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## Connections Newsletter v.13, #3-4 (2006)

# CONNECTIONS

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### Building trust and using technology to reach out to American Indians



Alzheimer's Disease Centers (ADCs) work hard to bring diagnosis, treatment, and education services to the diverse populations they serve, including rural and urban groups, the poor, Hispanics, African-Americans, Asian Americans, American Indians, and people with low health literacy. Providing the full range of services to American Indians is particularly challenging. Significant barriers include language, cultural differences,

distrust, location and geography, access to technology, and funding and allocation of resources. As difficult as these obstacles are, three ADCs in areas with large American Indian populations—in Oregon, Texas, and Arizona—are using a combination of technology and good old fashioned relationship-building to serve local American Indian communities.

### Population and health status of American Indians

Today there are an estimated 4.4 million American Indians according to the U.S. Census Bureau, with about 550,000 living on reservations or other trust lands. The largest tribes are the Cherokee (234,000) and Navajo (204,000). Other tribes with more than 50,000 include Apache, Chippewa, Choctaw, Lumbee, Pueblo, and Sioux.

According to the Census Bureau, 7 percent of American Indians and Alaska Natives are over age 65, while 12.5 percent of the population at large is over age 65. Thus, the proportion of American Indians who are older is considerably lower than the national average. American Indians have high rates of certain chronic and debilitating diseases or conditions, including diabetes, cardiovascular disease, alcoholism, and obesity, according to data from the National Center for Health Statistics. The interrelated conditions of diabetes and obesity are two of the most serious health challenges facing the American population overall, and American Indians especially.

Data from the Center for Health Statistics indicate that AD mortality rate is 8.9 per 100,000 in American Indians and is 19.0 per 100,000 for the population overall. In Caucasians, studies have shown that health problems like obesity, cardiovascular disease, and diabetes, when combined with poor access to health care, typically are associated with higher rates of dementia. Incidence and prevalence of dementia in the American Indian population, however, may be inadequately documented.

According to the Gerontological Society of America, "little is currently known about the prevalence of dementia among older American Indians despite anecdotal accounts by clinicians that it is rarely encountered." Genetics may play a role. One small 1996 study indicates that the Cherokee Indians may have a lower incidence of ApoE4. Roger Rosenberg, M.D., Director of the UT Southwestern ADC, studied the relationship of genetic factors in Cherokee Indians with the development of AD and ApoE allele type. He concluded that a greater genetic degree of Cherokee ancestry reduces the risk of developing AD; therefore, the Cherokee genetic background appears to have protective characteristics. The relationship between Cherokee background and the incidence of AD is independent of ApoE allele type, according to the study. Incidence of AD continues to increase with age, however, but to a lesser extent in Cherokees.

Most experts agree that while all tribes are different, most American Indians share certain cultural similarities, such as a strong spirituality and attachment to the land—believing in a balance between the body, mind, and spirit. Many American Indians feel strongly about retaining their culture and identity, including language. Researchers have learned that equivalent medical words or concepts may not exist in some native languages. For example, the concept of dementia can be different within American Indian cultures relative to the majority population. The ability to describe the concept of progressive memory loss varies from tribe to tribe and is an uncertain term at best (even in the English language). Researchers also say that spiritual and traditional forms of medicine practiced by many American Indians can influence acceptance of health care and research conducted by outsiders. In addition, American Indians may have a different understanding of some of the symptoms of AD. For example, hallucinations may be seen as "communication from the other side" and therefore may be viewed in a positive light.

Although incidence and prevalence of dementia may not be well

documented, mild cognitive impairment, Alzheimer's disease, and related dementias are considered by health care professionals to be serious medical problems facing American Indians. Three ADCs—in Arizona, Texas, and Oregon—are harnessing technology and a variety of other methods to overcome some of the barriers between American Indians and health care providers.

