Times,, Univision TV/Radio, La Opinion and Washington Post articles about LAMDA are increasing the number of individuals who are asking to attend our programs. Is for this reason it is very important to represent the Latino/Hispanic Community in the US by participate as a member on the Advisory Council on Alzheimer's Research, Care, and Services meeting held on Tuesday, September 27, 2011.

We appreciate your efforts and consideration on this important journey.

Please see attachments

Best regards,

Constantina Mizis
CEO
The Latino Alzheimer's and Memory Disorders Alliance

ATTACHMENTS: Chicago PSA.wmv
La Opinion LA.docx

Available as separate links:	
Para reflexionar sofre la memoria	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach13.pdf
Chicago PSA (Spanish-speaking video file)	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach14.wmv

DATE: September 10, 2011
SUBJECT: the prevention and treatment of Alzheimer's disease

My name is Lane Simonian. I am an historian. Seven years ago when my aunt and cousin were in the late stages of Alzheimer's disease and my mother was in the early stages of Alzheimer's disease, I began searching for ways to prevent and treat the disease. As an historian, I began to collect a mass of abstracts and articles in an attempt to tell the story of Alzheimer's disease. At first with a limited background in biology, I made very slow progress in understanding Alzheimer's. Now, though, I can explain almost every new finding in regards to the disease with the attached hypothesis. What used to take me months to figure out now usually only takes a matter of minutes.

The critical finding in regards to Alzheimer's disease was made by Mark Smith and his colleagues in 1997: Peroxynitrite-mediated damage is widespread in Alzheimer's disease. This damage includes the oxidation (loss of electrons and hydrogen) of glucose transport systems, choline transport systems, the enzyme choline acetyltransferase, g protein-coupled receptors (muscarinic, serotonin, dopamine, olfactory, adrenergic), the nitration of tau proteins, lipid peroxidation, and the influx of calcium. This damage results in a lack of focus and energy, impaired short-term memory due to a shortage of acetylcholine, disturbed sleep and mood, lack of awareness, impaired smell, behavioral problems (in some instances), disrupted neurotransmission, damage to cellular membranes, and neuronal cell death.

The factors that lead to peroxynitrite formation include (but again are not limited to) high glucose levels, high blood pressure, the APOE4 gene, presenilin gene mutations, bisphosphonate osteoporosis drugs, late estrogen replacment therapy, mercury, aluminum fluoride, and stress. Most or all of the factors that lead to peroxynitrite formation also lead to Alzheimer's disease (the connection has not been made as of yet between bisphosphonate osteoporosis drugs and Alzheimer's disease, but the fact that the numbers of cases of Alzheimer's disease has skyrocketed since the introduction of these drugs is perhaps concerning).

Phenolic compounds in various fruits, vegetables, spices, and essential oils and polyunsatured fats inhibit peroxynitrite formation and thus inhibit the development of Alzheimer's disease. The most direct and concentrated way to deliver phenolic compounds to the brain is through aromatherapy with essential oils high in phenolic compounds.

An impressive number of animal studies, case studies, and clinical trials indicate that Alzheimer's disease can be treated effectively with peroxynitrite scavengers (compounds that are hydrogen donors convert peroxynitrites into a nitrogen dioxide anion and water). These scavengers partially reverse or prevent all of the damage done by peroxynitrites listed above (for example, they add hydrogen back to muscarinic receptors allowing more choline to enter cells). In the reference section of the attached hypothesis you will find a partial list of peroxynitrite scavengers (most of them are phenolic compounds) which have helped correct cognitive deficits in animal models of Alzheimer's disease. These include rosmarinic acid, grape seed extract, cinnamon extract, eugenol in Cinnamomum zeylanicum essential oil, and thymol and carvacrol in Zataria multiflora Boiss. essential oil. In addition, Jimbo and colleagues in Japan were able to improve cognitive function in dementia patients after giving them rosemary and lemon to smell in the morning and lavender and orange to smell in the evening for 28 days. Akhondzadeh and his colleagues achieved similar results using tinctures of sage and lemon balm essential oils for four months. One reviewer looking at this (and perhaps other clinical trials) concluded "excellent results have been obtained with peroxynitrite scavengers, with reversals of Alzheimer's disease in human clinical trials being repeatedly demonstrated."

Several case studies add further validity to the findings from animal studies and clinical trials. Dramatic improvements in alertness and awareness and modest improvements in short-term memory have been noted. In my mother's case she recognizes her home again, feels comfortable around her brother who she used to think was an impostor, sleeps through the night, can recall her name and sometimes spell it, can sometimes remember the order of days and months, can complete phrases such as I scream, you scream, we all scream for...ice cream and April showers...bring May flowers, and is much more alert and aware than she was four years ago before we began aromatherapy.

Essential oils high in methoxyphenols (such as rosemary, sage, thyme, oregano, clove, and cinnamon leaf) and citrus based essential oils appear to work the best. The patient can smell them under each nostril for a few seconds. It takes about a month to begin seeing some improvement (perhaps because it takes time to reverse the damage that peroxynitrtes do to smell).

