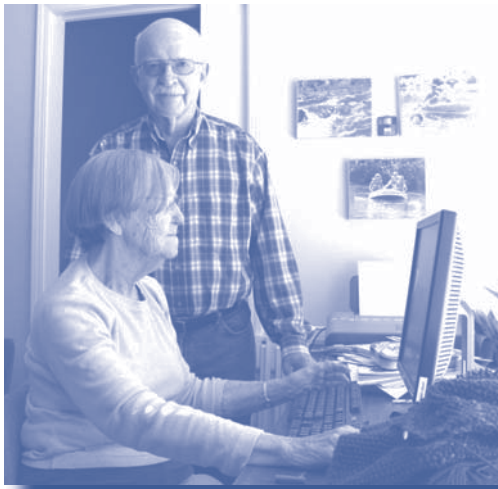


CONNECTIONS

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Margaret and Vernon Huffer at their Portland, Oregon, home, where researchers have installed motion sensors. One of the sensors can be seen between the photos on the wall.

Taking Technology Home

Researchers Test New Methods to Detect Cognitive Change

Margaret and Vernon Huffer's home in the Willamette View retirement community in Portland, Oregon, is under observation. As they go about their daily activities, sensors on the walls, doorways, and appliances gather information about their movements, from how long it takes to walk down the hall to how much they move around the kitchen.

Far from being characters in a spy novel though, the Huffers have volunteered to have their movements monitored as part of an innovative research project that could eventually help clinicians better detect early signs of Alzheimer's disease (AD).

The project, led by scientists at the Oregon Center for Aging and Technology (ORCATECH), part of the Oregon Health & Science University (OHSU), is one of several initiatives funded by the National Institute on Aging (NIA) to explore the use of unobtrusive

(see Technology, page 4)

Connections to Go Electronic

To offer research and health information on Alzheimer's disease and related dementias to an ever-widening audience, the NIA's Alzheimer's Disease Education and Referral (ADEAR) Center will begin offering *Connections* as an electronic "e-zine" starting with the next issue. Thus, this is the last printed issue of *Connections*. As technology improves and the costs of

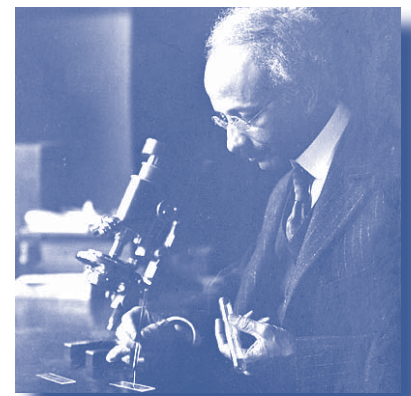
(see E-zine, page 3)

Memory Part 2 is coming...Look for it in the next Connections!

In Celebration of Black History Month

African-American Left Indelible Mark on Both Psychiatry and Alzheimer's Research

Solomon Carter Fuller's life story is a remarkable example of striving and accomplishment. He was the Nation's first black psychiatrist, and his name will be forever associated with Alzheimer's disease research. According to Creighton Phelps, Ph.D., director of the Alzheimer's



**Solomon Carter Fuller, M.D.
(1872-1953)**

Disease Centers Program at the National Institute on Aging, "Solomon Carter Fuller was a

(see Fuller, page 2)



Fuller (from page 1)

pioneer in more ways than one. As a contemporary of Dr. Alzheimer, Dr. Fuller's work helped support Alzheimer's initial conclusion that dementia is caused by disease, not aging. Dr. Fuller performed landmark research that would help shape the burgeoning field of neuropathology. He accomplished all this against tremendous odds."

During and after a distinguished career, Dr. Fuller received wide recognition for his groundbreaking work in neuro-pathology and psychiatry. Dr. Annette Primm, director of Minority and National Affairs at the American Psychiatric Association (APA), has described Dr. Fuller as "way ahead of his time."

Dr. Fuller attained considerable success at a time when African Americans faced many obstacles. He had good reason to be proud of his achievements, but according to a Boston psychiatrist who knew him, conceit and self-satisfaction were not in Dr. Fuller's nature. Rather, he was a self-effacing, inspirational teacher, researcher, and mental health practitioner who cared deeply about his work and approached each day with good cheer and optimism.

A Horatio Alger story

The grandson of slaves, Dr. Fuller was born in Monrovia, Liberia, in 1872. At age 17, young Solomon journeyed to America to continue his education. Four years after his arrival, he graduated with an A.B. degree from Livingstone College in Salisbury, NC. He received his medical degree from Boston University (BU) School of Medicine

in 1897. After graduation, Dr. Fuller accepted an appointment at Westborough State Hospital for the Insane, near Boston—the start of a long association. At Westborough, he worked as a pathologist for 22 years—rising to chief pathologist—and then as a consultant for an additional 23 years.

In 1899, Dr. Fuller was appointed part-time instructor in pathology at BU. By 1919, he was associate professor of neuropathology (a recent branch of the field). Dr.

