NAPA Research Progress Report

NAPA Advisory Council Meeting

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Informal Caregiving

What contributions has research made?

Resources for Enhancing Alzheimer's Caregiver Health (REACH II)

Objective of Intervention

- Improve quality of life and reduce clinical depression in caregivers.
- Reduce the rate of institutional placement of care recipients.

Intervention addressed

- Caregiver depression, burden, self-care and social support, and care recipient's problem behaviors.

Resources for Enhancing Alzheimer's Caregiver Health (REACH II) Study Design

Randomized Clinical Trial
- Active treatment and control implemented in five sites: (Birmingham, Memphis, Miami, Palo Alto, and Philadelphia)
- Stratified by spouse and non-spouse caregivers
- Recruited equal numbers of African Americans, whites, and Hispanic Americans (N=200 each group)

Dissemination
- Veterans Health Administration in 29 sites from 24 facilities in 15 States, with a total of 127 caregiving dyads participating, and was implemented by 2 Area Agencies on Aging in Kentucky and Illinois.
- Translated in Spanish.

From: **Translation of a Dementia Caregiver Support Program in a Health Care System—REACH VA**

Table 1. Department of Veterans Affairs Medical Center (VAMC) Facilities Participating in REACH VA

Facility
VA Northern California HCS, Sacramento
Denver VAMC, Denver, CO
VA Connecticut HCS, Newington
Atlanta VAMC, Atlanta, GA
Charlie Norwood VAMC, Augusta, GA
Ann Arbor VAMC, Ann Arbor, MI
Battle Creek VAMC, Battle Creek, MI
Minneapolis VAMC, Minneapolis, MN
Albuquerque VAMC, Albuquerque, NM
Samuel S. Stratton VAMC, Albany, NY
Bath VAMC, Bath, NY
VA New York Harbor HCS, New York, NY
Northport VAMC, Northport, NY
Syracuse VAMC, Syracuse, NY
Durham VAMC, Durham, NC
Cincinnati VAMC, Cincinnati, OH
Butler VAMC, Butler, PA
Philadelphia VAMC, Philadelphia, PA
VA Pittsburgh HCS, Pittsburgh, PA
Memphis VAMC, Memphis, TN
James H. Quillen VAMC, Mountain Home, TN
Michael E. DeBakey VAMC, Houston, TX
Salt Lake City VAMC, Salt Lake City, UT
Huntington VAMC, Huntington, WV

Abbreviations: HCS, health care system; REACH, Resources for Enhancing Alzheimer's Caregiver Health.

Figure Legend:

Department of Veterans Affairs Medical Center (VAMC) Facilities Participating in REACH VA

Translation Studies of REACH II

State	Funding Source	Year
Alabama	AoA/ADSSP	2004
Florida	AoA/ADSSP	2008
Georgia	AoA/ADSSP	2008,2010
Hawaii	RCI and J&J	2012
Nevada	RCI and J&J	2012
New York	RCI and J&J	2012
North Carolina	AoA/ADSSP	2008,2010
Texas	RCI and J&J	2007,2012

Administration on Aging (AoA); Alzheimer's Disease Supportive Services Program (ADSSP);
Rosalynn Carter Institute for Caregiving (RCI);
Johnson & Johnson (J&J)

Alleviating Stress for Caregivers:
Benefits of Adult Day Services

Depressive Symptoms

Legend:
— Non-ADS day
---- ADS day

Y-axis: 1.40, 1.30, 1.20, 1.10, 1.00, 0.90, 0.00

X-axis: Low (-1 SD) — High (+1 SD)

Number of Stressful Events
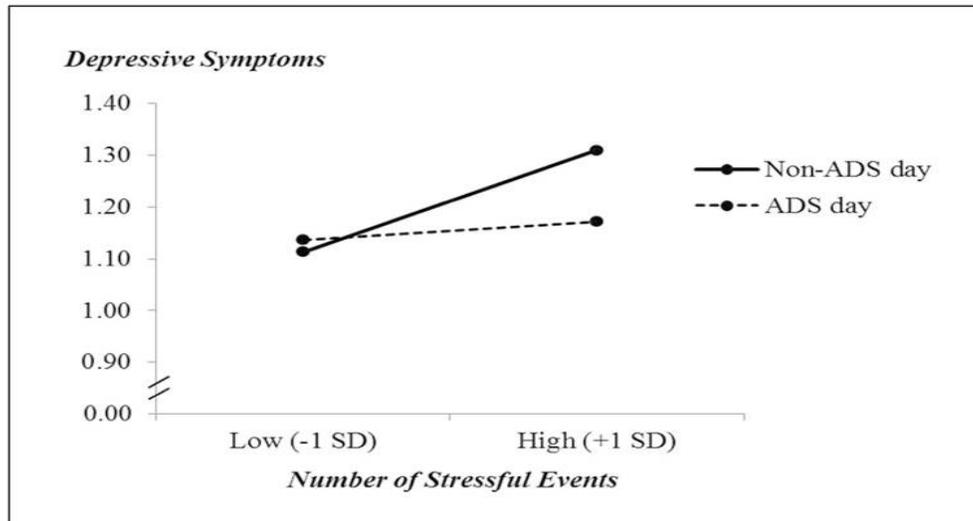
Zarit, SH et al. (2013) *Gerontologist* Epub Jun 19.

