

About people and efforts that bring the knowledge we seek on Alzheimer's disease and healthy brain aging ever closer in sight

Science often finds the right answers by first finding wrong ones.

One family confidently stays in a partially terminated drug study, believing the benefits to all outweigh the risks.

The Bickford family had put together a pretty good plan.

Phyllis Bickford, now 89, felt isolated on her small farm in rural West Virginia. So her son, Peter Bickford, 58, a mechanical engineer, and his wife Audrey, 60, minister of Unity Spiritual Center in Asbury, New Jersey, bought some woodsy acreage in rural Bucks County, Pennsylvania, so Phyllis could come to live with them. There, they would keep chickens, grow vegetables, and erect two small, modern houses connected to each other, to give Phyllis “the sense of home, companionship, and privacy she wanted,” Audrey said.

Life's best plans are --- adjustable

But frequent visits with Phyllis in preparation for the move forced Peter and Audrey to do some serious rethinking. “We knew she'd been occasionally forgetful, but things had really spiraled downward,” Peter said. “She had Post-It notes stuck everywhere, reminders for each step of her day, which didn't help. She told

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photo: Carol Edwards

Phyllis Bickford, pictured with her son Peter, enjoys the tale warbled to her by the gentle Rhode Island Red hen perched on her shoulder. Peter and his wife Audrey brought Phyllis from her isolated farm in West Virginia to share their country acreage in rural Pennsylvania. Phyllis' subsequent Alzheimer's diagnosis changed all their plans for how their lives would fit together; but “life's best plans are adjustable,” said Audrey. “We learn that everyday.”



drug trials

stress and aging study



about testing



money and cognition



thank you breakfast



your gifts | more

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us she was eating, but the refrigerator was bare." One fall stranded her hours in the tub until a cousin's surprise visit.

Phyllis's take on it all? "I'm ancient, what do you expect?"

Several nearby doctors apparently felt the same way. "They basically told us, 'she's old, this is what happens,'" Peter said. "I've heard that again and again in my ministry," Audrey

Phyllis' evaluation "from the most wonderful and attentive staff" resulted in a diagnosis of Alzheimer's disease. "Not what any of us had in mind — especially Phyllis, I'm sure — when we first decided to live together, but it's what life brought us and we all had to adjust," said Audrey.

By their natures, the three "are inclined to support research," Audrey said. "So when Dr. Karlawish explained that drug studies are so vital to learning

Investigational drug research runs on guidelines from the US Department of Health and Human Services. For drug trials like TTP, oversight by a Data Safety Monitoring Board (DSMB) is required.

DSMBs are made up of scientific experts not linked to the particular study. "They have privileged access to data on

Board found patients in the high dose group had experienced greater than expected cognitive decline, psychiatric problems, and falls. The DSMB terminated that arm of the study and notified individual study sites which patients were in the high dose group. Those patients were informed and told to stop study medication immediately.

"In science, an experiment that proves the wrong way to go still gives valuable information." . . . Peter Bickford

agreed. "Older people go to a doctor with memory complaints and are brushed off with 'Oh, it's just your age.' We wanted better information."

what could be effective against this disease, and described the TTP study, we agreed Phyllis would join."

Not the hoped-for choices, but the right ones

Even before a diagnosis of Phyllis' problems, Peter and Audrey knew the two-house plan was out, so they all moved into a small cottage on their property that Peter is now restoring and expanding room-by-room. Meanwhile, in Audrey's internet search for a memory evaluation, "the Penn Memory Center popped up all over the place, and reading about it, we knew it would be right for her."

Studies are themselves studied

The TTP study began in 2008. Also called the RAGE Inhibitor study (Receptors for Advanced Glycated Endproducts), it tests whether an experimental oral compound formulated to prevent "binding" of amyloid-beta into plaques in the brain can slow progression of the disease. It is co-sponsored by Pfizer Pharmaceuticals and the Alzheimer's Disease Cooperative Study, a research organization funded by the National Institute on Aging.



photo: © carol edwards

Audrey and Peter Bickford on their land in rural Bucks County, PA.

the physical and cognitive status of participants, which they regularly review, seeking patterns of unusual or negative results" said Jason Karlawish, Penn Memory Center's TTP site investigator. "If those are found, they end a study, or initiate a change in study design."

The value of a bigger picture

And in TTP, the DSMB did the latter. Reviewing 6-month data on all patients at the 43 sites conducting the study, the

No problems have been identified with patients in the low dose or placebo group, and the study hypothesis that the drug may slow Alzheimer's disease remained viable.

"I informed all patients in the low dose and placebo groups that the high dose testing had been halted," Dr. Karlawish said. "That information may have affected their decision to remain in the study, so we also explored the option of dropping out of the trial."

All politics is local, all research is personal -- and often more

Peter and Audrey fully understand that the TTP trial may have harmed some patients, and it's an even chance that Phyllis is receiving only placebo. Still, they "are quite happy to stay with the study" for a number of reasons.