Fuller became the acting chair of the Neurology Department in 1928. He served in that capacity until 1933, when he retired after being passed over for the appointment as

chair. He felt that his skin color was a factor in the decision.

Pioneering work in Alzheimer's disease

In 1904 and 1905, Dr. Fuller worked under Alois Alzheimer at the University of Munich. He was one of five foreign doctors invited to assist Dr. Alzheimer in his investigation of the pathology of mental illnesses. Dr. Alzheimer relied on his research assistants to carry out much of his lab work. This gave Dr. Fuller a golden opportunity to learn about neuropathology. Soon after that period, Dr. Alzheimer reported his discovery of the disease that bears his name.

Back in America, Dr. Fuller spent long hours in his lab at Westborough concentrating on photographing and analyzing brain tissue from the cadavers of people diagnosed with various mental illnesses.



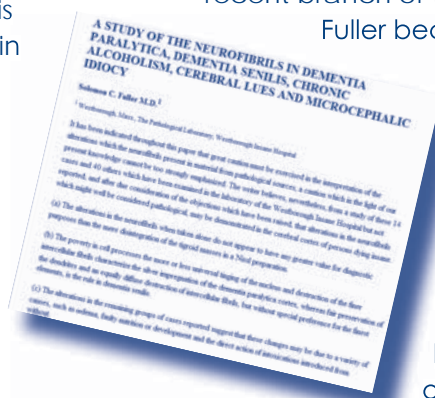
Alois Alzheimer, M.D., under whom Dr. Fuller worked

Dr. Fuller found plaques composed of amyloid protein and tangles of neurofibrils—threadlike parts of neurons, in the brain tissue of some subjects, including people with "senile dementia," which was considered a form of insanity. He was one of the first people to describe neurofibrillary tangles and to use the term "amyloid."

In 1907, the *American Journal of Insanity (AJI)*, later the *American Journal of Psychiatry*, published Dr. Fuller's "A study of the neurofibrils in dementia paralytica, dementia senilis, chronic alcoholism, cerebral lues and microcephalic idiocy" (*AJI* 63: 415-46813, 1907). In the abstract, he observed:

"The writer believes... after due consideration of the objections which have been raised, that alterations in the neurofibrils which might well be considered pathological, may be demonstrated in the cerebral cortex of persons dying insane."

In 1911, *AJI* published his paper on plaques in the brains of older adults, "A study of miliary plaques found in brains of the aged" (*AJI* 68: 147, 1911), which noted, "The



plaques were the deposits in brain tissue of a chemical substance resulting from pathological metabolism of nervous elements."

Due recognition

Recognition of Dr. Fuller's importance to the field of psychiatry would transcend factors including race. His obituary was published in the *New England Journal of Medicine* after he died in 1953. In 1974, BU dedicated the Dr. Solomon Carter Fuller Mental Health Center. Today, Dr. Fuller's portrait hangs with those of psychiatry's founding fathers at APA headquarters in Washington, DC.

Adds Taylor Harden, R.N., Ph.D., acting NIA deputy director, and assistant to the director for special populations, "Solomon Carter Fuller was a selfless, brilliant, innovative man and an exemplar for anyone who is considering a career in research, psychiatry, or medicine."

E-zine (from page 1)

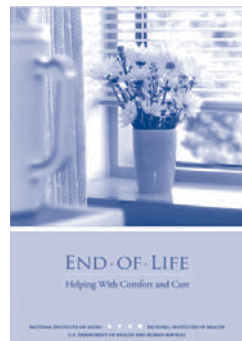
printing, mailing, and distribution rise, many organizations are turning to their websites to provide a wider forum for readers of their newsletters.

This new electronic resource will continue to feature helpful information on Alzheimer's disease and related dementias for researchers and health care professionals. Content of the ezine will also expand to include topics of interest to family caregivers and other health information consumers. Future electronic issues of *Connections* will include links to additional information resources, as well as links to related health information on the ADEAR, NIA, NIH, and other government websites. The new version of *Connections* will join NIA's other new electronic newsletter, *Spotlight on Aging Research*.

We invite you to subscribe to receive the new *Connections* ezine by email. Please visit www.list.niapublications.org/adealert/lists and check the box marked "Connections Ezine." For *Spotlight on Aging Research* subscriptions, please visit: <http://list.niapublications.org/niaalert/lists>. You may also call the ADEAR Center toll free at 1-800-438-4380 to have your name added to the email alert lists or use the order form on the back of this issue of *Connections*.

End of Life: Helping with Comfort and Care

A new booklet on end-of-life care is available from the National Institute on Aging.