Making Caregiving Easier:
Improving Mobility for Older Individuals

- The ability to walk without assistance is critical for older people to live in a community and function well.

- The study showed that a regular, balanced and moderate exercise program followed for an average of 2.6 years *reduced the risk of major mobility disability by 18 percent* in an elderly, vulnerable population.

- Exercises included walking, and strength, flexibility, and balance training activities.
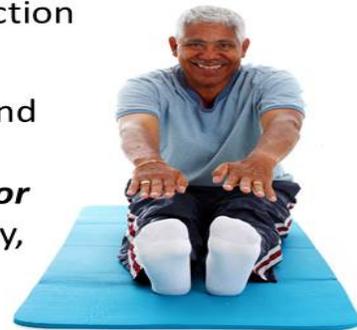
Pahor, M et al. (2014) *JAMA* 2014 May 27 [Epub ahead of print].

Making Caregiving Easier:
Reducing Risks for Caregivers and Those Receiving Care

**NIA & Patient Centered Outcomes Research Institute (PCORI) Collaboration on Falls-Injury Prevention**

- Falls are a common and serious problem among the elderly
  - ➤ The best prevention strategy is not known
  - ➤ Funds a large clinical trial on prevention of fall-related injuries in non-institutionalized older adults
  - ➤ Meaningful involvement of patients and stakeholders as partners with researchers
- $30 million, 5-year study supported with funds from PCORI and led by NIA and team of investigators: *"Randomized Trial of a Multifactorial Fall Injury Prevention Strategy"*
- Investigators at Brigham and Women's/Harvard, Yale, and UCLA
- Award announced June 4th

Generating/Collating Data on Population Impact

Findings from the newly-released "65+ in the United States: 2010" Report:

- Fewer than 1/5 of older people have enough personal resources to live in a nursing home for more than 3 years, and nearly 2/3 cannot afford 1 year

- Home and community-based services for long-term care are becoming increasingly popular; Medicaid funding for these services increased from 13% of total funding in 1990 to 43% in 2007

- NIA-funded Health and Retirement Study data suggest that a significant percentage of older Americans engage in caregiving:
  - ➤ Among individuals aged 65-74, 37.8 percent provided caregiving
  - ➤ Among individuals aged 75 and older, 19.2 percent provided caregiving
  - ➤ An estimated value of these unpaid activities was $83.4 billion in 2002

Alzheimer's Disease Research Summit 2015
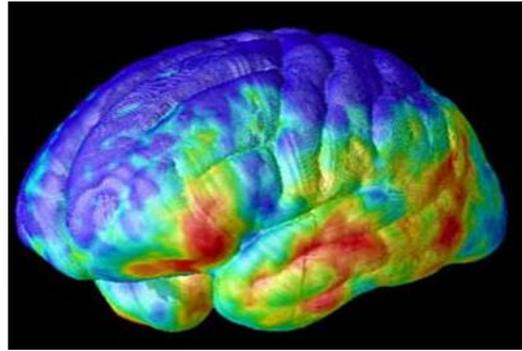
- **February 9-10, 2015**
  National Institutes of Health
  U.S. Department of Health & Human Services
  Bethesda, MD

2015 Summit Features

- An agenda reflecting input from the Trans-NIH AD Working Group and National Advisory Council on Aging

- International involvement, including representatives from G7 countries

- Expanded international perspective in the plenaries

- A presentation from the World Health Organization on its international research plan analysis (tentative)

Updated Draft Summit Agenda Outline

- *NAPA Research Milestones*: Process and Progress

- *Plenary Lecture(s)*:
  - Socioeconomic Burden of AD: Update on National and International Trends
  - Socioeconomic Burden of AD: Global Trends with a Focus on Developing and Under-Developed Countries
  - Deconstructing the Complexity of AD

- *Session I*: Interdisciplinary Research to Understand the Heterogeneity and Multifactorial Etiology of AD

