

## TABLE OF CONTENTS

What is ADNI?	1
Understanding AD	2
Why the Alzheimer's Disease Neuroimaging Initiative is So Important	2
Maya Angelou Speaks Out in PSAs	3
One Woman's Story – A Gift for Future Generations	3

## A Message from the Heart



Welcome to the first issue of our participant newsletter, ADNI Exclusive, written especially for our participants and your families to report our study progress.

As we look at an aging America, we recognize the value and urgency of the Alzheimer's Disease Neuroimaging Initiative (ADNI). This groundbreaking

study will create the first ever standards to measure new treatments for Alzheimer's Disease (AD) and provide a stronger foundation for diagnosing AD, tracking the course of this disease, and monitoring how well people respond to new treatments.

Investment in AD will no doubt help change the course for future generations, slowing the progression, or even preventing this tragic disease.

To the growing number of participants, families, and friends committed to ADNI, we say thank you! Thank you for getting involved and helping fuel scientific discovery that we hope will turn the possibilities of research into promises for a better tomorrow.

As a participant myself, I am deeply committed to this study and appreciate your support and continued involvement. As discovery partners in our research, please share your experience with others who might be interested in joining our effort.

Michael Weiner, M.D.  
Fellow Participant and ADNI Principal Investigator  
University of California, San Francisco

## What is ADNI?

The Alzheimer's Disease Neuroimaging Initiative (ADNI) is a \$60 million, 5-year study to identify brain and other biological changes associated with memory decline. The project is seeking 800 adults ages 55 to 90 to become a part of this landmark research. Scientists hope that brain and biological changes can be detected before memory decline and other symptoms appear, allowing the effectiveness of drugs to be evaluated at the earliest possible time. We also hope to lessen the time and cost of testing drugs and to bring treatments to participants much sooner.

Investigators at about 60 local study sites across the U.S. and Canada will divide participants into three groups—approximately 200 cognitively normal older people will be followed for 3 years, 400 people with mild cognitive impairment will be followed for 3 years, and 200 people with early Alzheimer's Disease will be followed for 2 years. At the end of the study, the researchers will compare neuroimaging, biological, and clinical information data to develop standards for tracking the progression of memory decline.

*Continued on page 3*

## Enrollment Update

We've reached the halfway mark to ADNI's recruitment goal – 408 people have successfully enrolled in the study. Our goal is to enroll participants who:

- are in good general health with no memory problems\*, OR
- are in good general health but with memory problems or concerns, OR
- have a diagnosis of early Alzheimer's disease.

### Immediate recruitment needs include:

- People with a diagnosis of MCI or early AD
- Minority participants

If you know of anyone who might be interested, please have them contact NIA's Alzheimer's Disease Education and Referral (ADEAR) Center at 800-438-4380 or at [www.alzheimers.org/imagine](http://www.alzheimers.org/imagine).

*\*Currently, ADNI sites are only recruiting volunteers age 70-90 among people with no memory problems.*

## Understanding AD

### *What is it?*

Alzheimer's disease is an irreversible, progressive brain disease that slowly destroys parts of the brain that control thought, memory, and language. Although the risk of developing AD increases with age, it is **NOT** a part of normal aging. Around 4.5 million people now have AD and this number is expected to rise to 13 million by 2050.

### *What are the symptoms?*

Most people with AD start to notice symptoms after age 60. Memory loss, such as not being able to remember recent events or familiar people, is the first visible sign and is often the initial phase between normal aging and AD. It is called mild cognitive impairment or MCI.

People in the middle stages of AD may experience confusion, problems recognizing people, mood changes, increased anxiety, difficulty with language and thoughts, restlessness, agitation, wandering, and repetitive statements. In the later stages of AD, people can lose weight, develop skin infections, sleep more often, and may lose bladder and bowel control.

### *How is AD treated?*

A treatment to stop AD from progressing has not yet been found, however, for some people in the early to middle stages of AD, certain drugs may help prevent certain symptoms from becoming worse for a limited time. Other medications may help control behavioral symptoms associated with AD.

### *Can AD be prevented?*

AD is a complex disease that develops when genetic, environmental, and lifestyle factors work together to cause a disease process to start and then progress. ADNI is an important step in our work to accomplish this goal. We are hoping to find ways to delay the progression of the disease, which can lead to faster evaluation of drugs and new treatments and hopefully, even a cure in the near future.