### Telemedicine serves Oklahoma Choctaws

One approach at the University of Texas Southwestern ADC, includes new uses for an older technology. Myron Weiner, M.D., and his colleagues are working on a telemedicine program with the Choctaw Nation in Southeastern Oklahoma. Telemedicine is not new, particularly as it has been used to provide health services to rural communities, but Dr. Weiner's team has found a novel application for it in follow-up dementia care in American Indian patients. According to Dr. Weiner, members of the Choctaw tribe, which was displaced from the Carolinas in 1830, may be more comfortable than other, more remote tribes in using contemporary technology.



*Myron Weiner, M.D., conducting the telemedicine program*

Since 1991, the UT Southwestern ADC has screened and interviewed 212 American Indians for dementia. Dr. Rosenberg and ADC physician Kyle Womack, M.D., travel to Talihina, Oklahoma about five times a year to conduct initial patient examinations and diagnostic testing. The telemedicine program provides a live video feed, connecting Dr. Weiner and his colleagues in Texas to Oklahoma, where patients diagnosed with dementia are followed in a monthly video clinic conducted via satellite. Connected to the Choctaw Nation Health Care Center in Talihina, the telemedicine program serves as a checkup on the patients and their respective caregivers as well. "Our program allows us to stretch limited resources and provide comprehensive follow-ups. It's very difficult for Choctaws to arrange to come to our ADC Center. But it's much easier on them and their caregivers to come to the Talihina Center, where we can conduct follow up visits," says Dr. Weiner.

Depending on the length of time since their initial assessment, patients may be given a battery of psychological tests to assess cognitive abilities shortly before the "telemeeting." The caregiver is also interviewed before the patient (and not in the presence of the patient) over the live video feed. Using this information and scores from several rating scales (two full-time people in Oklahoma rate the patients), Dr. Weiner discusses with staff the possible need for clinical intervention. In most cases (60%), patients will need intervention. According to Dr. Rosenberg, "We are very pleased with the telemedicine program. It allows us to focus collective clinical dementia expertise on a population that otherwise might not have access to these services. Members of the Choctaw Nation are pleased with this service, are responding well, and are spreading the word throughout their community." The UT Southwestern group plans soon to undertake an experiment in administering neuropsychological tests by live video.

Drs. Weiner and Rosenberg are also studying the relationship between

cardiovascular risk factors in American Indians and whether they correlate with the risk of developing AD. The most recent research indicates that certain cardiovascular factors may increase the risk of AD, including high cholesterol and high blood pressure.

### **Circuit rider program also successful**



*Carey Fuller at a recent conference*

Telemedicine is not the only outreach program at UT Southwestern. The Education Core also employs a "circuit rider," who visits the 10 counties of the Choctaw Nation throughout the year, traveling to senior centers and medical clinics to build relationships with the tribe. During short, informal presentations, Carey Fuller, the "circuit rider," becomes better

acquainted with tribal Elders and talks about memory loss and offers "memory checkups." According to Margaret Higgins, M.S., Education Core Director, the word "Alzheimer's" is never used in publications or on signs. "Memory loss" is more culturally and linguistically acceptable to the tribes. Those patients who have memory problems are asked to return to have a private exam at their respective senior center. Although the plan is only in its second year, it is being welcomed by increasing numbers of tribal Elders, says Higgins.

### **In Arizona, building relationships**

Eric Reiman, M.D., Director of the Arizona ADC and his colleagues have been meeting regularly with representatives from several regional tribes. "We have been working closely with our American Indian partners to explore how we could address some of their needs in the most culturally sensitive and effective way. We have begun to provide some of these services, promoting further communication through a series of conferences, and only then to consider the studies that will best serve their needs. Our outreach efforts are based on common goals, shared commitments, close communication, and the patience, persistence, and small steps needed to make a real difference," says Dr. Reiman.

