

# ADNI Exclusive

A SPECIAL NEWSLETTER FOR PARTICIPANTS IN THE ALZHEIMER'S DISEASE NEUROIMAGING INITIATIVE

WINTER 2009

## Dear Friends and Supporters of ADNI

The final year of the Alzheimer's Disease Neuroimaging Initiative is underway. As we continue along this groundbreaking path, it's useful to reflect back on what you have helped accomplish over these last few years. With your dedication and support, ADNI research continues to pave the way towards effective treatments. Data collected from ADNI is being used by AD researchers around the globe and continues to bring us one step closer to finding out how to prevent and cure this terrible disease. My hat goes off to all of you who have played a role in making this research possible. With your continued help, we will be able to go beyond imagining a world without Alzheimer's disease to actually living in one. Thank you doesn't quite seem adequate enough to express our gratitude. You are truly heroes.

Sincerely,



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### ADNI Enrollment Update: Continued Success!

Now in its fifth year, the Alzheimer's Disease Neuroimaging Initiative (ADNI) is continuing to make inroads in Alzheimer's disease research. Its goal of informing effective treatments and eventually prevention for AD has remained constant and ADNI data is currently being used by thousands of researchers worldwide.

At this point, all participants have successfully passed the 12-month mark and nearly 700 people are still being monitored. Many participants have also agreed to undergo the lumbar puncture (LP) procedure which allows researchers to draw cerebral spinal fluid (CSF) and helps accurately gauge disease progression.

We are very thrilled to have been awarded additional funding, as part of an extension of ADNI, to continue to track study participants. This extension will allow us to gather additional information from participants and will help us take another step closer to finding a cure.

Also, as a result of the exciting and promising data being collected through ADNI, industry partners are seriously engaged in discussions about ADNI 2, an even larger scale continuation of this research. Discussions and planning for a continuation of ADNI will continue for the next nine months.



## NIH News: National Institutes of Health

### *Ginkgo Evaluations of Memory (GEM) Study Fails to Show Benefit in Preventing Dementia in the Elderly*

The dietary supplement Ginkgo biloba was found to be ineffective in reducing the development of dementia and Alzheimer's disease in older people, according to a study published in the *Journal of the American Medical Association*. Researchers led by Stephen T. DeKosky, M.D., formerly of the University of Pittsburgh, vice president and dean of the School of Medicine at the University of Virginia in Charlottesville, conducted the trial known as the Ginkgo Evaluation of Memory (GEM) study at four clinical sites over 8 years. GEM is the largest clinical trial ever to evaluate ginkgo's effect on the occurrence of dementia. This research was co-funded by five components of the National Institutes of Health.

"According to the 2007 National Health Interview Survey, ginkgo is one of the top 10 natural products used by Americans," said Richard L. Nahin, Ph.D., M.P.H., acting director of the Division of Extramural Research at NCCAM. "It is important to conduct studies and build the scientific evidence base regarding botanical supplements through rigorous research, such as the GEM trial."

The study was conducted primarily to determine if ginkgo would decrease the incidence of all types of dementia and, more specifically, reduce the incidence of Alzheimer's disease.

Secondarily, the study evaluated ginkgo for its effects on overall cognitive decline, functional disability, incidence of cardiovascular disease and stroke, and total mortality. The primary endpoint was the diagnosis of dementia as determined by an expert panel of clinicians using standard criteria for diagnosis. The patients with a diagnosis of dementia underwent magnetic resonance imaging scans to determine their dementia type.

"The results of this study confirm the importance of randomized trials in the development of new therapies for dementia and Alzheimer's disease and in determining therapeutic benefit not only for conventional therapies but also complementary therapies like ginkgo," said Dr. DeKosky, principal investigator on the GEM study. "If older patients are considering using ginkgo for preventing dementia, I urge them to speak with their health care providers about the results of this study and work together to create the best treatment plan."

Study participants were followed for an average of approximately 6 years (maximum of just over 7 years). Cognitive status was known for more than 93 percent of all participants at the end of the trial and 60 percent of active participants were taking their assigned study medication. There was no difference in adherence to taking medication between the ginkgo group and the placebo group.