## Why the Alzheimer's Disease Neuroimaging Initiative is So Important

*By Michael Weiner, M.D., ADNI Principal Investigator  
University of California, San Francisco*

ADNI is the first study of its kind to develop standards that can measure the effectiveness of many new drug treatments aimed at slowing the progression or even preventing this devastating, costly, and tragic disease. The goals of this \$60 million study are to:

- Develop a set of standardized methods for collecting imaging and biomarker data
- Collect all the data and put it into a common database
- Process the data in a variety of ways to find out which methods are best
- Correlate biomarker data with clinical data
- Use ADNI methods in clinical trials

To measure progression of AD, we use scans to study brain structure, function, and metabolism. We search for the brain abnormalities found in AD and how the disease progresses over time. We use magnetic resonance imaging (MRI), a scanning technique with magnetism and radio waves that shows brain structure, and Positron Emission Tomography (PET), that uses radioactive tracers to measure brain sugar metabolism and generate images.

In this study we are looking at "biomarkers" that measure amyloid plaques (dense deposits of protein and other molecules that accumulate outside and around nerve cells) in the brain and other substances in blood, urine, and cerebrospinal fluid. Some of the questions that ADNI is designed to answer include:

- Which are the best methods to scan study participants?
- Which MRI method is most reliable, most sensitive, most robust?
- What should we measure: change of hippocampus, change of whole brain volume?
- How do we collect all this data in a clinical trial at many centers, using scanners made by different manufacturers?

By working together on ADNI, we all participate in a noble goal—to slow and prevent AD.

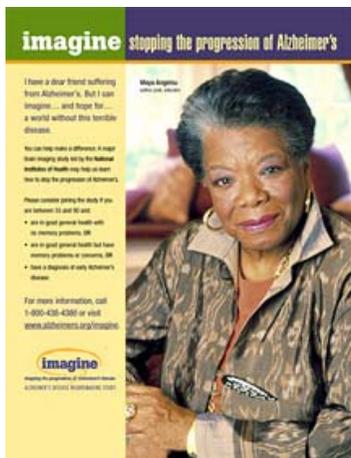
## Maya Angelou Speaks Out in PSAs

Her life has been celebrated as one of the greatest poets of our times. She also hails as a best-selling author (the first African American woman to do so), well-known educator and historian, and tireless civil rights advocate.

And now, ADNI is honored to have Dr. Maya Angelou's support, through the facilitation of Dr. Jeff Williamson, an ADNI principal investigator at Wake Forest University.

In print and radio public service ads, Dr. Angelou addresses the importance of joining the NIH study.

"I have friends and loved ones suffering from Alzheimer's. But I can imagine...and hope for... a world without this terrible disease."



Radio spots have aired across the country with more than 37 million listeners tuning in. In the coming months, look for Dr. Angelou's message and photo in magazines and newspapers.

## One Woman's Story – A Gift for Future Generations

By Ann Hedreen, filmmaker and research study participant



Photo: Susie Fitzhugh

It's an impulse I've felt many times: when a friend or relative falls ill, I want to help, somehow, to find a cure. I felt this impulse most powerfully when my mother moved into the late stage of Alzheimer's disease. I wanted to do more than write a check, especially since I didn't have much money to give. And I learned that I could do more:

that there is a gift we can give researchers that is just as vital as cash and often much harder to obtain: ourselves.

My mother first showed signs of Alzheimer's 14 years ago, around the age of 60, and if your family or friends have been down this road, you know what a long 14 years it's been for Mom and for us. There's not much we can give her anymore besides love and hugs. We understand that volunteering for research is not going to help her personally. But it is a gift we can give in her honor.

Two weeks ago, I watched as my sister Caroline took part in an Alzheimer's study. For this study, Caroline was asked to give three things: time, blood, and spinal fluid.

Her time commitment was two mornings with the first spent on medical and neuropsychological evaluation and a battery of cognitive tests. But her most precious gift—the focus of her second morning at the research center—was a two-tablespoon sample of cerebrospinal fluid, which can only be obtained by a procedure called a lumbar puncture, better known as a spinal tap.

Without cerebrospinal fluid, brain researchers cannot do their work. Two tablespoons of cerebrospinal fluid provide 50 samples for use in research.

Two years ago, while filming a documentary about my mom (Quick Brown Fox: an Alzheimer's Story), I too participated in a study and gave my own two tablespoons of fluid. But it wasn't until I watched Caroline undergo the procedure that I fully understood how much this means to researchers.

Before the procedure, Caroline admitted to being nervous. But after it was over, she was ready to urge others to sign up. "Why not do it?" she said. "There's not a reason not to do it. It was a small investment on my part and it's benefiting hundreds of thousands of people."

We can't all write large checks. But we can contribute to scientific progress that will benefit future generations.