- *Session II*: Transforming AD Therapy Development: from Targets to Trials

- *Session III*: New Strategies for Prevention

- *Session IV*: Innovating disease monitoring, assessment and care

- *Session V*: Enabling Partnerships

- *Session VI*: Empowering Patients, Engaging Citizens

G8 UK
United Kingdom 2013

Global action against dementia

G8 Dementia Summit Declaration and Communique
- Identify a cure, or a disease-modifying therapy, for dementia by 2025
- Significantly increase the amount spent on dementia research
- Increase the number of people involved in clinical trials and studies

G7/8 Summit Legacy Meetings 2014-2015
- Social impact investment – United Kingdom
- New care and prevention models – Japan
- Academia-industry partnerships – Canada and France
- International research coordination – treatment, cure, and prevention – USA

G7/8 Legacy Wrap-Up
- Tentatively to be organized by the World Health Organization, in Geneva in March 2015

http://dementiachallenge.dh.gov.uk/2013/12/12/g8-dementia-summit-agreements/

NIH Conference on Small Vessel Disease

- Two-day workshop to be held on the NIH Main Campus -- **September 18-19, 2014.**
- Sponsored by NINDS, in collaboration with NHLBI and other NIH ICs
- Focus will be on sharing discoveries, identifying challenges, and fostering collaboration
- Topics include: basic biology of small vessels, vascular dynamics, vessel-cellular interactions, small vessels and disease, effects of the environment, research tools and innovation
- This workshop will inform research on the basic mechanisms of and experimental models for Vascular Cognitive Impairment/Dementia, which are among the recommendations from the ADRD 2013 workshop.

https://meetings.ninds.nih.gov/meetings/small-vessel-workshop2014/

INTERNATIONAL ALZHEIMER'S DISEASE RESEARCH PORTFOLIO (IADRP)   http://iadrp.nia.nih.gov/cadro-web/

- Web-based portal developed by NIA and the Alzheimer's Association: Alzheimer's and related dementias research funded projects since 2008
- Enables funders to coordinate planning, leverage resources, avoid duplication, and identify new opportunities
- Currently includes: U.S. federal agencies, state agencies, not-for-profit organizations, foundations, and international funders from the public and private sectors
- Summer 2014: 2013 data will be available

IADRP – Current Members	
US Organizations	**International Organizations**
• US Federal Government (6 agencies) • Alzheimer's Association • Alzheimer's Drug Discovery Foundation • Ellison Medical Foundation • Cure Alzheimer's Fund • Geoffrey Beene Foundation • Patient-Centered Outcomes Research Institute • State of Texas • State of California • State of Wisconsin • State of Oregon • State of Virginia	• Government of Poland • Government of Australia • Alzheimer's Society of Canada • Alzheimer's Research UK • Alzheimer's Society of UK • Alzheimer's Australia Dementia Research Foundation Currently in discussion with: - UK MRC - Canada - Brazil - Brain Canada - Italy - Other US States
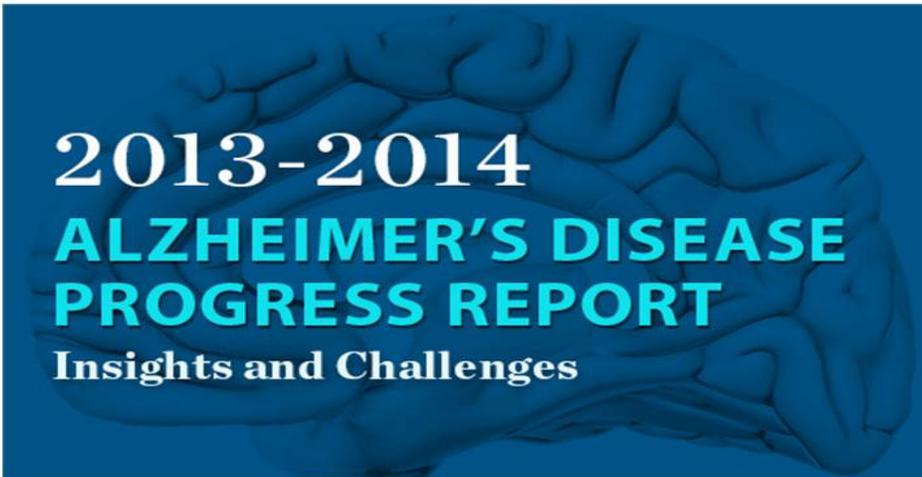
2013-2014
ALZHEIMER'S DISEASE PROGRESS REPORT
Insights and Challenges

www.nia.nih.gov/alzheimers/progress-report