End of Life: Helping with Comfort and Care is written and designed to help caregivers and families make the period just before

the death of an older person as comfortable as possible for everyone involved. The booklet provides an overview of issues faced by caregivers and families, such as:

- providing comfort for the dying person
- making health care decisions
- actions to take right after the person dies
- ways to handle grief

The booklet is based on research, augmented by suggestions from practitioners with expertise in helping individuals and families through this difficult time. The booklet can help readers better understand what is happening

and give them a framework for making care decisions. *End of Life: Helping with Comfort and Care* is available online at www.nia.nih.gov/HealthInformation/Publications/end-of-life.htm. You can also call the ADEAR Center at 1-800-438-4380, or use the order form on the back of the newsletter.

New Tipsheet on Legal, Financial Planning Now Available

The Alzheimer's Disease Education and Referral Center is pleased to announce availability of a new tipsheet: *Legal and Financial Planning for People with Alzheimer's Disease*. Important and sometimes difficult subjects are discussed and presented in clear, understandable language to caregivers and families dealing with AD. The publication explains basic legal and financial planning for people with AD and their families, outlining the essential steps to take and documents to complete. Written in an easy-to-read format with brief explanations, legal terminology is defined, but is also kept to a

minimum. Contact information for other useful resources appears at the end of the tipsheet.



Legal and Financial Planning for People with Alzheimer's Disease is available online at www.nia.nih.gov/Alzheimers/Publications/legaltips.htm. You can also call the ADEAR Center at 1-800-438-4380, or use the order form on the back of the newsletter.

Technology (from page 1)

technology to help diagnose AD or improve care for people with dementia. Much of this research is conducted by or involves OHSU investigators. One initiative, the home-based cognitive assessment project, also involves researchers nationwide.

ORCATECH, a unique academic-industry-community collaboration involving companies such as Intel and SPRY Learning, as well as OHSU scientists and retirement communities, has been supported by NIA since 2004 as an Edward R. Roybal Center for Research on Applied Gerontology. In late 2006, NIA also awarded ORCATECH a 5-year, \$7 million Bioengineering Research Partnership grant to study the use of "intelligent systems" to detect aging-related changes that may impair a person's ability to live independently.

ORCATECH Director Jeffrey Kaye, M.D., explains that around-the-clock, in-home assessment might one day reveal possible signs of cognitive decline, such as changes in walking speed or dressing speed. This would allow clinicians to address emerging problems earlier in the disease process than they can today.



Jeffrey Kaye, M.D.

"The traditional model for studying cognitive change is to identify volunteers and follow them over time, using assessment batteries that are most often administered annually," says Dr. Kaye, who also directs the Layton Aging and Alzheimer's Disease Center at OHSU, one of the 29 Alzheimer's

Disease Centers supported by NIA. "Typically in our field, we bring people into a clinic once or twice a year, evaluate them, and then they go home. It can take years to map the trajectory of cognitive decline, and the testing is not done in people's natural environments, so we're not seeing individuals' normal daily ups and downs."

In contrast to this traditional approach, ORCATECH researchers are studying simple, off-the-shelf technology for continuous, "naturalistic," in-home assessment of people's activities, to detect subtle changes in movement that may indicate cognitive decline. Previous research has shown that motor-activity changes may arise before memory changes become apparent.

"We recognize that motor changes may be from other causes, but this research will help us understand the relationship between changes in daily activity and memory," Dr. Kaye explains.

All of the 225 study volunteers, most of whom are 80 years or older or have an octogenarian spouse, live independently in Portland area retirement communities, and meet health and memory criteria. Wireless, infrared motion sensors like those that automatically open grocery store doors have been placed strategically throughout the volunteers' homes to gather data about changes in their movement over time. Special software also



Study participant Alice Price points to a sensor used by ORCATECH investigators to gather data about movement in her home.

has been installed on each volunteer's home computer, provided by the project as needed, to capture data about his or her computer use. In addition, each volunteer will undergo standard, annual memory assessments and clinical exams for comparison.

The sensors and computer software collect data about motion, not about what the volunteer is doing. The volunteers are not directly observed, and no video or still photographs are taken, so privacy is largely not a concern.

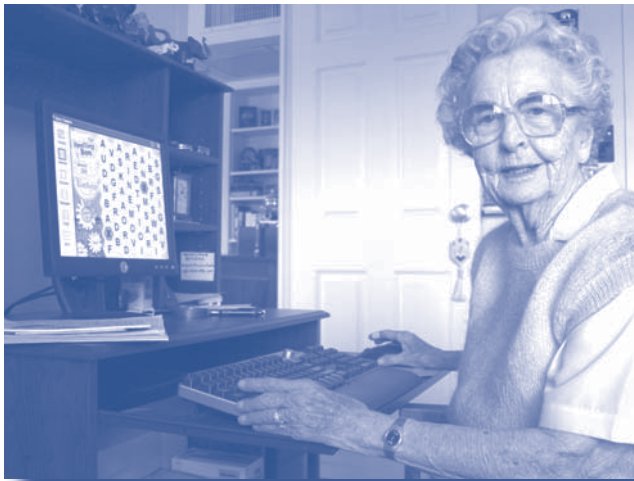
"We've established a living laboratory of homes in the community. We're using the sensors to study total activity around the home, how long it takes to do activities, where activity occurs, walking speed, and differences in nighttime versus daytime and weekend activity," says Dr. Kaye.

