

# Research Subcommittee Update

Richard Hodes

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## NAPA Goal #1: Research Update

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### NAPA Advisory Council Meeting

Richard J. Hodes, M.D.  
Chair, Federal Research Subcommittee

July 19 , 2013

MAY 1-2  
2013



# ALZHEIMER'S DISEASE-RELATED DEMENTIAS: Research Challenges and Opportunities

Sponsored by the  
**National Institute of Neurological Disorders and Stroke**  
in cooperation with:

- National Institute on Aging
- Alliance for Aging Research, ACT-AD
- Alzheimer's Association
- Association for Frontotemporal Degeneration
- USAgainst Alzheimer's

[www.ninds.nih.gov/ADRelatedDementias2013](http://www.ninds.nih.gov/ADRelatedDementias2013)



## ALZHEIMER'S DISEASE-RELATED DEMENTIAS: Research Challenges and Opportunities

MAY 1-2, 2013

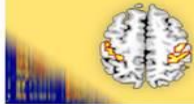
Natcher Auditorium, NIH Campus, Bethesda, MD

### May 1, 2013

- 8:00 a.m. **Welcoming Remarks:** Story Landis, PhD, Director, NINDS
- 8:05 a.m. **Introduction:** Ronald Petersen, PhD, MD, Mayo Clinic
- 8:25 a.m. **Developing Research Recommendations and Timelines for the AD-Related Dementias**  
Thomas Montine, MD, PhD, Scientific Chair
- 8:30 a.m. **Session 1: Non-AD and Multiple Etiology Dementias**  
Chairs: Bruce Miller, MD, and David Knopman, MD
- 9:30 a.m. **Session 2: Lewy Body Dementias (LBD, PDD)**  
Chairs: Dennis W. Dickson, MD and Karen S. Marder, MD, MPH
- 1:15 p.m. **Session 3: FTD and AD-Related Tauopathies**  
Chairs: Michael Hutton, William Seeley

### May 2, 2013

- 8:30 a.m. **Session 4: Vascular Contributions to AD-Related Dementias**  
Chairs: Steven Greenberg, Berislav Zlokovic
- 12:30 p.m. **Session 5: Health Disparities in AD-Related Dementias**  
Chairs: Maria Glymour, ScD and Jennifer Manly, PhD
- 2:45 p.m. **Final Panel Discussion and Questions**
- 4:00 p.m. **Closed Session: Session Chairs, NIH Leads, Steering Committee**



- **Draft recommendations were prioritized, assigned timelines and distributed for presentation.**
- **Attendance: 567 registered, 322 attended, ~200 watched the webcast, which is archived here:**  
<https://meetings.ninds.nih.gov/index.cfm?event=location&ID=4077>
- **Recommendations revised with input from conference attendees.**
- **Dr. Tom Montine will present ADRD research recommendations to the NINDS Council on September 12<sup>th</sup>, 2013.**
- **ADRD recommendations will be presented to the NAPA Council and shared publically at the October 2013 meeting.**

## The Alzheimer's Disease Sequencing Project (ADSP) – Background

- ▶ **Presidential Initiative:** February 7, 2012 to fight AD
  - NIA and NHGRI to develop and execute a large scale sequencing project
  - Identify AD risk and protective gene variants
- ▶ **Long-term objective:** Facilitate identification of new pathways for therapeutic approaches and prevention
- ▶ **Support:** \$25M already committed to NHGRI's Large-Scale Sequencing Centers (LSSC) for genomic studies (no new dollars)
- ▶ **Infrastructure:**
  - U19 FOA <http://grants.nih.gov/grants/guide/pa-files/PAR-12-183.html> to be reviewed autumn 2013.
  - Data Coordinating Center – NIAGADS <https://www.niagads.org/>; partnered with dbGaP

# ADSP

▶ **PARTICIPANTS:**

2 NIA funded AD Genetics Consortia,  
3 NHGRI Large Scale Sequencing Centers, NIH staff  
Memorandum of Understanding in place

▶ **PUBLICATION:** Immediate release of data.

▶ **TIMING:** Three year plan.

▶ **COMPONENTS:**

- ❑ **Family-based:** Whole genome sequencing (WGS), ~100 multiplex families; at least two members per family.
- ❑ **Case-control:** Whole exome sequencing (WES) on 5,000 cases and 5,000 controls. WES on 1,000 additional cases from families multiply affected by AD.
- ❑ **Replication and validation** of regions identified from the case-control and family based sample sets; target ~50,000 subjects.
- ❑ **Deep targeted re-sequencing** of candidate AD regions.

