



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



## *Recruitment in the 21<sup>st</sup> 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



## Alzheimer's Disease Memory Matters

- Alzheimer's disease is the #1 cause of memory loss in older people.
- Early symptoms are easy to overlook. Today more than half of all Americans with Alzheimer's disease are undiagnosed and untreated.
- The good news is that Alzheimer's disease can be diagnosed, even in the early stages, and medicines are available to help.
- Older adults with mild memory problems are needed to participate in research studies on Alzheimer's disease at the Washington University Memory and Aging Project.
- Family members and friends are usually the first to recognize symptoms and they provide the bulk of care. Call 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.

*"I'm Aeneas Williams of the St. Louis Rams. Do you know an older person with memory problems? Memory problems are not part of normal aging. I know. My grandmother suffered from Alzheimer's 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**



**ST. LOUIS BLACK  
REPERTORY COMPANY**

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



**alzheimer's  association™**

# Community Events



## For Pete's Sake

A play by DaNine K. Ward

**An educational performance honoring National Alzheimer's Disease Awareness Month**

For Pete's Sake tells the story of Pete, a recently retired, African American postal worker with a passion for Scrabble. Walk with Pete, his family, and friends as he faces the reality of memory loss and journeys through denial, acceptance and eventually hope. Join us for this special dramatic reading by actors of The Black Rep.

**Thursday, November 3, 2005**  
**8 P.M. Performance**  
**6:30 P.M. Coffee & dessert**  
**with the playwright**  
 Touhill Performing Arts Center  
 University of Missouri-St. Louis  
 (enter from Natural Bridge)

To register, please call the Alzheimer's Association at (800) 980-9080 or visit <http://alzheimer.wustl.edu/play>

A black and white photograph of a hand holding several Scrabble tiles. The tiles are arranged to spell out 'FOR PETE'S SAKE' in all caps. The background of the flyer features a pattern of Scrabble tiles.


# 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](http://alzheimer.wustl.edu/adrc2)  
(314) 286-2881

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Draft 2

### Brain Donation:

A Gift for Future  
Generations

**Memory & Aging Project**  
Alzheimer's Disease Research Center  
Washington University, St. Louis



## 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 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 everyone.

**\*\* 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, call (314) 612-5911.



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

### Warning Signs of Alzheimer's

- 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](http://www.alz.org)

**AD Education & Referral Center**  
(800) 438-4380 / [www.alzheimers.org](http://www.alzheimers.org)

**Alzheimer List E-mail Support Group**  
[www.adrc.wustl.edu/alzheimer](http://www.adrc.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.adrc.wustl.edu](http://www.adrc.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*

	Before		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	M	AA	Completed	Scheduled	Completed
Control	Enrolled	73	M	CAU	Completed	Scheduled	Completed
Control	Enrolled	74	M	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	M	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