The computer component measures psychomotor ability and speed in typing or using a mouse. "Once a volunteer is trained to use the computer to a certain level of proficiency, that person becomes his or her own control," Dr. Kaye explains. "Even if the person is a hunt-and-peck typist, he or she has

a usual working speed, and we can collect information about changes in speed over time.”

The 5-year study began in early 2007, so results are not yet available. However, a small pilot study using the same type of sensors showed a clear difference in the walking speeds of people age 65 and older who had mild cognitive impairment (MCI) compared with age-matched cognitively normal people, over time periods averaging 315 days.

“Even with this small sample, we found a consistent pattern—a greater variability in walking speed in the MCI group compared with the control group,” Dr. Kaye



Willamette View resident Elizabeth Patton uses her computer. Special software has been installed to detect changes in psychomotor ability and speed in typing or using a mouse that might indicate cognitive changes.

reports. “These results are encouraging. They speak to the sensitivity of the system in potentially differentiating groups when monitoring them remotely.”

“This intriguing research takes a fresh perspective on ways to identify early clues pointing to cognitive decline in people at high risk for AD,” says Richard Suzman, Ph.D., director of NIA’s Behavioral and Social Research Program,

which has provided significant funding for ORCATECH. “Their research program also is distinctive in that it represents a true partnership of academia, business and industry, and local senior communities.”

Testing home-based cognitive assessment methods

In a related NIA-funded initiative, researchers at 26 academic research institutions nationwide are comparing the use of in-home computer “kiosk” technology with the use of an interactive voice-response system or mail-in questionnaires to assess thinking ability over time. This research, part of the NIA’s multi-center Alzheimer’s

Disease Cooperative Study, (ADCS) will ascertain which of those three home-based methods is most efficient and sensitive in measuring cognitive change and how the methods compare with traditional, standardized, in-person assessments.

The investigators plan to apply what they learn to clinical trials studying primary prevention

of AD. “Participants in primary prevention trials are those most at risk for dementia—the very elderly who often have physical, social, and health restrictions that make it difficult to participate in clinic-based assessments,” says the project’s principal investigator Mary Sano, Ph.D., director of the Mount Sinai Alzheimer’s Disease Research Center.

A total of 600 community-dwelling, cognitively healthy volunteers over

age 75 will be randomly assigned to the three cognitive assessment methods and further randomized to be assessed annually, 3 times a year, or monthly over a 4-year period. All three methods gather the same data about several domains known to be important in early detection of cognitive decline:



Mary Sano, Ph.D.

- memory,
- language skills,
- attention and concentration, activities of daily living,
- quality of life,
- health care and resource use, and
- changes in “global” well-being as measured by self-rating of health, cognition, and mood.

The stand-alone computer kiosk was developed by ORCATECH researchers at the OHSU Center for Spoken Language and Understanding. It combines a touch-screen computer monitor with a telephone handset. At designated times, the kiosk “wakes up” and a pre-recorded video of a friendly interviewer appears on the screen to walk the user through a series of questions, in a manner similar to that used during in-person assessment. The virtual interviewer cues the volunteer to answer a battery of questions by speaking into the telephone handset or touching the computer screen.

The second method, the interactive voice-response system, prompts the volunteer to answer questions verbally using technology like that used to make airline or train reservations. The third method involves filling out and mailing in

paper forms and completing a validated cognitive assessment by telephone.

"This research is looking at questions such as how likely people are to complete the questions by using each assessment method, which method is the most efficient, and how sensitive each method is," says Dr. Sano.

"This project will provide evidence that we hope can be used to increase participation in trials and reduce the expense and burden of traditional, in-person assessment," says Marcelle Morrison-Bogorad, Ph.D., director of NIA's Neuroscience and Neuropsychology of Aging Program, which sponsors the ADCS.

Although the nationwide project only recently began, an earlier ADCS pilot study showed that the in-home computer kiosk is both usable and acceptable to older adults. "At first, there was a little bit of skepticism about installing the kiosk, and people were worried about the size of the kiosk when it was delivered in a large box," Dr. Sano reflects. After it was installed and they learned to use the technology, however, the participants became enthusiastic and excited about the project.

Assessing change through medication compliance

NIA-funded researchers also are studying the use of a high-tech pill box called the MedTracker as a tool to measure cognitive change. The device, developed by ORCATECH researchers, is a typical daily pill dispenser mounted on wireless electronics that record the time of day the user opens one of the pill compartments and when the person refills the compartments.

"Medication taking is one of the

most important instrumental activities of daily living, and lack of adherence to medication regimens is one of the main reasons people are admitted to nursing homes," says Dr. Kaye. "Even a minor impairment in cognitive function can affect a person's ability to adhere to a medication regimen."