"We haven't seen any problems with my mother that would seem related to the test medication," said Peter. "Plus, she's getting the highest quality and amount of medical care and attention she's ever had in her life through being in the study. And because one part was halted, I'm sure the remaining patients receive an unprecedented level of scrutiny for any possible problems."

But Audrey and Peter also see far beyond Phyllis' personal experience in the study. "In science, an experiment that proves the wrong way to go still gives valuable information," Peter said. Like many medicines, "maybe this is a case where some is good, but too much is not. Quitting now won't get you that answer. You wouldn't accomplish anything."

Most meaningful to Audrey and Peter "is knowing Phyllis is changing the future by joining in this research," Audrey said. "Today, tomorrow, and long after she is dead and gone, maybe after we're all dead and gone, the information she's contributing to this study will absolutely benefit people." Phyllis, who has a lot of trouble following a conversation, seemed clear enough

when she said, "I've got the time, I'm happy to help."

And the ever-changing beat of living with AD goes on

So, Audrey will still drive the 67 miles each way to the PMC for Phyllis' study visits. As long as she's able, Phyllis will attend Upper Bucks Senior Center, Wednesday through Friday. There, she tends the plants — "which have never looked better, staff tell us," said Peter.

about our frustrations, laugh about things when we can, and we work hard to give everyone at least a few minutes of 'alone time' in a day."

Peter and Audrey know that Phyllis' day-to-day needs will only increase, and if she lives long enough, she will eventually need care they can't provide at home. Long ago, they discussed Phyllis's wishes regarding end of life care. She wrote a living will and medical

A timeless story of caring

In the Bible, the Story of Ruth describes a daughter-in-law who loves and cares for her mother-in-law, Naomi, just as she would her own mother. "Until you mentioned it, I didn't think of Ruth's story in relation to my role in Phyllis's life," said Audrey, "but there are some corollaries. My own mother, living in Vermont, had Alzheimer's for many years before she died. Because



"Phyllis is changing the future by joining this research. Today, tomorrow, and long after she's dead and gone, the information she's contributed to this study will absolutely benefit people." . . . Audrey Bickford

But living with and caring for someone with Alzheimer's disease is not an easy beat to follow. Being upfront about "the pressure of multiple demands and mixed emotions that are part of being an Alzheimer's caregiver helps reduce everyone's stress level," said Melissa Livney, Psy.D., clinical psychologist at the PMC. Peter and Audrey agree.

"I won't kid you, there are times any one of us is close to a meltdown," said Audrey. "Thankfully, it's not all of us at once, so we help calm one another." Audrey is now looking for an Alzheimer's caregiver support group. "We try to be open

directive. They also made sure she's financially prepared if assisted living or skilled nursing care is required.

And at her death, Phyllis will donate her brain to the Penn Memory Center. That tissue, and data obtained from her participation in research at the PMC will be studied at Penn, and shared with investigators across the nation and around the world.

I lived so far away, several of my sisters had all the duties of caring for her. I feel that, in some ways, the care I give Phyllis is the care I would have given my own mother if it had been possible."



from the

News & Journals

Advanced dementia is a terminal illness

When families and healthcare staff understand this, patients are subjected to fewer distressing interventions to "fix" problems that are part of end-of-life.

The progressive, relentless, and ultimately fatal dementia caused by Alzheimer's disease is now the 6th leading cause of death in the United States. But dementia is under recognized as a terminal illness, according to a study in the October 15, 2009 *New England Journal of Medicine*.

This lack of understanding on the part of health care providers and proxies (family members or others with the legal authority to make medical decisions on behalf of the patient) about the realities of final stage dementia often means patients are subjected to burdensome and ineffective interventions, and receive insufficient levels of palliative care. Palliative care aims only to prevent or reduce the severity of suffering or distress caused by disease or illness, not to try to halt, delay, or reverse its course.

Lead author Susan L. Mitchell, M.D., MPH, of the Hebrew SeniorLife Institute for Aging Research at Harvard University, and colleagues followed 323 patients with advanced dementia in 22 nursing homes in or near Boston, and

their proxies, for a period of 18 months. They identified symptoms, treatments, and problems patients experienced, and how well the proxy understood the complications and extent of physical suffering that are to be expected in patients with advanced dementia.

Over the 18 months, the patients experienced notable suffering and 55% of the patients (177) died. Of those, 47% had experienced pneumonia, 44% had experienced febrile (high fever) episodes, and 39% had eating disorders. Other distressing symptoms were common; 46% experienced breathing difficulties;



photo: © Tyler Olsen | dreamstime.com

Knowledge can mean fewer detours from a care plan dedicated solely to improving comfort and reducing suffering

39% experienced pain. Seizures, hip and other bone fractures, pressure ulcers, and aspiration (inhaling matter into the lungs) were also common.