Let me highlight the critical points:

> Peroxynitrite-mediated damage is widespread in Alzheimer's disease and directly or indirectly causes all the features of the disease.
>
> Most or all of the factors that lead to peroxynitrite formation can cause Alzheimer's disease.
>
> Compound which inhibit peroxynitrite formation inhibit the onset of Alzheimer's disease.
>
> In animal studies, clinical trials, and case studies, peroxynitrite scavengers have lead to improvements in cognitive function.
>
> Phenolic compounds can be used both to prevent and treat Alzheimer's disease. In both cases, aromatherapy is likely the most effective way to deliver these compounds to the brain.
>
> This disease can be treated effectively immediately with few side effects.

I wish you good luck in your work. If the opportunity arises, I would like to meet each of you in person. In the meantime, please feel free to contact. Nothing pleases me more when I receive questions from people interested in my research.

Best Regards,

Lane Simonian

ATTACHMENTS: Hypothesis for Alzheimer’s Disease
img005.jpg
img007.jpg
img009.jpg
img010.jpg
img035.jpg
img036.jpg
img050.jpg
img051.jpg

img052.jpg
img054.jpg

Available as separate links:	
Hypothesis for Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach1.pdf
Effect of Aromatherapy on Patients with Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach2.pdf
Aromatherapy in the Treatment of Alzheimer's Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach3.pdf
The Psychopharmacology of European Herbs with Cognition-Enhancing Properties	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach6.pdf
Current Pharmaceutical Design, 2006, Vol. 12, No. 35, pg 4617	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach7.pdf
Current Pharmaceutical Design, 2006, Vol. 12, No. 35, pg 4619	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach8.pdf
Evidence Based OTC Treatment of Alzheimer's Disease I	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach9.pdf
Alzheimer's Disease and Dementia Message Board	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach10.pdf
ECU Therapist Studies Links Between Scent and Memory	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach11.pdf
Texas State Research on Aromatherapy	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach12.pdf

DATE: September 7, 2011
SUBJECT: public input

Thank you for the opportunity to give suggestions regarding areas for inclusion into the National Plan for Alzheimer's Disease. I am a Board Certified Family Nurse Practitioner working in a Primary Care Internal Medicine practice and also the daughter of a person with Alzheimer's (late stage, diagnosed in 2000 with symptoms for at least 3 years prior to diagnosis).

- I would like to see changes in the current care delivery when it is not possible for people affected by the disease to be primarily cared for by family members in their private homes. I believe the current wide spread choices of secured Assisted Living facilities or Long term Intermediate Care in Nursing Facilities are not the best solutions and we need to do a major overhaul in our traditional way of thinking about this type of housing and care. It is not cost effective and certainly does not result in high levels of satisfaction among persons with the disease or their loved ones.

- Secondly I believe it is a travesty that we have allowed the federal funding of this illness to be so grossly inadequate that we have no significant answers about how we can prevent this illness and no hope of being able to offer treatments that will change the course of this disease. This illness is sapping a huge amount of funding from federal, state and private resources and yet our legislators can't commit to setting aside more than a pittance as compared to funding for other major illnesses. Please imagine the devastation of being diagnosed with AD and having no hope for cure or even remission of symptoms for any period of time but knowing the illness is progressive and fatal. When you look at the history of how concentrated and dedicated effort to research and development changed the outlook for those with HIV/AIDS you have to believe it IS possible to change how a person diagnosed with Alzheimer's could expect the rest of their life to unfold.

- In this time of advanced electronic communication we should be able to conduct research without burdening people and their families with the need to travel long distances to be seen in major research centers. With the use of (and low intensity training of) qualified people in areas remote to research centers patients could easily undergo periodic evaluations and assessments using tools such as Skype and other Internet communications.

- Continue to involve mass media resources such as newspapers, television and e-communications to inform and update the public of the realities of Alzheimer's. There has been too long a stigma attached to this illness that keeps even intelligent and otherwise forward thinking people and families from allowing any common knowledge of being diagnosed or affected with the illness. These same people would not hesitate to inform others if they were diagnosed with cancer or heart disease but act as if the diagnosis of Alzheimer's is shameful or an indicator of a personality weakness. It is time for AD to come "out of the closet"!

Thank you for the work you are undertaking and for being dedicated to providing real change for those Americans affected by Alzheimer's either personally or by witness of the illness with anger, sadness and hopelessness. We MUST change the impact of this disease for the millions of Americans who live it daily.

Jana Powell
Lutheran Medical Group
Fort Wayne, IN

AUGUST 2011 COMMENTS

DATE: August 29, 2011
SUBJECT: Stopping Alzheimer’s Completely

Alzheimer's has a very simple and avoidable cause: steam-refined polyunsaturated vegetable oils. I have been working this out since 1990.