## FY 2013 Alzheimer's Disease Funding Opportunity Announcements

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RFA's
<a href="#"><u>Interdisciplinary Approach to Identification and Validation of Novel Therapeutic Targets for Alzheimer's Disease (R01)</u></a>
<a href="#"><u>Alzheimer's Disease Therapeutics Program (U01)</u></a>
<a href="#"><u>Alzheimer's Disease Prevention Trials (R01)</u></a>
<a href="#"><u>Alzheimer's Disease Phase I Clinical Trials (R01)</u></a>



# Research Update

- ▶ **NIA-ACL joint webinars:**  
<http://www.nia.nih.gov/newsroom/announcements/2013/05/2013-webinar-series-alzheimers-disease-and-resources>
- ▶ **HHSignite. Recruiting Older Adults into Research (ROAR)**
  - one of the 13 awarded HHSignite projects
  - Strengthens a cross-departmental partnership of ACL/NIA/CDC
  - Goal” To improve the recruitment of older adults for clinical research, beginning with Alzheimer’s
- ▶ **June 20–21, 2013 – National Institute of Neurological Disorders and Stroke Workshop: Improving Neurology Subject (and Provider) Participation in the Research Enterprise**
  - Follow up reports will suggest concrete action steps for stepped up recruitment
- ▶ **National Institute for Nursing Research Grants: RFA-NR-13-001:**
  - Addressing Needs of Informal Caregivers of Individuals with Alzheimer’s Disease (R01)
  - Two grants awarded and focus on diverse and minority caregiver interventions.

## Launch of Cognitive Impairment Detection Instruments Searchable Database

The screenshot displays the National Institute on Aging website's interface for a searchable database of cognitive impairment detection instruments. The page is titled "RESEARCH & FUNDING" and "Instruments to Detect Cognitive Impairment in Older Adults". It features a search bar with "Instrument Name" and "Instrument Name Abbreviation" fields. Below the search bar, there are several filterable criteria: Administration Method, Administration time, Level of Expertise to Administer, Measures Change over time, Cost, Target Age Range, Sample Source, Education level required to understand test, and Special Population Samples. Each criterion has a dropdown menu for selection. To the right of the filters, there is a "For More Information Contact:" section with the contact details for Samir Sauma, Ph.D., M.P.H., National Institute on Aging, NIH, Bethesda, MD, with the email address saumas@mail.nih.gov. The page also includes a navigation menu at the top with links for Home, Health and Aging, Research and Funding, Newsroom, About NIA, and Contact Us.

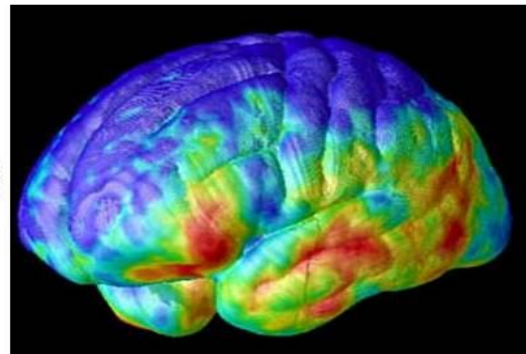
## New blog for researchers

Join the conversation.  
[www.nia.nih.gov/research/blog](http://www.nia.nih.gov/research/blog)



SAVE THE DATE

## Alzheimer's Disease Research Summit 2015



February 9–10, 2015  
National Institutes of Health  
U.S. Department of Health & Human Services  
Bethesda, MD

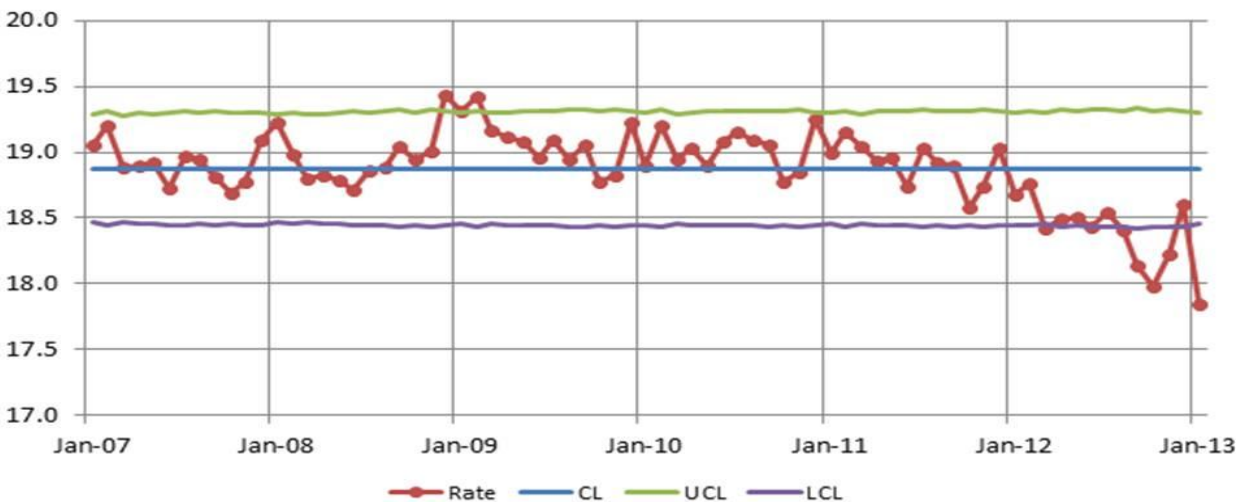
# Clinical Care Subcommittee Update

Shari Ling

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## National Medicare 30 Day Readmissions