While 96% of all proxies said they believed patient comfort was the primary goal of care, in the last 3 months of life, 41% of patients who died underwent at least one aggres-

sive, burdensome intervention (hospitalization, emergency room visit, tube feeding, or feeding via an intravenous needle). Such treatments are not consistent with a palliative care approach.

Patients whose proxies understood the patient's dementia was a terminal illness, and were aware of the problems to be expected in advanced dementia, were three times less likely to undergo burdensome interventions like those noted above than patients whose proxies did not accurately understand the prognosis and the normal course of the disease.

Mitchell summed up the study's practical value for families and health care providers. "These findings can be used to inform families and care providers that infections, feeding problems and other difficulties should be expected in advanced dementia, and often indicate the end of life is near."

Families and providers should also understand that while these problems signal the end of life, as they do in other terminal diseases such as AIDS, cancer, and emphysema, "it is the major illness, in this case, the dementia, that is the actual cause of death."

<http://content.nejm.org/cgi/content/short/361/16/1529>



photo: johnwilsonpaintings.com

"Gentle Comfort" watercolor

by John Wilson

Show me the money, families are advised

Basic money management skills can erode fast in older adults with even mild memory trouble, and may signal more problems to come

Mistakes managing finances may be a clue that mild memory problems are developing into Alzheimer's disease, suggests a study published in *Neurology*, September 2009.



photo: © Dibrova | dreamstime.com

"We wouldn't want to cost dad his pride . . ." Families who avoid checking into an elder's finances could cost him a whole lot more.

Conducted at the NIA-designated Alzheimer Disease Research Center at the University of Alabama, it involved 76 older people with no memory problems, and 87 people with amnesic Mild Cognitive Impairment (MCI).

A diagnosis of MCI generally applies when cognitive problems are present but not severe enough to be Alzheimer's, and a person can still adequately manage activities of daily living. In amnesic MCI, memory problems are primary; in non-amnesic MCI, prob-

lems with thinking, reasoning, and/or visual-spatial skills predominate.

All participants took the Financial Capacity Instrument (FCI) test, which required counting coins, making grocery purchases, understanding and using a checking account, and detecting likely fraud, such as letters or phone calls soliciting financial information.

Cognitively normal participants outscored the 87 MCI participants in almost every area of the test, and in overall test scores. After one year, 25 of the 87 people with MCI had "converted" — that is, declined in cognitive and functional abilities sufficient to warrant a diagnosis of Alzheimer's disease. When the researchers compared the baseline FCI score of these "converters" to "nonconverters," they found an interesting difference.

At the initial test, the 25 converters were found to have scored significantly lower in multiple FCI test areas and in their overall FCI overall score at the initial test than the MCI participants who did not later convert to AD. Converters also showed larger percentage declines in individual and overall test scores at the one-year period than non-converters, dropping an average of 9% on checking account management skills alone.

Dan Marson, lead author of the study explained the significance of these findings. "Changes in money management skills are detectable, and families and doctors should watch older people with mild cognitive impairment for signs of problems in this area."

Marson advised families to "consider overseeing a person's checking transactions, contacting the bank to identify issues such as bills being paid twice, or become a required cosigner on checks written above a certain amount. Online banking and bill payment services are also good options."



Start the decade with 4 Healthy Brain tips

The Alzheimer's Association offers guidance to reduce your risk for AD and "maintain your brain." You're never too old — or young — to start.

Stay mentally active

Mentally stimulating activities are fun, and may strengthen connections between brain cells.

Get socially involved

Social activity not only makes physical and mental activity more enjoyable, it can reduce stress levels. More and more, stress is seen as a risk factor for AD.

Stay physically active

Physical exercise is essential for maintaining good blood flow to the brain, and reducing risk for heart attack, stroke and diabetes, which are also risk factors for Alzheimer's and other dementias. And it builds neurotrophins — proteins that exert survival-promoting and nourishing actions on nerve cells.

Adopt a brain-healthy diet

High cholesterol contributes to stroke and brain cell damage. Choose a low fat, low cholesterol diet, rich in antioxidants from vegetables and fruits to help protect brain cells.

www.alz.org/we_can_help_brain_health_maintain_your_brain.asp

Finding better ways to diagnose and foresee Alzheimer's generates as much research as finding ways to treat it.

Improving cognitive testing is vital in that effort



What we need is a “pregnancy test” for Alzheimer’s—a simple, inexpensive blood or urine test that would reveal the presence of the disease with 99.9% certainty, long before symptoms becomes apparent -- to the person who has it, or anyone else,” said John Trojanowski, M.D., Ph.D., Co-Director of Penn Medicine’s Center for Neurodegenerative Disease Research, in the PBS documentary *Alzheimer’s Disease: Facing the Facts*. “We’re not there yet, but we’re working on it.”