"While this study revealed that ginkgo does not have an effect on reducing dementia in the study population, it does provide us with important information about how to design and conduct large dementia prevention trials in older adults," said Dr. Jeff Williamson, a geriatrician and principal investigator of the GEM Clinical Coordinating Center at Wake Forest University. "Future analyses will provide us with additional information on ginkgo's possible effects on cardiovascular disease, cancer, depression and other age-related conditions. We are especially grateful to the more than 3,000 older adults who dedicated many hours to helping us answer the important questions addressed by GEMS."

The GEM results will prove useful in determining how many participants are needed in future trials to provide clinically significant measures on outcomes such as occurrence of dementia. Future analysis of this study may also identify subgroups of these participants who may be at greater risk for developing dementia.

*(Condensed from NIH News press release)*

## Research Abounds: New Gammaglobulin Alzheimer's Partnership (GAP) Study Now Recruiting



Immune Globulin Intravenous (IgIV) has been approved and used successfully for over 20 years to treat a variety of autoimmune and immunodeficient diseases. Because it contains anti-amyloid antibodies IgIV is being investigated in a Phase III study as a treatment for Alzheimer's disease. The purpose of this study is to determine whether IgIV treatment slows the rate or prevents the decline of dementia symptoms in individuals with mild-to-moderate Alzheimer's Disease. For study information and locations, please call the Alzheimer's Disease Education and Referral Center at 1-800-438-4380 or visit their website at <http://www.alzheimers.org/clinicaltrials/fullrec.asp?PrimaryKey=282>.

## Alzheimer's Disease in the News: Just Another Day in the Office?

The world of sports fans is still abuzz after the most-watched Superbowl in history, but how many of us take time out to think about the toll "a day in the office" takes on professional football players' bodies...and brains! Read the **Washington Post** article below to learn more.

### Brain Condition Raises Concussion Concerns

Doctors who have been studying the long-term effects of concussions on football players have discovered another case of a player suffering from a brain condition that could lead to dementia or Alzheimer's.

Recent studies of the brain tissue of former Tampa Bay Buccaneers player Tom McHale showed he had chronic traumatic encephalopathy, a degenerative brain disease caused by head trauma most often associated with a condition that plagues former boxers called punch-drunk syndrome.

McHale, who died at age 45 eight months ago of a drug overdose, is the sixth player to show signs of CTE.

Doctors at Boston University's Center for the Study of Traumatic Encephalopathy, who examined McHale's brain, said he is the sixth out of six former players whose brains have been examined and shown to have CTE (although that of a seventh, former Denver Bronco Damien Nash, showed no signs of the condition).

Several doctors and researchers have been saying for more than two years that repeated blows to the head in football games lead to debilitating later-life afflictions such as dementia. They said the fact that six out of seven players have shown signs of CTE is definitive evidence that something is wrong.

"Is this something that happened by chance?" asked Ann McKee, a neuropathologist at Boston University pointing to pictures of McHale's brain that she said resembled that of a 72-year-old boxer. "I can tell you I've been looking at brains for 22 years, and this is not a normal part of aging. This is not a normal part of the brain."

The problem doctors have in studying CTE in football players is that the link was made just a few years ago, and the only way to test for it is to study an actual piece of brain tissue, meaning the subject must be deceased before he can be tested. This is why only seven former players have been examined.

The center also announced it has tested an 18-year-old high school football player who had suffered many concussions and who recently died. The test showed the boy also had CTE.

"This is something you should never see in an 18-year-old's brain," McKee said.

## Brain Teasers: Give Your Brain a Workout

Just like exercise is good for your body, brain teasers or puzzles can be a good workout for your brain. Try these brain games below. Guess the meaning of the word pictures (answers below).



If word puzzles aren't for you, consider finding another mentally stimulating activity to keep your brain sharp!