In a pilot project led by Tamara Hayes, Ph.D., assistant professor of biomedical engineering at OHSU, 38 octogenarians without MCI used the MedTracker pill box to dispense a low-dose vitamin C tablet twice a day at a time of their choosing.

"What they found was very interesting," Dr. Kaye says. "When they looked at this normal group, those who scored on the lower end of normal functioning were only able to adhere correctly to the medication regimen 30 percent of the time, and the others adhered about 78 percent of the time." The pilot study, he explains, demonstrated that even minor impairment in cognitive function can be detected and may affect a person's ability to adhere to a regimen.

"We think this bodes well for the use of these kinds of unobtrusive devices to detect when important changes begin to occur," Dr. Kaye says.

For more information

- Oregon Center for Aging and Technology: www.orcatech.org
- Home-Based Assessment for Prevention of Alzheimer's Disease Project: www.nia.nih.gov/Alzheimers/ResearchInformation/ClinicalTrials

To learn more


- Hayes TL, et al. An electronic pillbox for continuous monitoring of medication adherence. Proceedings of the 27th Annual International Conference of the

IEEE Engineering In Medicine and Biology Society. *Conf Proc IEEE Eng Med Biol Soc.* 2006;1:6400-3.

- Hayes TL, Kaye J, Pavel M. A novel marker of mild cognitive impairment. Proceedings of the 10th International Conference on Alzheimer's Disease and Related Disorders. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association.* 2006;2(3):S302.
- Hayes TL, Pavel M, Kaye JA. Continuous health assessment using in-home sensors. Presented at the 2007 Festival of International Conferences on Caregiving, Disability, Aging, and Technology (www.ficcdat.ca).
- Kaye J, et al. Deploying wide-scale in-home assessment technology. Presented at the 2007 Festival of International Conferences on Caregiving, Disability, Aging, and Technology (www.ficcdat.ca).
- Pavel M, et al. Unobtrusive assessment of mobility. Proceedings of the 28th Annual International Conference of the IEEE Engineering In Medicine and Biology Society. *Conf Proc IEEE Eng Med Biol Soc.* 2006;1:6277-80.

Other resources

From the ADEAR Center: *Caregiver Guide: Tips for AD Caregivers.* Copies may be ordered by calling the ADEAR Center at 1-800-438-4380 or online from: www.nia.nih.gov/Alzheimers/Publications/caregiverguide.htm.

From the NIA Information Center: *So Far Away: Twenty Questions for Long-Distance Caregivers.* Copies may be ordered by calling the NIA Information Center at 1-800-222-2225 or online from: www.nia.nih.gov/HealthInformation/Publications/LongDistanceCaregiving. 

Necessity: The Mother of Invention

Necessity, it has been said, is the mother of invention. Ken Nixon and his two brothers have demonstrated the truth of that adage, in their case inventing an innovative way to help meet the daily needs of their mother who had Alzheimer's disease (AD). With funding from the National Institute on Aging (NIA), they created a multi-purpose, Internet-based system called AttentiveCare, which has been further developed and is currently being field-tested by others faced with long-distance caregiving challenges.

The Nixon brothers, like so many long-distance caregivers, needed to solve a difficult problem—how to care for their mother and enable her to remain in her own home as long as possible when they were hundreds of miles from her.

"We were facing a tough question: What are we going to do with Mom? She wanted to stay where she was," reflects Ken Nixon of Oklahoma City.

Back in 2001, broadband Internet service had just become available in their mother's Arkansas rural community, so the brothers put their heads together and came up with the idea of using



Ken Nixon and his grandson, in Overland Park, Kansas, use videoconferencing technology to talk with Ken's mother, Louise, at home in Lavaca, Arkansas.

videoconferencing to keep in touch with her. They installed a computer with a webcam in her home so they could check on her daily, helping fulfill her wish to continue living independently on the family farm while assuring themselves that she was faring well, Ken explains.

"We had a need, and we patched the system together at first. It exceeded our expectations in being able to keep our mother independent and connected to the family. We could call and have coffee with her every morning and it got her day started off right. She had something to look forward to every day—one or two of her boys were going to visit."

After 6 months of using the home-grown system themselves, Ken Nixon decided to develop it to help other caregivers. He applied for and in 2003 received a Phase I Small Business Innovation Research (SBIR) grant from NIA to refine the AttentiveCare prototype and test its feasibility in providing informal, long-distance care to people with AD.

He later received a Phase II SBIR grant to evaluate the software, services, and caregiver usage and benefits of the system in a variety of caregiving situations. Phase II study participants are caregivers of people with early-to moderate-stage AD who have had the AttentiveCare system installed in their own homes and the homes of their family members with AD.

In addition, Nixon has received research and development funding from the Oklahoma Center for the Advancement of Science and Technology.

AttentiveCare now features videoconferencing, multimedia reminders to help care recipients function independently, and slide shows to keep care recipients connected with family. The system's journal and data logging capability also allows multiple caregivers to maintain and share information about the care recipient's health and well-being, whether they are across the street or thousands of miles away.