No kit for CSF at your local CVS

For example, home pregnancy tests screen for a hormone known as hCG, -- the “biomarker” of pregnancy -- secreted by the body during pregnancy and at no other time, and present in urine. “Right now, the best place to find the chemical changes that are the likely biomarkers of Alzheimer’s disease is in cerebrospinal fluid (CSF), obtained through lumbar puncture,” said Dr. Wolk. “That’s not something you could get at home or at a health screening at the mall.”

life than just identifying the presence of pathology itself. Cognitive tests can show that specific impact.”

The mission: better screening for more people, earlier and cheaper

Increasing rates of Alzheimer’s disease and an aging populace “signal a looming Alzheimer’s epidemic,” said Dr. Trojanowski. “So as a public health matter, the objective will be to screen more people with less invasive, less expensive measures,” explained Dr. Wolk. If a problem is identified, one would then move to more focused — and likely costlier — testing. Ideally, meaningful preventatives or treatments would then be available. “More sophisticated and pin-pointed cognitive tests may be the most pragmatic way to test and ultimately treat as many people as possible far earlier than we do now.”

Dr. Wolk believes that “a combination of genetic and other biomarkers; new, high-

“That which makes the body of current cognitive testing so valuable also may be holding back adoption of potentially valuable new testing approaches in the field” . . . David Wolk, M.D.



photo: carol edwards

Dr. David Wolk

Could such a test be the ultimate diagnostic tool for Alzheimer’s?

“Perhaps someday,” said David Wolk, M.D., a neurologist and Assistant Director of the Penn Memory Center. “But even if that happens, ever-evolving cognitive testing will be vital to diagnosing, differentiating, and measuring effectiveness of treatments of Alzheimer’s disease and related disorders.”

An easy test to find the pathology of AD is more complicated than it may sound.

And unlike pregnancy, “Alzheimer’s is not functionally a yes-or-no condition,” said Dr. Wolk. “There is not always a one-to-one relationship between pathology and symptoms of disease. About 30% of people with no symptoms of cognitive problems in life are found to have significant amounts of AD pathology in their brains upon autopsy. And some people who die very impaired actually have very little brain pathology. So learning how the pathology specifically affects an individual is far more valuable in helping him or her function and maintain quality of

ly sophisticated cognitive measures; and measures of brain activity, like Functional MRI (fMRI) or ERP — a time-locked measurement of brain activity” — will likely become the gold standard of determining risk for, diagnosing, and treating age-related cognitive disorders as we move forward.

A strength, and a weakness?

“But that which makes the body of current cognitive testing so valuable also may be holding back adoption of potentially valuable new testing approaches in the field,” he said. Alzheimer’s clinicians and researchers across the nation and the world have used many of the same tests with patients and normal controls for more than twenty years. Those huge sample sizes and decades of results means test norms are highly valid, which is critical for accurate wide scale comparisons of individuals in testing.

“But much of this testing was developed to identify dementia from non-dementia,” Dr. Wolk explained. “Now we need ways to identify the smallest deviations from the course of normal brain aging as early as possible, before any symptoms of dementia occur, and new testing approaches will certainly be required.” He is active in efforts to develop and validate new cognitive testing approaches “that can even more precisely identify and quantify subtle impairments earlier and earlier” in an aging brain.

When symptoms are evident, pinpointed cognitive testing can help differentiate Alzheimer’s disease variants or forerunners, such as visual-spatial impairments and other conditions that have a different disease course, at least initially, than typical cases of Alzheimer’s.

Treatment success means function

And as treatments or preventatives for Alzheimer’s emerge and are refined, ever-evolving cognitive testing will be critical to demonstrate their value. “If a treatment removes all the amyloid plaques from the brain, but the patient still can’t function, what’s the point? Treatment value must ultimately be proven by measuring patient capability on cognitive tests.”

Could enhanced testing for visual-spatial problems in older adults let us see if Alzheimer’s lies ahead?

Memory problems are most typically thought of as the early symptoms of Alzheimer’s disease. But a study published in *Archives of Neurology*, October 2009, found declines in other skills — most notably, visual-spatial ability — can be identified years before memory problems appear.

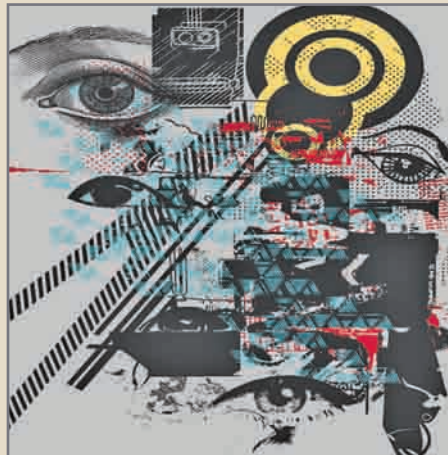


photo: © Sekose | dreamstime.com

Does visual-spatial confusion signal you’re on track for AD?

Pennsylvania, which has been an NIA-designated center since 1991).