### Medicare All Cause, 30 Day Hospital Readmission Rate



## Clinical Care (cont)

- ▶ **QIO Patient and Family Engagement Campaign (PFEC):** The Campaign supports person-centeredness and family engagement.
- ▶ Five projects received funding related to dementia:
  - Assisting Caregivers with Dementia Care (CA)
  - Improving Quality of Life for Beneficiaries with Dementia through Patient and Family Engagement
  - Online Resource Center (KY): A Unique Approach to Engaging Medicare Beneficiaries with Dementia and their Families in their Care
  - Partners for Dementia Care (MI)
  - Self-Management and Empowerment Program for Caregivers/Medicare Beneficiaries with Dementia/Alzheimer's Disease

## Health Care Innovation Awards Round 2 Proposal Categories

Will support public and private organizations in four defined areas that have a high likelihood of driving health care system transformation and delivering better outcomes.

- ▶ Models that are designed to rapidly reduce Medicare, Medicaid, and/or CHIP costs in outpatient and/or post-acute settings.
- ▶ Models that improve care for populations with specialized needs.
- ▶ Models that test approaches for specific types of providers to transform their financial and clinical models.
- ▶ Models that improve the health of populations – defined geographically (health of a community), clinically (health of those with specific diseases), or by socioeconomic class – through activities focused on engaging beneficiaries, prevention, wellness, and comprehensive care that extend beyond the clinical service delivery setting.

CMS specifically seeks new payment models to support the service delivery models funded by this initiative.



# Clinical Care

- ▶ **National Alzheimer's Call Center:** The ACL/AoA Funding Opportunity Announcement for the nationwide, 24/7 call center was released.
- ▶ **Nursing and Indian Health:** IHS made a presentation to the Nurse Leadership in Indian Care Conference outlining a strategic approach to improving care for persons with Alzheimer's disease and related dementias.
- ▶ **NIA–HRSA collaboration:** Teleconference for HRSA Geriatric Education Center network involved staff from NIA, University of Pittsburgh, and the Pittsburgh Alzheimer's Disease Center. Staff presented information on collaboration opportunities using NIH Alzheimer's Disease and Education and Referral Center resources.

The screenshot shows the CMS Medicare & Medicaid Services website. The main content area displays a proposed decision memo titled "Proposed Decision Memo for Beta Amyloid Positron Emission Tomography in Dementia and Neurodegenerative Disease (CAG-00431N)". The URL is <http://www.cms.gov/medicare-coverage-database/details/nca-proposed-decision-memo.aspx?NCAId=265&NcaName=Beta+Amyloid+Positron+Emission+Tomography+in+Dementia+and+Neurodegenerative+Disease&bc=ACAAAAACAAAA%3d%3d&>. A red circle highlights the "COMMENT" button. Below the title, there is a "Need a PDF?" button. The page also features a "Decision Summary" section with two paragraphs of text.

**Decision Summary**

A. The Centers for Medicare & Medicaid Services (CMS) proposes that the evidence is insufficient to conclude that the use of positron emission tomography (PET) amyloid-beta (A $\beta$ ) imaging improves health outcomes for Medicare beneficiaries with dementia or neurodegenerative disease, and thus PET A $\beta$  imaging is not reasonable and necessary under §1862(a)(1)(A) of the Social Security Act ("the Act").

B. However, there is sufficient evidence that the use of PET A $\beta$  imaging could be promising in two scenarios: (1) to exclude Alzheimer's disease (AD) in narrowly defined and clinically difficult differential diagnoses, such as AD versus frontotemporal dementia (FTD); and (2) to enrich clinical trials seeking better treatments or prevention strategies for AD, by allowing for selection of patients on the basis of biological as well as clinical and epidemiological factors.

