

New Age in Recruitment of ADC Participants

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Recruitment in the Mid-80s

- Motivation
 - Altruism ("want to help; if not for us, then for our children")
 - Expert diagnosis
 - Caregiver needs
- Reasons to decline participation
 - Seeking care, not research



Recruitment in late 80s and 90s - The Golden Age

- Additional motivation
 - Access to drug trials
 - Develop infrastructure, experience
 - Typical clinical sample:
 - » ADCS Prednisone trial

ADCS Prednisone Study

(Aisen et al., Neurology; 54:588-593)

- 22 sites; enrollment 1995
- WU Informed Consent = 5 pages
- 190 participants screened, 138 randomized
- Characteristics

	Placebo	Prednisone
	(n=69)	(n=69)
Age (y)	72	73
F	51%	49%
Educ (y)	14	14
White	93%	94%

Recruitment in the 21st Century

- Treatments available to PCPs;
 more caregiver resources
- Survey of 86 participants in 2002-2003 (31 controls, 55 DAT)
 - Want to help 62%
 - Seek knowledge/information 22%

Barriers to recruitment

- Informed consent (can exceed 10 pages; develop "Cliff Notes" version)
 - More 'standard language' required by IRBs
 - » HIPAA and confidentiality
 - » Injury and third party payers
 - » Research vs medical care
 - More complex studies
 - Greater risk
- Tighter eligibility criteria (e.g., MRI)

Barriers to Recruitment (cont.)

More demanding protocols; arduous procedures and time points

ADNI

- Controls/MCI, every 6 m for 3 y
- AD, every 6 m for 2 y
- Clinical assessment and MRI at each visit
- PET in 50% of participants at each visit
- LP in 20% of participants (entry and y1)

Barriers to Recruitment (cont.)

- Higher risk clinical trials
 - Vaccine study
 - Other immunotherapy protocols
 - Secretase inhibitors
 - Gene therapy (e.g., nerve growth factor

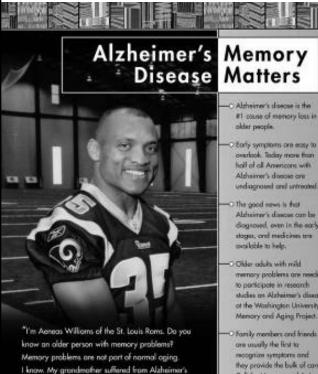
Local Issues

- All volunteers (participants, not patients)
- Emphasis on diversity

African American Advisory Board



Partners in Outreach



disease. Doctors in St. Louis are addressing the needs of African-American elders and their families. Call the Washington University Memory and Aging Project and the Alzheimer's Association to learn more about Alzheimer's disease and available services."

TO LEARN ABOUT RESEARCH STUDIES AND HOW TO GET INVOLVED, CALL THE WASHINGTON UNIVERSITY MEMORY AND AGING PROJECT.

(314) 286-2683

Altheimer's disease in the #1 cause of memory loss in

Early symptoms are easy to overlook. Today more from half of all Americans with Alcheimer's disease are

undiagnosed and untreated

Alzheimer's disease can be diagnosed, even in the early stages, and medicines time available to help. Older adults with mild memory problems are needed to participate in research studies as Alpheimer's disease at the Washington University

Memory and Aging Project.

they provide the bulk of care.

Coll the Memory and Aging

Project Satellite to learn more

about free in-home services for families: (314) 612-5911.

Alzheimer's Association, St. Louis

Chapter: (314) 432-3422

are usually the first to recognize symptoms and



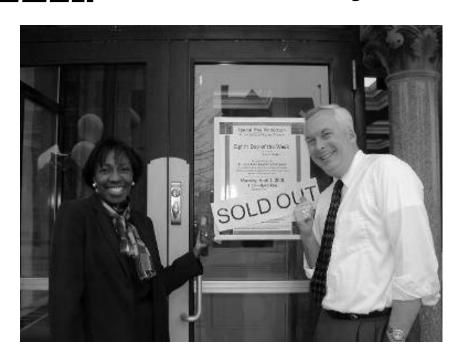


LOUIS BLACK ST. REPERTORY COMPANY

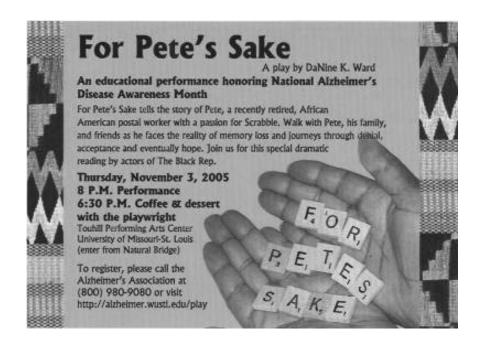
City of St. Louis St. Louis Area **Agency on Aging**

alzheimer's Ω 5 association

Community Events











Educational Materials





Reflections on Memories Lost

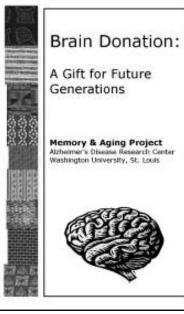
Stories of Early Alzheimer's disease

With Expert Commentary on Symptoms, Diagnosis & Treatment

Produced by Alzheimer's Disease Research Center Washington University School of Medicine, St. Louis Http://alzheimer.wustl.edu/adrc2 (314) 286-2881