"This project is an excellent example of how a real need, in this case the challenge of long-distance caregiving for people with AD, can be addressed through research and the inspiration of individuals at the grassroots level," says Sidney M. Stahl, Ph.D., program officer and chief of the Individual Behavioral Processes Branch of NIA's Behavioral and Social Research Program.

Nixon reports that his company's research has shown the system to be well-accepted by caregivers and care recipients alike. "There was not a large body of knowledge about how computer-based technology can be used with people with dementia," he says. "One of the questions we needed to answer was what capability does a person with dementia need to use the system. Our research has shown that if users still have language capability and can follow directions, they can effectively interface with their caregivers using the system."

For more information

Caregiver Technologies, Inc:
<http://caregivertech.com>

AD Library Highlights

These highlights describe materials recently added to the Alzheimer's Disease Library (AD Lib). The items selected represent topics and formats of general interest to readers of *Connections* and ADEAR Center users or their clients. Please order directly from the source listed for each item. Journal articles are available in many university and medical school libraries. AD Lib is accessible on the Internet at www.nia.nih.gov/Alzheimers/Resources/SearchHealthLiterature.

Planning for Emergencies

Ready America: Prepare. Plan. Stay Informed., 2007

Available from the Federal Emergency Management Agency (FEMA), Website: www.ready.gov/america. Single print copies can be ordered by calling 1-800-237-3239; multiple copies can be ordered by calling 1-800-480-2520. Price: Free.

The Federal Emergency Management Agency (FEMA) maintains this website to provide emergency preparedness information for individuals and population groups with special needs, such as older Americans and people with disabilities. The site lists contact information to reach State and local emergency assistance organizations. It provides downloadable publications about emergency planning and order forms to obtain print publications. Lists of items to have on hand in the family emergency kit are separated into basic items (e.g., water, food, hygienic supplies, first aid supplies, basic tools) and additional items (e.g., bleach, cash and change, reference books, pastimes). A section titled Disabled and Special Needs lists steps (e.g., show others how to operate your wheelchair) and supplies (e.g., extra wheelchair batteries, oxygen, hearing-aid batteries) specifically for this group.

Information Resources for Early-Onset AD

Early Onset Alzheimer's Disease, 2006

Available from the Alzheimer's Association as a free online information resource list at www.alz.org/national/documents/EarlyOnset_RL.doc

The Alzheimer's Association library staff has compiled an extensive list of information resources about early-onset AD. The list includes Alzheimer's Association products, conference recordings, books and journal articles, videos, audio recordings, websites, newsletters, and theses. The resources are grouped into the following categories:

- General
- Person with Early-Stage Dementia
- Care
- Clinical Features/Research in Early Stage
- Diagnosis and Assessment
- Mild Cognitive Impairment
- Programs

Items in the early sections are primarily directed toward non-professionals—people with the disease, others concerned about risk factors, caregivers, and family members. Items in later sections are more appropriate for treatment professionals.

Brain Health Reference

The Dana Guide to Brain Health, 2006

Bloom, F.E., Beal, M.F., and Kupfer, D.J., Editors

Available from Dana Press, 900 15th Street, N.W., Washington, DC 20005. Phone: 202-408-8800. Fax: 202-408-5599. Website: www.dana.org. PRICE: \$25.00.

This guide from the Dana Foundation is an updated, thorough general reference about the brain. The 104 contributors are medical, mental health, and scientific experts. The guide comprises 733 pages and includes a 30-page index plus CD-ROM:

- Part I explains the "concepts and lingo" used to discuss the brain in the rest of the book.
- Part II explains how the brain develops throughout life.
- Part III explains how the brain functions.
- Part IV, comprising nearly two thirds of the book, discusses numerous brain disorders and diseases.

Most readers will want to use this book as a topical reference, for example, to read about a specific type of brain disorder. The CD-ROM contains the complete book—enabling word searching.

Reaching African-Americans Through the Church

Book of Alzheimer's for African-American Churches. 2006

Available from the Sanders-Brown Center on Aging, University of Kentucky, 101 Sanders-Brown Building, Lexington, KY 40536-0230. Phone: 859-257-1412. Website: www.mc.uky.edu/coa. PRICE: free print copy.

This manual is a brief overview of AD, dementia, and caregiving. The primary intended audience is African-American church leaders who want to help families or individuals in their communities cope with dementia, particularly AD. African-American church leaders are in good position to be sources of information because "African-American families look to their churches and ministers for guidance in their times of need," say the authors. The manual is a cooperative effort by experts in dementia research and care; advocates for dementia and Alzheimer's disease research, education, and support; experts on African-American culture; and members of the African-American religious community.