Data came from 444 volunteers aged 60 to 101 who did not have dementia when they enrolled in the study, which ran from 1979 to 2006. At enrollment, and at least once again several years later, participants were tested on overall cognition, verbal memory, visual-spatial skills, and working memory.

Of 444 participants, 134 developed dementia. Test scores of those individuals showed that significant declines in working memory and verbal memory (such as the ability to add two numbers in your head or recall a short list of words), and loss of overall cognitive abilities could be identified about one and two years, respectively, ahead of a diagnosis of AD. But sudden and steep drops in visual-spatial skill could be pinpointed as early as three years before the Alzheimer’s diagnosis. Visual-spatial skills are assessed by “connect the dot” tests, or shape-identification and construction exercises.

Galvin notes that this finding has potentially significant clinical implications. “Screening tests that better recognize visual-spatial decline could help identify incipient disease years earlier,” Galvin said. “After a sharp departure from the relatively flat course of normal aging, we see a preclinical period in Alzheimer’s disease where memory loss alone is insufficient to warrant an AD diagnosis, but significant loss in other cognitive areas is present.”

From stories by Catherine Paddock, PhD., Medical News today, www.medicalnewstoday.com/articles/167266.php

and Michael Purdy, Washington University, www.mednews.wustl.edu/news/page/normal/14858.html

Inn at Penn | Woodlands Ballroom
Saturday October 3, 2009

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**Research Partner
Thank You Breakfast**



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Dr. John Trojanowski

Without RESEARCH, there is no progress against Alzheimer's Disease.

Without YOU, there is no research.



Over 5 million people in the US have Alzheimer's disease. Someone is newly diagnosed every 70 seconds.

Families are often emotionally, physically, and financially overwhelmed by the impact of this illness.



Dr. Steven Arnold

Only research can change that.

Yet, fewer than 4% of patients eligible to join trials of potential AD medications do so. And only a tiny fraction of seniors

with normal cognition join studies of healthy brain aging. To gain the knowledge we so critically need, research participation must grow.



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So we recognize and applaud our Penn Memory Center Research Partners, and those who help make their participation possible — at the Research Partner Thank You Breakfast, and daily — as we and our dedicated staff work with you in pursuit of your mission and ours: a world free of Alzheimer's. Again, thank you.



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John Q. Trojanowski, M.D., Ph.D.
● Co-Director, Center for Neurodegenerative Disease Research,
● Director, Alzheimer's Disease Center

Steven E. Arnold, M.D.,
● Director, Penn Memory Center
● Co-Director, Alzheimer's Disease Center



200 people attended, including ...

- 1.** Mary Humphreys and Nancy Flicker, seen here applauding a presentation
- 2.** Gene and Phyllis Perry (Phyllis' leopard print jacket was fabulous!)
- 3.** Joseph and Mary Vasho
- 4.** Doug Hill and Carol Hill
- 5.** Jane McPhee, Karen Feeney, Cheryl Kaniuk, and Jane Feeney
- 6.** Kelli Bonds, Doloris Bonds, and PMC's Staci Hoops
- 7.** José Miguel Torres and Gregorio Torres
- 8.** Betty and Henry Cecil
- 9.** Nancy and Donald Rhodes, among a number of PMC research partners from Foulkeways
- 10.** Dr. Steven Huege
- 11.** Jane Dougherty Smith
- 12.** James and Pauline Catrikes
- 13.** PMC staff Felicia Barnack, Deb Rooney, and Patricia Martinez
- 14.** Dr. Virginia M-Y. Lee, Director, Center for Neurodegenerative Disease Research
- 15.** Barbara and Clay Bridgers
- 16.** Dr. Jason Karlawich
- 17.** PMC's Marianne Watson
- 18.** Phyllis McCullough
- 19.** Max Buten, who, as usual, rode his bike to and from Narberth for the event

Photos by the photography team of Chris and Faye Silag



photo: Carol Edwards

Are you an older man or woman with normal memory, or only mild memory problems? If so, we invite you to join the Stress, Cognition, and Resilience in Aging Study

This new study aims to further understand the relationship between stress and cognition in older people without dementia. It is funded by a generous gift from the Ware Family Foundation.

One of the most intriguing concepts in Alzheimer's research over the past decade is that of brain resiliency, or neural reserve.

It is generally believed that the devastating symptoms of Alzheimer's disease result from build-up in the brain



photo: Peggy Peterson

Dr. Steven Arnold

of two pathological proteins -- amyloid plaques and tau tangles. Yet, brain autopsy studies reveal that about 30% of elderly people who show no obvious problems in life have significant degrees of Alzheimer's pathology -- amyloid plaques, tau tangles, or both -- in their brain. What are the physiological, psychological, and other factors that allow some people to function normally despite that pathology? What's behind their brain resiliency?