### What is ADNI?

Continued from page 1

ADNI is the largest public-private partnership on brain research sponsored by the National Institutes of Health (NIH). It was begun by the National Institute on Aging (NIA) and is supported by more than a dozen other federal agencies and private-sector companies and organizations. In addition to the NIA, the Federal ADNI partners are the National Institute of Biomedical Imaging and Bioengineering and the U.S. Food and Drug Administration. Through the Foundation for the NIH, the following organizations have joined the partnership: the Alzheimer's Association; Pfizer Inc; Wyeth Research; Bristol-Myers Squibb; Eli Lilly and Co.; GlaxoSmithKline; Merck & Co., Inc.; AstraZeneca AB; Novartis Pharmaceuticals Corporation; Eisai Global Clinical Development; Elan Corporation, plc; Alzheimer's Drug Discovery Foundation; and Innogenetics. Siemens, Philips, and General Electric, manufacturers of imaging equipment, are providing software support for the imaging aspects of the project.

For more information about "Quick Brown Fox: an Alzheimer's Story," go to [www.quickbrownfoxfilm.com](http://www.quickbrownfoxfilm.com)

## RESOURCES

### National Institute on Aging at the National Institutes of Health

Phone: 301-496-1752

Web site: [www.nia.nih.gov](http://www.nia.nih.gov)

### Alzheimer's Disease Education and Referral Center (ADEAR)

A Service of the National Institute on Aging

Phone: 800-438-4380

Web site: [www.nia.nih.gov/Alzheimers/](http://www.nia.nih.gov/Alzheimers/)

### Alzheimer's Association

24/7 Helpline: 800-272-3900

E-mail: [info@alz.org](mailto:info@alz.org)

Web site: [www.alz.org](http://www.alz.org)

### Family Caregiver Alliance (FCA)

Toll Free: 800-445-8106

Phone: 415-434-3388

E-mail: [info@caregiver.org](mailto:info@caregiver.org)

Web site: [www.caregiver.org/caregiver/jsp/home.jsp](http://www.caregiver.org/caregiver/jsp/home.jsp)

### National Family Caregivers Association

Toll Free: 1-800-896-3650

Phone: 301-942-6430

E-mail: [info@thefamilycaregiver.org](mailto:info@thefamilycaregiver.org)

Web site: [www.nfca cares.org](http://www.nfca cares.org)

## FREE PUBLICATIONS

A Sampling of NIA Publications

To order, visit:

[www.nia.nih.gov/Alzheimers/Publications/BrowserAndOrder.htm](http://www.nia.nih.gov/Alzheimers/Publications/BrowserAndOrder.htm)

or call, 800-438-4380.

### English:

Bound for Your Good Health – A Collection of Age Pages

Understanding Alzheimer's Disease (New)

Can Alzheimer's Disease be Prevented?

Forgetfulness: It's Not Always What You Think

AD: A Caregiver and Participant Resource List

Caregiver Guide: Tips for AD Caregivers

Home Safety for People With Alzheimer's Disease

Hospitalization Happens: Visits for AD Participants

### Spanish:

La Enfermedad de Alzheimer (Spanish AD Guide)

La Mala Memoria

Guia para Quienes Cuidan (AD Caregiver Guide)

Medicamentos para la enfermedad de Alzheimer

Protección en el Hogar (AD Home Safety)

## GLOSSARY OF ALZHEIMER'S DISEASE TERMS

**Amyloid Precursor Protein (APP):** A gene, found in the brain, which becomes mutated and forms an amyloid. This process is one of the possible causes of AD.

**Amyloid Plaque:** A protein abnormally deposited in blood vessels and neuritic plaques.

**Beta-Amyloid:** A part of the APP protein found in the insoluble deposits outside neurons and that forms the core of plaques.

**Biomarker:** A substance introduced to an organism making it possible to examine organ functions.

**Clinical trial:** A research study involving humans that rigorously tests how well an intervention works.

**Cognitive functions:** All aspects of conscious thought and mental activity, including learning, perceiving, making decisions, and remembering.

**Dementia:** The loss of certain cognitive capabilities such as memory capacity ranging from amnesia to the inhibition of social functions.

**Early-onset Alzheimer's disease:** A rare form of AD that usually begins to affect people between ages 30 and 60; it is called familial AD (FAD) if it runs in the family.

**Hippocampus:** A structure in the brain that plays a major role in learning and memory and is involved in converting short-term to long-term memory.

**Late-onset Alzheimer's disease:** The most common form of AD, which occurs in people aged 65 and older.

**Magnetic resonance imaging:** A diagnostic and research technique that uses magnetic fields to generate a computer image of internal structures in the body; MRIs are very clear and are particularly good for imaging the brain and soft tissues.

**Mild Cognitive Impairment:** MCI is different from AD and normal age-related memory change. It causes cognitive losses such as confusion, attention problems, and difficulty with language.

**Neuron:** A nerve cell in the brain.

**Neurotransmitter:** A chemical messenger between neurons; a substance that is released by the axon on one neuron and excites or inhibits activity in a neighboring neuron.

**Positron Emission Tomography or PET Scan:** A non-invasive test that scans the whole body for cellular functions.