# Long Term Services and Supports– Related Activities April – June 2013

Jane Tilly

## Long Term Services & Supports (LTSS)

- ▶ **ACL/AoA ADSSP Funding Opportunity Announcement *Creating and Sustaining Dementia-Capable Service Systems for People with Dementia and their Family Caregivers***: This set of grants will provide up to 6 states with funds to implement dementia-capable, home and community-based services systems. Each grantee will have to designate a lead state agency for dementia capability.
- ▶ **ACL/AoA & VA webinars** : Two webinars occurred: 1. ACL/AoA webinar for the VA network – *Partnering to Serve Veterans and Family Caregivers: Collaborative Opportunities with the Aging and Disability Services Network*; and 2) VA Webinar for the Aging Network – *Partnering to Serve Veterans and Family Caregivers: Collaborative Opportunities with the Caregiver and Geriatrics and Extended Care Programs*. The goal of these webinars was to promote cross-program collaboration between the VA and the Aging and Disability Services Networks at state and local levels. Webinar attendance totaled about 600.
- ▶ **ADEAR publications**: Tip Sheets for Alzheimer’s Caregivers are now available for mobile devices. Topics range from managing behavior changes to disaster preparedness. The tip sheets can help caregivers of people at any stage of the disease—mild, moderate, or severe. People can download tip sheets for their mobile devices from the ADEAR website at [www.nia.nih.gov/alzheimers/topics/caregiving](http://www.nia.nih.gov/alzheimers/topics/caregiving).

## LTSS (cont)

### ▶ American Indian activities:

- Periodic updates and webinars about Alzheimer's disease are targeted to American Indians through ACL's website: [www.olderindians.aoa.gov](http://www.olderindians.aoa.gov).
- Tribal LTSS webinar series jointly sponsored by IHS, CMS, and AoA/ACL featured presentations by a Standing Rock Sioux Tribal program using targeted case management services to support aging in place for older persons with dementia and other disabilities and a presentation by the Gila River Indian Community on their Adult Day Program, featuring services for persons with dementia.
- IHS began its solicitation for pilot testing of the REACH VA in Indian Country.
- The National Indigenous Elder Justice Initiative is addressing the lack of culturally appropriate information and community education materials on elder abuse, neglect and exploitation in Indian Country. Persons with dementia are at particularly high risk of such mistreatment.

## National Partnership to Improve Dementia Care in Nursing Homes: Project Overview

- ▶ CMS works closely with its partners to improve behavioral health and safeguard nursing home residents from unnecessary antipsychotic drug use.
- ▶ National goal of reducing antipsychotic use in long-stay nursing home residents by 15%.
- ▶ Tactics:
  - *rethink* our approach to dementia care
  - *reconnect* with people using person-centered care approaches
  - *restore* good health and quality of life in nursing homes across the country.



# National Partnership to Improve Dementia Care in Nursing Homes: Recently completed actions

- ▶ Release of revised interpretative guidance released related to quality of care and unnecessary drugs in nursing homes
- ▶ Training & education
  - Three new mandatory surveyor training videos completed and launched in January & May 2013
  - Major presentations to various public and private partners around the country
- ▶ Outreach calls by CMS core team to various public and private partners to providers that have a high rate of antipsychotic medication use
- Research
  - 200 case studies from 25 nursing home in five states
  - Focused on how decisions to use or not to use antipsychotic medications were made

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## Antipsychotic Use by CMS Region and Quarter

Percent of long-stay residents receiving an antipsychotic medication

Region	2011Q1	2011Q2	2011Q3	2011Q4	2012Q1	2012Q2	2012Q3	2012Q4	2013Q1	Percentage point difference (2011Q4to2013Q1)	Percent change
National	23.50	23.64	23.74	23.87	23.82	23.21	22.98	22.33	21.71	-2.16	-9.06%
Region 01	25.88	25.94	26.16	26.22	26.02	25.10	24.49	23.66	22.41	-3.82	-14.55%
Region 02	20.07	20.12	20.27	20.10	20.00	19.52	19.42	18.71	18.44	-1.66	-8.24%
Region 03	21.60	21.31	21.64	21.81	21.80	21.08	20.98	20.62	20.10	-1.71	-7.84%
Region 04	25.05	25.20	25.21	25.51	25.42	24.88	24.20	22.90	21.70	-3.81	-14.92%
Region 05	22.19	22.40	22.45	22.71	22.65	22.14	22.22	21.78	21.34	-1.37	-6.05%
Region 06	27.69	27.83	28.05	28.19	28.27	27.59	27.62	27.22	26.61	-1.58	-5.60%
Region 07	23.98	24.27	24.50	24.47	24.42	23.82	23.62	23.36	22.93	-1.53	-6.27%
Region 08	21.20	21.47	21.30	21.44	21.45	21.40	20.87	20.45	19.84	-1.61	-7.50%
Region 09	21.33	21.48	21.36	21.34	21.19	20.40	20.05	19.16	18.92	-2.42	-11.33%
Region 10	22.03	22.54	22.60	22.30	22.14	21.47	21.28	20.44	20.07	-2.23	-9.99%

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