Better understanding of brain resiliency is the aim of the Stress,

Cognition, and Resilience in Aging Study. Steven E. Arnold, M.D., Director of the Penn Memory Center, describes it as "part of the next line of Alzheimer's research; namely, identifying key factors in lifelong brain health that may someday allow us to stop the development of Alzheimer's disease before it starts."

The Stress, Cognition, and Resilience in Aging study builds on findings of earlier research Dr. Arnold has contributed to, including the renowned Religious Order Study. One of many significant findings still emerging from that research is evidence of a relationship between stress and Alzheimer's disease.

"People who are more prone to stress, who feel more distressed by day-to-day and major events in life, who report stress early in life, show more late-life memory impairments and dementia," Dr. Arnold said.



Dr. Melissa Livney



Hannah McCoubrey

"We're seeking more data on how elders experience stress, and how that affects brain health and overall aging.



photo: zweethooth | sxc

How does stress affect brain aging?

What's involved?

- The Stress and Aging Study is open to men and women age 65 and older who do not have dementia.
- Participants attend a 2-3 hour session to complete interviews and questionnaires covering your health and life history, and how you experience and cope with stress. You'll also complete some cognitive testing, and provide a small sample of blood and hair to measure the presence of chemicals produced by the body in response to stress.
- This will be repeated approximately one year later, and a third time one year after that. Participants receive \$50 at completion of each session.

Melissa Livney, Psy.D., clinical psychologist at the PMC, will oversee the study. PMC cognitive tester Hannah McCoubrey is the study coordinator.

Call Hannah McCoubrey at 215-573-0844 to learn more.

OPEN

Investigational Drug Trials: Major Studies are now open at the Penn Memory Center



• S-connect: Overview

This study tests if a daily multi-nutrient drink containing Fortasyn™ Connect, a proprietary combination of nutrients) has a positive effect on cognitive performance in AD.

Key Study Elements: • 4.2 ounces daily of a shake-type drink, vanilla or strawberry flavored
• 6 study visits over 7 months

Who may be eligible?: Those age 50 and above with mild to moderate AD who have not used omega-3 fish oil within 30 days.

Contact Patricia Martinez ■ 215-746-2557 ■ patricia.martinez@uphs.upenn.edu

• I.G.I.V.

Immune Globulin Intravenous Study

Overview

Immune Globulin Intravenous (IgIV) has been approved and used successfully for over 20 years to treat autoimmune and immunodeficiency disorders. Increasing evidence suggests that immunotherapy targeting amyloid beta (Aβ) peptide can be used to treat Alzheimer's disease.

Because it contains anti-amyloid antibodies, IgIV is being investigated in a Phase III, double blind, randomized placebo controlled study as a treatment for Alzheimer's.

Key Study Elements

- Infusions 2 weeks apart over 14 months
- Infusions can be delivered at the patient's home by an RN
- you may be asked to participate in MRI, PET imaging, and cerebrospinal fluid sampling

Who may be eligible?

Those age 50-89 with mild to moderate Alzheimer's

• ELAN

Also called the "ICARA" study

Overview

This Phase III, double blind, placebo controlled randomized study tests the safety and effectiveness of Bapineuzumab, a humanized monoclonal antibody, in slowing the progression of Alzheimer's disease.

Bapineuzumab is designed to provide antibodies to amyloid beta (Aβ) directly to the patient, which would bind to and clear Aβ plaques characteristic of the disease.

Key Study Elements

- 6 infusions, 13 weeks apart over 18 months
- MRI exams
- you may be asked to participate in PET imaging and cerebrospinal fluid sampling

Who may be eligible?

Those age 50-89 with mild to moderate Alzheimer's

• L-ZAM

Overview

Because Alzheimer's disease is thought to be caused by an excess of amyloid beta (Aβ) in the brain, a sticky protein that forms pathological amyloid plaque, treatments to slow the build-up of amyloid beta (Aβ), or increase its clearance from the brain might be expected to slow the progression of AD.

This Phase III, double blind, randomized placebo controlled study tests if L ZAM, an anti-Aβ humanized monoclonal antibody, can slow functional decline in persons with Alzheimer's disease.

Key Study Elements

- 20 infusions, 4 weeks apart over 18 months
- you may be asked to participate in MRI, PET imaging and cerebrospinal fluid sampling

Who may be eligible?