- |                                    |   |
|------------------------------------|---|
| 1. STANDS<br>No One                | 12. EEE<br>iii                                      |
| 2. Insult + injury                 | 13. Big big<br>Ignore ignore                        |
| 3. R<br>Y<br>S                     | 14. Either weigh or whey                            |
| 4. CUS TOM                         | 15. Must get here<br>Must get here<br>Must get here |
| 5. Bad bad                         | 16. To rn   |
| 6. Dribble<br>Dribble              | 17. Give Get<br>Give Get<br>Give Get                |
| 7. You the past                    | 18. Roforkad  |
| 8. Chawhoworge                     | 19. B B<br>U U<br>R R<br>N N                        |
| 9. High way<br>Pass                | 20. NV Green  |
| 10. My own heart a person          |   |
| 11. Gone let gone<br>Gone let gone |   |

- |                                 |                            |
|---------------------------------|----------------------------|
| 1. No one understands           | 11. Let bygones be bygones |
| 2. Adding insult to injury      | 12. Easy on the eyes       |
| 3. Syrup                        | 13. Too big to ignore      |
| 4. Breaking a custom            | 14. One way or the other   |
| 5. Too bad                      | 15. Three Musketeers       |
| 6. Double dribble               | 16. Torn in half           |
| 7. Put the past behind you      | 17. Forgive and forget     |
| 8. Who's in charge?             | 18. Fork in the road       |
| 9. Highway overpass             | 19. Side burns             |
| 10. A person after my own heart | 20. Green with envy        |

## New Alzheimer's Disease Cooperative Study (ADCS) Web site

The ADCS, formed in 1991 as a cooperative agreement between the National Institute on Aging (NIA) and the University of California San Diego, is a consortium of over 70 sites around the United States and Canada. The ADCS is a major initiative for Alzheimer's disease (AD) clinical studies to facilitate the discovery, development and testing of new drugs for the treatment of AD.

Learn more about the ADCS at <http://www.adcs.org>. General information on AD and other dementias, AD research studies and helpful links are also provided.

An exciting component of the new ADCS Web site is the Alzheimer's Disease Information Network. The goal of the Information Network is to register a significant portion of the 5 million people affected by AD, as well as people who have undiagnosed memory disorders or those who are interested in learning more about AD and dementia. The Information Network helps educate the public with updates on AD research and treatment and upcoming clinical research studies.

To register for the Information Network, visit <http://www.adcs.org/Research/registry.aspx>. Or, you can link to it from the home page of the ADCS Web site at <http://www.adcs.org>.



### Free Alzheimer's Resources

Charged with the leading federal effort on aging research, the National Institute on Aging offers free publications through the Alzheimer's Disease Education and Referral Center (ADEAR). These materials can be ordered online through the Web site at [www.nia.nih.gov/Alzheimers/](http://www.nia.nih.gov/Alzheimers/).



### Progress Report on Alzheimer's Disease: Discovery and Hope

The National Institute on Aging's (NIA) AD research program is integral to one of its main goals, which is to enhance the quality of life of older people by expanding knowledge about the aging brain and nervous system. This

**2007 Progress Report on Alzheimer's Disease** summarizes recent AD research conducted or supported by NIA and other components of NIH, including the National Center for Research Resources, National Heart, Lung, and Blood Institute, National Human Genome Research Institute, National Institute of Biomedical Imaging and Bioengineering, National Institute of Diabetes and Digestive and Kidney Diseases, National Institute of Mental Health, National Institute of Neurological Disorders and Stroke, and National Institute of Nursing Research.



### Alzheimer's Disease: Unraveling the Mystery

Over the past few decades, Alzheimer's disease (AD) has emerged from obscurity. Once considered a rare disorder, it is now seen as a major public health problem that has a severe impact on millions of older Americans and their families. This book

explains what AD is, describes the main areas in which researchers are working, and highlights new approaches for helping families and friends care for people with AD.



### Hospitalization Happens: A Guide to Hospital Visits for Individuals with Memory Loss

A trip to the hospital with a person who has memory loss or dementia can be stressful for both of you. This brochure can relieve some of that stress by helping you prepare for both unexpected and planned hospital visits.

Inside, you will find: steps you can take now to make hospital visits less traumatic; tips on making your relative or care partner more comfortable once you arrive at the hospital; and suggestions on how to work with hospital staff and doctors.