> April 2003 Draft 2







African American Seniors Invited to Help Doctors Learn About Memory Loss

African American seniors are invited to help in an effort to learn more about memory loss and normal aging. The Memory & Aging Project at Washington University, founded in 1979, seeks to understand why some people lose their memory skills and how this problem can be corrected. Those who agree to help receive a free evaluation of memory and thinking ability once each year.

Both healthy seniors and those concerned about memory changes are welcome. If you decide to help in this effort, you can choose to have your test results sent to your regular medical doctor in support of your ongoing care. Taking part is your choice. All information is kept Warning Signs of Alzheimer's confidential.

Alzheimer's disease (AD) is the # 1 cause of memory loss in older age, yet this disease is often overlooked by health professionals and family members alike. It has been estimated that of the over 4 million Americans with Alzheimer's disease, only half have been formally evaluated and treated. At the Memory & Aging Project, we are committed to improving the diagnosis process and making sure that memory research applies equally to

** To learn how you can help and benefit from our services, call 314-286-2683 **

Helping Seniors Live Independently



The Memory and Aging Project Satellite (MAPS) is an outreach program in the St. Louis area. We help people with memory loss and confusion to live as independently and safely as possible in their own homes.

Our free services include:

- · An in-home memory assessment by a nurse
- Education and counseling for client and family
- · Help to identify needs and eligibility for support services
- An evaluation to assess independence and safety
- · For more information on MAPS or to make a referral. cal (314) 612-5911





Dr. Consuelo Willere (right) talks about memory loss with an interested volunteer

- Memory loss
- Misplacing things
- Difficulty performing familiar tasks
- Problems with language
- Disorientation to time or place
- Poor or decreased judgment
- Problems with abstract thinking
- Changes in mood or behavior
- Changes in personality
- · Loss of initiative

Resources on Memory Loss

Alzheimer's Association, St. Louis (314) 432-3422 / www.alz.org

AD Education & Referral Center (800) 438-4380 / www.alzheimers.org

Alzheimer List E-mail Support Group www.adro.wustl.edu/alzheimer

Memory & Aging Project Alzheimer's Disease Research Center Washington University 4488 Forest Park Avenue, Suite 101 St. Louis, MO 63108 (314) 286-2683; Fax (314) 286-2448. www.adro.wustl.edu



African American Enrollment in the ADRC Clinical Core (2000-2004)

	Total Participants Enrolled	# of African Americans	% of Total Represented by African Americans
2000	60	7	12%
2001	73	6	8%
2002	61	14	23%
2003	70	23	33%
2004	67	17	25%

WU ADRC Recruitment Policy (8/1/04)

- Limited capacity
- All new enrollees commit "up front" to:
 - Longitudinal participation
 - Genetic studies
 - Imaging (MRI; fMRI; PET)
 - LP for CSF analysis

African American Recruitment 12 months before and after LP/MRI requirements

	Bef	ore	After		
	AA	Cau	AA	Cau	
Enrollment N (%)	38 (30%)	90 (70%)	8 (13%)	52 (87%)	
Age Mean & SD	75.8 (8.6)	75.8 (8.8)	69.5 (9.4)	72.2 (6.2)	
Educ Mean & SD	13.9 (3.3)	13.9 (3.0)	14 (3.3)	15.6 (3.2)	
% Female	79	52	63	60	

Lumbar Puncture

- Refusers
 - Afraid (e.g., of pain and paralysis)
 - "Too much just for memory testing"
- No clear racial/ethnic difference
- Information helpful
- 70% return for serial LPs

WU ADNI Recruitment 9/20/05

Group	Status	Age	Sex	Race	MRI	PET	LP
Control	Enrolled	65	М	AA	Completed	Scheduled	Completed
Control	Enrolled	73	М	CAU	Completed	Scheduled	Completed
Control	Enrolled	74	М	CAU	Completed	Scheduled	NO
Control	Enrolled	84	F	CAU	Completed	Scheduled	Scheduled
Control	Screen scheduled 9/26-27/05	72	F	AA	Agreed	Agreed	NO
Control	Screen scheduled 9/26-27/05	63	M	AA	Agreed	Agreed	Agreed
Control	Screen scheduled 9/26-27/05	71	M	AA	Agreed	Agreed	Agreed
Control	Screen scheduled 10-05	72	F	CAU	Agreed	Agreed	Agreed
AD	Enrolled	81	М	CAU	Completed	Scheduled	Completed
AD	(Screen scheduled 10/05)	63	F	CAU	Agreed	Agreed	Agreed

Keys to Success

- Staff
- Expectation and support of Director
- Community Advisory Board