The information in the first three chapters would be informative for any group dealing with these diseases:

- Differences between dementia and AD
- Progression of AD
- Warning signs and symptoms
- Diagnosis and treatment
- Preparing to visit a doctor
- Common causes of behavioral changes
- Communication
- Dealing with common behavioral issues such as aggression, sleep problems, wandering,

- personal hygiene, and driving
- Maintaining safety

Chapter 4 discusses the impact of AD and dementia on African-Americans, noting that dementia is more common in African-Americans than in Caucasians. Some theories about this disparity are examined. A chapter summarizes lessons learned by individuals who have experience working with African-American families. It concludes with a discussion of the role of faith and spirituality in caring for a person with dementia.

Seminar Series for Professional Caregivers

Seminar Series on Alzheimer's Disease for Professional Caregivers

Alzheimer's Disease: An On-line Course, 2005

Available from Alzheimer's Association Star Chapter, Midland Regional Office, 4400 North Big Spring, Suite C-32, Midland, TX 79705. Phone: 800-272-3900. Fax: 432-683-2345. Website: www.alz.org/txstar. PRICE: \$21 (with 3 hours CEU credit); \$10 (with certificate of completion); free online access.

Alzheimer's Disease: An On-line Course is actually four online courses about AD for professional caregivers. The courses are presented as separate, consecutive educational seminars, arranged based on the progressive stages of AD. The objectives of each course are defined in terms of participant competencies. Vignettes give examples from life that clarify instructional concepts. Each seminar includes a bibliography, list of additional resources—in most cases with hyperlinks to the sources, a seminar evaluation form, and a post-test. The courses are structured to enable caregivers to

read only the parts that are immediately pertinent if they prefer.

In The Beginning

This initial seminar in the series provides background on AD and describes the early stages:

- Defining AD and its causes
- Comparing and contrasting AD and normal aging
- Warning signs of AD
- Diagnosing AD
- Medications
- Behavioral triggers
- Financial and legal documents and planning

The Journey Continues

The second seminar in the series addresses topics for caregivers related to the middle stages of AD, including:

- Differences between early- and middle-stage AD
- Communication strategies
- Challenging behaviors
- Wandering

The River's End

This third seminar in the series addresses topics for caregivers related to late-stage AD, including:

- Common changes in the late stage
- Coping with grief
- Stress management
- Making end-of-life decisions

Life Goes On

The fourth and last seminar in the series discusses "topics important to life after Alzheimer's," such as:

- Interventions for coping with grief
- Emotions associated with grief
- Estate settlement

Alzheimer's Disease Cooperative Study Update

The Alzheimer's Disease Cooperative Study (ADCS), a nationwide consortium of study sites funded by the NIA and coordinated by the University of California, San Diego, has several new studies underway:

Home Based Assessment Study

(HBA) – The ADCS is currently recruiting participants for the HBA study. This study is evaluating three methods of performing home-based assessments, recognizing that mobility and health issues may keep some individuals from participating in clinical trials. The HBA study is examining the use of mail, telephone, and computer assessments that can be done by the participant at home. By reducing the number and length of clinic visits, future AD prevention trials may be able to increase participation while reducing costs.

Currently, 26 sites are participating in the study, seeking a total of 600 individuals without dementia. Participation will last 4 years, primarily in the participant's own homes. *(For more information, see the Technology article on page 1.)*

Two additional ADCS trials will begin recruiting soon:

Gammaglobulin Liquid for Alzheimer's Disease (GLAD)

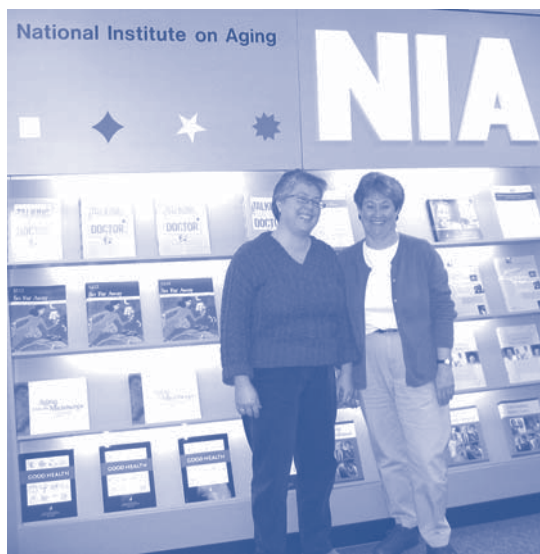
– a passive immunization trial of intravenous immunoglobulin (IGIv) for reducing brain amyloid. IGIv is a well-known treatment with an established safety record, approved for use for other indications for more than 25 years. Thirty-six to 40 sites are expected to participate through a partnership with Baxter Pharmaceuticals,

recruiting 360 individuals between the ages of 55 to 90 with probable AD. Most sites will use home-health nurses to administer the IGIv bi-weekly for 72 weeks.

Receptor for Advanced Glycation Endproducts (RAGE) Inhibitor Trial

– This Phase II trial is sponsored by Pfizer and the NIA and will test whether RAGE inhibitors will decrease amyloid's downstream effects on neurons. Approximately 40 sites are expected to participate, recruiting 399 individuals with mild to moderate AD for this 18-month trial.