Those age 55 and above with mild to moderate Alzheimer's

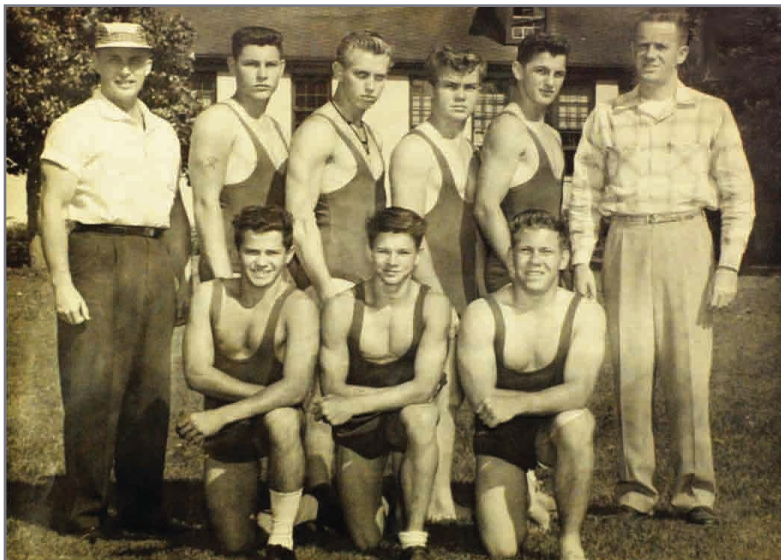
For more information contact Deb Rooney, RN, CCRC ■ 215-662-7057
■ deb.rooney@uphs.upenn.edu

For more information contact Staci Hoops ■ 215-615-3082
■ staci.hoops@uphs.upenn.edu

Did you Know?

“Normal Controls” — Older Adults with Normal Memory and Thinking — are vital partners in Alzheimer’s Research

Studying the physiological and other aspects of people in their 60s, 70s, 80s with normal cognition helps science better understand exactly what goes wrong, and when, in the brains of those with age-related cognitive problems. These very important participants in AD research are known as “normal controls.”



Even if you didn’t participate in sports as a youth, you can still join our research team. Help us pin down the answers to many questions about Alzheimer’s disease -- as a normal control.

The basics of being a normal control are simple.

Once a year, you’ll come to the Penn Memory Center for cognitive testing, a brief neurological exam, and blood and urine samples—about a 2-hour visit. You’ll leave knowing you’ve accomplished something — helping find the answers we need about AD.



Participation by Latinos and African-Americans is especially needed

To learn more, contact Marianne Watson, RN ■ 215-662-4373
■ marianne.watson@uphs.upenn.edu

Honors . . .



CNDR Retreat on Biomarkers

The Center for Neurodegenerative Disease Research (CNDR) held its 9th annual retreat on October 16, 2009. Ten internationally known Alzheimer’s researchers presented talks related to the retreat theme, “Current Research in Alzheimer’s Biomarkers.” Streaming video of the speakers and their presentations can be viewed on the CNDR website. <http://tinyurl.com/CNDRretreat>



Trojanowski and Lee speak at the Leon Thal Symposium

In October, Drs. John Trojanowski and Virginia Lee lectured at the Leon Thal Symposium held at the Wynn Encore Hotel in Las Vegas, NV, hosted by Penn alumnus CEO Steve Wynn. Until his death in 2006, Dr. Thal was the long-time Director of the Alzheimer’s Disease Cooperative Study (ADCS) a consortium of AD research sites across North America, including the Penn Memory Center /ADC. Dr. Trojanowski presented *ADNI Biomarkers/ Neuroimaging Experiences with MCI*. Dr. Lee spoke on *Novel Biomarkers*.

. . . Appearances . . . Awards . . . Involvement



Alzheimer's Forum for 55 and up

In November, Dr. John Trojanowski, (pictured, left), Co-Director of CNDR was the keynote speaker at the *Alzheimer's Forum for the 55-and-Up Expo*, sponsored by the office of Pennsylvania State Rep. Duane Milne, 167th Legislative District. (pictured, right). It was held at the Great Hall at Immaculata University. Dr. Trojanowski showed highlights of the Emmy-award winning PBS documentary *Alzheimer's Disease: Facing the Facts* and briefed attendees on the latest developments in AD research.



Steven Arnold on "What is an ADC?" See it on the web

Dr. Steven Arnold, Director of the Penn Memory Center, explains the mission and role of the National Institute on Aging-designated Alzheimer's Disease Centers (ADCs), in a video posted on the *Alzheimer's Weekly* website in October 2009. The Penn Memory Center has been one of 30 ADCs nationwide since 1991. See Dr. Arnold's video and other PMC videos, at our YouTube page.

www.youtube.com/pennmemorycenter



Dr. Arnold addresses Society for Neuroscience

Later that month, Dr. Arnold also spoke at the Society of Neuroscience Annual Meeting in Chicago. His talk, entitled *Amyloid- β Expression in Olfactory Epithelium is Selectively Increased in Alzheimer's Disease and Correlates with Brain Amyloid- β Deposition*, was the platform presentation during the "A-beta and Assembly Deposition I" session.



Jason Karlawish: At World Congress of Neurology, RWJ Award recipient

In September, Dr. Jason Karlawish, Associate Director of the Penn Memory Center, spoke at the World Congress of Neurology conference in Bangkok, Thailand, about neuroethics in the 21st century.

Earlier this year, he received the prestigious Robert Wood Johnson Foundation Investigator Award in Health Policy Research, to examine how the latest advances in the diagnosis and treatment of Alzheimer's disease affects public health initiatives, economic policy, clinical care standards, medical ethics, and more.