The unsuspected vitamin E deficiency in these widely consumed food oils leads to brain cell membrane oxidation, that impairs the function of important enzymes that normally degrade the beta-amyloid protein. This protein therefore accumulates, incredibly slowly, in the brain of a regular consumer of deodorized vegetable seed oils.

After the age of 65 or so, accumulated beta-amyloid may release highly toxic soluble aggregates (called oligomers), that are the immediate cause of synaptic toxicity and neuronal death.

That is exactly how over 5 million Americans have ended up with Alzheimer's disease.

My suggestion to your Government, is simply to legislate a requirement for all refined seed oils in your country to have any vitamin E deficit (usually 30%) corrected before distribution and sale. This simple step will also prevent ADHD occurring during pregnancy.

Already, this basic preventive step is under consideration by the Australian Government's Food Standards Authority, and we may be the first nation in the world to eliminate the twin brain epidemics of Alzheimer's and its prenatal partner, ADHD.

The USA--where vacuum steam-refining of seed oils was invented, in 1899 (David Wesson, Savannah)--has no shortage of brain power. What you lack is a safe level of vitamin E in your brain-oxidizing vegetable oils.

Can you fix the problem, and catch up with Australia?

When your Norfolk, Virginia shipyards were mass-producing Liberty ships for WW2 Atlantic convoys, a large banner was hung across the docks, saying:

IT CAN AND WILL BE DONE!!

Can you make vegetable oils safe? Can you do this too?

I attach a draft hypothesis for your inspection: I shall be trimming it down shortly, for submission to The Lancet, in London.

Here, at long last, is the direct cause of the disease: knowing this, we can easily prevent it.

Best To All,

Dr Robert Peers MBBS (Unimelb)
General, Preventive & Nutritional Medical Practitioner
North Carlton. Vic. Australia

ATTACHMENT: Alzheimer's.pdf
ATT00001.htm

Available as separate links:	
Alzheimer's Disease And Attention Deficit Disorder May Share A Single Cause: Refined Vegetable Oil	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach5.pdf

DATE: August 29, 2011
SUBJECT: Suggestion for Alzheimer research

I think that the most urgent problem in Alzheimer's research is the need for a soul-searching by policymakers for a correct perception of the disease.

Alzheimer research has been misled by hypes and illusions for too long. We believe that the ultimate strategy to delay it and ameliorate its social impact will take two basic approaches. First, motivate society as a whole to supports the elderly for better social connections and healthy lifestyles; and second, develop medications to extend the lifespan of old neurons by activating their lifeline metabolisms, rather than "inhibiting" the farfetched "causal" factors as widely believed today.

Please see our recent article (attached) in which the rationale for this strategy is discussed.

Thank you for sharing this letter to the members of the NAPA Advisory Council

Respectfully,

Ming Chen, Ph.D.
Associate Professor and director of Aging Research Laboratory
Bay Pines VA Medical Center and University of South Florida

ATTACHMENT: Alzheimer Truth.pdf

Available as separate links:	
Scientific Truth or False Hope? Understanding Alzheimer's Disease from an Aging Perspective	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach4.pdf

DATE: August 25, 2011
SUBJECT: Alzheimer’s advisory committee questions and information

I have two questions: will there be public comment at any or all of the advisory council meetings and what would be the best way to communicate with members of the committee?

Based on animal model studies, clinical trials, and case studies (including my mother), I know how to treat this disease and likely how to delay its onset. In the hypothesis, you will find references that show that peroxynitrite-mediated damage is widespread in Alzheimer's disease and that this damage can partially be corrected with peroxynitrite scavengers. Some of the most effective scavengers are methoxyphenols (eugenol, thymol, and carvacrol) in various essential oils (such as cinnamon leaf, clove, oregano, thyme, rosemary, and sage) in part because they can be inhaled directly into to the part of the brain affected by Alzheimer's disease: the hippocampus.

With some help from this committee, it is likely that Alzheimer's disease could be effectively treated within this next year.

Best Regards,

Lane Simonian

ATTACHMENT: Hypothesis for Alzheimer’s Disease.doc
img007.jpg
img005.jpg

Available as separate links:	
Hypothesis for Alzheimer’s Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach1.pdf
Effect of Aromatherapy on Patients with Alzheimer’s Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach2.pdf
Aromatherapy in the Treatment of Alzheimer’s Disease	http://aspe.hhs.gov/daltcp/napa/Comments/cmtach3.pdf

DATE: August 24, 2011
SUBJECT: Meeting Agenda: National Alzheimer's Project Advisory Council

I was a caregiver to my mother who recently passed in New York. My years as a caregiver was for the most part stressful and more so due to the everyday care issues that came up in connection with her home-care agency and home health aides.

I do not live in the US anymore but would like to be keep informed as to NAPAC agenda and advocacy goals.

Thank you

Cory Lemos

JUNE 2011 COMMENTS

DATE: June 9, 2011
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 though 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