For more information on these and other clinical trials, visit the ADEAR Center's clinical trials database at www.nia.nih.gov/alzheimers/ResearchInformation/ClinicalTrials.



FAREWELL AND WELCOME! After 16 years of dedicated service to NIA and ADEAR, Pat Lynch, at right, retired in early 2008. Her successor is Jennifer Watson, left, former project director for the ADEAR Center.

A Fond Farewell to Pat Lynch & Welcome to Jennifer Watson!

On January 4, 2008, the staffs of the National Institute on Aging, NIA Information Center, and ADEAR Center bid farewell to Patricia D. Lynch, MA, MS, MAPS. After 16 years of service, Pat retired from her position as Senior Public Affairs Specialist and Clearinghouses Project Officer in the NIA Office of Communications and Public Liaison (OCPL).

Richard Hodes, M.D., NIA director, recognized Pat's many contributions, saying, "Unanimously and gratefully, her colleagues acknowledge Pat's leadership in the high-quality and timeliness of many audience-specific information products conceived, developed, and disseminated by the NIA during her tenure."

Pat's successor is Jennifer Watson, M.A., former project director for the ADEAR Center at the NIA's clearinghouses contractor, JBS International. Jennifer had the opportunity to work closely with Pat for more than 6 years. Vicky Cahan, director, OCPL, stated, "We thank Pat for her tremendous dedication and energy, and we will deeply miss her wit and wisdom. We welcome Jennifer as an experienced professional who is very knowledgeable about our audiences and their many health information needs."



March 27 - 30, 2008

Aging in America: 2008 NCOA-ASA Conference

Washington, DC

Contact:

American Society on Aging and
National Council on Aging
833 Market Street, Suite 511
San Francisco, CA 94103
Telephone: 415-974-9675
Fax: 415-495-6509
Email: registrar@asaging.org
Website: www.agingconference.org

March 29, 2008

A Meeting of the Minds: The Dementia Conference 2008

St. Paul, MN

Contact:

Carla Zbacnik
The Alzheimer's Association
Minnesota/North Dakota Chapter
4550 W 77th Street, Suite 200
Minneapolis, MN 55435
Telephone: 952-857-0526
Email: Carla.Zbacnik@alz.org
Website: www.alzmindak.org

April 18, 2008

Symposia on Mild Cognitive Impairment: An Evolving Concept in Research and Clinical Practice, and Impact on Patient and Family

Indianapolis, IN

Contact:

Indiana University School of
Medicine

Division of Continuing Medical
Education

714 North Senate Ave., EF 200
Indianapolis, IN 46202

Telephone: 317-274-4220 or
toll-free: 888-615-8013

Fax: 317-274-4638

Website: [http://iucar.iu.edu/
images/alz05_419.pdf](http://iucar.iu.edu/images/alz05_419.pdf)

April 17, 2008

15th Annual Spring Education Conference: The Many Faces of Dementia 2008: Making a Difference

Charlotte, NC

Contact:

Beth Croom
Alzheimer's Association
Telephone: 704-532-7391
Email: Beth.Croom@alz.org

April 30 - May 4, 2008

American Geriatrics Society Annual Scientific Meeting

Washington, DC

Contact:

American Geriatrics Society
The Empire State Building
350 Fifth Avenue, Suite 801
New York, NY 10118
Telephone: 212-308-1414
Fax: 212-832-8646
Email: info@americangeriatrics.org
Website: www.americangeriatrics.org

May 8, 2008

Northwestern University Feinberg School of Medicine 14th Annual Alzheimer Day

Chicago, IL

Contact:

Cognitive Neurology and
Alzheimer's Disease Center
Northwestern University
Feinberg School of Medicine
320 E Superior, Searle 11
Chicago, IL 60611
Telephone: 312-503-2486
Email: [CNADC-Admin@
northwestern.edu](mailto:CNADC-Admin@northwestern.edu)
Website: [www.brain.northwestern.
edu/events/adday.html](http://www.brain.northwestern.edu/events/adday.html)

May 12, 2008

Alzheimer's Association Town Hall Meeting for People with Early-Stage Dementia

Washington, DC

Contact:

The Alzheimer's Association
225 N. Michigan Ave., Fl. 17
Chicago, IL 60601
Telephone: 1-800-272-3900
Email: info@alz.org
Website: [www.alz.org/townhall/
meetings.asp](http://www.alz.org/townhall/meetings.asp)

May 22, 2008

Alzheimer's Disease: Update on Research, Treatment and Care

San Diego, CA

Contact:

University of California, San Diego
Continuing Medical Education
9500 Gilman Drive, MC0617
La Jolla, CA 92093-0617
Telephone: 1-888-229-6263
Website: [http://cme.ucsd.edu/
alzheimers/reg.html](http://cme.ucsd.edu/alzheimers/reg.html)

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