Felicia Barnack leads Alz. Assoc. Early Stage group

Felicia Barnack, MSW, PMC's Director of Operations, co-lead one of 18 Alzheimer Association education and support groups in the tri state area for those with early stage Alzheimer's, and their caregiving partners this fall. Felicia, a social worker, received association-run leader training to help prepare. The group met six consecutive Wednesday evenings at Ralston House. All attendees meet together at the start of each session, then patients and caregivers separate into their own respective groups. Felicia led the caregivers section.

For more information on all Alzheimer's Association support groups in the area, call them at 215-561-2919.



At Ann's Choice

In November, designated as National Alzheimer's Disease Awareness Month, Ann's Choice Senior Living Community in Warminster, PA, hosted PMC's Carol Edwards at a community session on "Understanding Alzheimer's and the Newest Research." A town in itself, Ann's Choice Warminster is home to over 2000 older residents.

At this season of reflection, thanks, and hope . . .



image: © Harry/fn | Dreamstime.com

Every gift of noble origin
is breathed upon by
hope's
perpetual breath
• William Wordsworth



**lease consider supporting the work of the Penn Memory Center.
We rely on your gifts and bequests to ADVANCE.**

Even at this time, as Alzheimer's disease threatens to grow into the largest public health crisis ever faced by our nation, federal and other funding for our efforts has been cut back. This hard reality makes your fully tax deductible gifts and bequests even more vital, to help support our research and nurture our advances.

We acknowledge donors here and on our website. (To view, go to www.pennadc.org, click on "How to make a donation," then click on "Our List of Donors."

Planned giving and matching gift programs are available. To learn more about how your support can advance the work of the Penn Memory Center, the only federally-designated Alzheimer's Disease Center in our tri-state region, please call Irene Lukoff at 215-573-0187.

Thank you

We gratefully acknowledge these recent gifts

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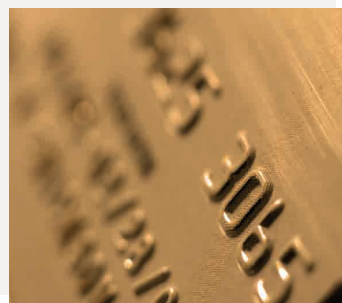
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William Bole
- **In honor of Dr. Jason Karlawish**
Norma and James McClain
- **In honor of Thelma M. Walker**
Diane Walker Elam



Year-end tax considerations

Gifts to the Penn Memory Center/ Alzheimer’s Disease Center may offer valuable tax benefits. To learn more about tax-advantageous ways to support our vital research, please call Irene Lukoff at 215-573-0187.



Make a gift on-line

You can make a gift easily, instantly, and securely — on-line. At our website — www.pennadc.org --- click on “How to Make a Donation.” You’ll be directed to the on-line donation form.



In lieu of flowers

In contemplating your own final arrangements, or those of a loved one, please consider an obituary request that, instead of flowers, donations for Alzheimer’s research be made to:

“Trustees of the University of Pennsylvania”
(write “ADC-PMC ” on the memo line)

Attn: Faye Silag
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3615 Chestnut St.
Philadelphia, PA 19104

Questions? Call Faye at 215-615-0975



inSight

WINTER | YEAR END 2009

Newsletter of the Penn Memory Center

*About people and efforts that bring the knowledge we seek on Alzheimer's disease and healthy brain aging ever closer **in sight***

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- inSight is produced by the Penn Memory Center, a part of Penn Medicine of the University of Pennsylvania.
- The Penn Memory Center is a National Institute on Aging-designated Alzheimer's Disease Center (ADC), one of only 30 centers in the United States, and the only one in our tri-state region.
- Our staff and programs are dedicated to research in Alzheimer's disease and age-related cognitive problems, and improving the well-being and quality of life of our patients and their families.
- We welcome and encourage your questions, comments, suggestions, requests, and gifts.

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contact Faye Silag at
215-615-0975 OR
faye.silag@uphs.upenn.edu

and just say "Please drop me from your mailing list."
Thank you.

For updates on driving directions and parking



Construction on the ramp and patient parking area at Ralston House continues, and the direction of traffic on Ludlow St. may soon be reversed. For current information check our website or call 215-662-7810 to learn more.

Classes for Caregivers of Relatives with Dementia

The Penn Memory Center now offers a 6-week series of psychoeducational classes led by qualified mental health professionals open to anyone who cares for someone with dementia.



photo: © carlosh | sxc

The classes emphasize skills related to patients earlier in the disease course, but caregivers of patients at any stage are welcome to join. You'll learn ways to better care for yourself and your loved one as you move through the changes of Alzheimer's disease and other dementias.

Take better care of yourself and all those you love this new year with help from these classes. Day and evening sessions are offered. Call 215-662-7810 to learn more.