Alfred Kaszniak, Ph.D., directs the Arizona ADC Education Core. He promotes awareness of AD in Latino and American Indian groups through a Diversity Committee. In educational pamphlets and booklets on AD, the Core carefully evaluates the material to identify possible cultural sensitivities. The materials encourage Latinos and American Indians to learn about memory impairment and how they can get help. "In addition to providing educational seminars and brochures to the local tribes about memory loss, we're also stepping up our efforts to increase participation of American Indian Elders in AD research and developing assessment tools that are culturally relevant and sensitive to the Elders we evaluate," says Dr. Kaszniak.

A partnership with the Desert Southwest Chapter of the Alzheimer's Association helps develop outreach programs to minority health care professionals as well. The Chapter maintains an active Medical and Scientific Advisory Committee which coordinates the publication of a newsletter. Although aimed at a general audience, the newsletter includes information on recent AD research on American Indians and research

participation opportunities. Joint education and outreach projects target Latinos and American Indians, provide speakers and information for caregiver conferences and public television spots, and offer opportunities for ADC staff to “shadow” a family care consultant at the chapter’s offices in Sun City.

Minnie Jim, an American Indian and the program assistant and Outreach Coordinator, helped initiate a support group in the Navajo Nation to build relationships and provide useful caregiver support.



Brochures and videos on memory loss produced for American Indians are distributed as well. Efforts to use an

internet-based education program with Navajos at a local community center did not fare well because residents did not utilize this resource. Staff concluded that more direct contact was necessary, so presentations to Elders and health care professionals in tribal communities are underway throughout Arizona.

A Native American Memory Disorders Clinic near Phoenix began 2 years ago under the guidance of Marwan Sabbagh, M.D. He is planning more presentations to Elders and health care professionals in tribal communities and at health conferences and fairs. Dr. Sabbagh and Ms. Jim collaborate with Association Chapter staff to help Elders recognize the early signs of AD and how to access appropriate health care. According to Dr. Kaszniak, “Overall, our American Indian outreach program goal is to increase awareness of AD and other age-related illnesses. As we get to know the tribes and they get to know us, and as awareness of the symptoms of AD increases, we hope interest and participation in our research will gradually increase as well.”

### **Oregon ADC reaching American Indians through face-to-face contact**

Oregon ADC Director Jeffrey Kaye, M.D., and his staff have been working closely with the Confederated Tribes of the Warm Springs Reservation for the past 10 years. The project, funded by the ADC Satellite program, focused on geriatric assessment in this remote community. ADC staff worked hard to earn trust and carefully build relationships. Setbacks were encountered when Elders who are community leaders became ill or died. Other challenges included using assessment instruments that were not designed to be used in the rural American Indian setting. Dr. Kaye says that being on site as much as possible is key because travel to distant parts of Oregon is especially daunting during winter months or in the summer during wild fire season.

In fact, Dr. Kaye reports now that the ADC may have to close the Warm Springs program because of a number of constraints, including loss of the Elder leading the project on site, certain issues with data collection standards and requirements, and the cost of supporting on-site staff.

According to Linda Boise, Ph.D., Educational Core Director, the Oregon ADC is encouraging relationships between Ed Core leaders and local native Elders by increasing participation at regional events geared to American Indian audiences. For example, the local Aging Services Office held a Native American Caregiver Conference attended by ADC staff, and another conference in southern Oregon is planned so that American Indians can learn more about health issues.

One way Dr. Boise plans to expand the ADC's outreach is to involve a younger audience. At Portland State University, an American Indian Community Center offers a facility where students and local American Indians can gather. "The younger generation of American Indians is an effective outreach medium to the Elders, as they are more socially acclimated to varied cultures and less inhibited with modern communication techniques such as email and the Internet," commented Dr. Boise. The younger generation of American Indians in Portland is comfortable using more modern communication technologies, but Dr. Boise also relies on the occasional spontaneous visit and one-on-one personal discussions to build trust and meaningful relationships.

### **A slow but rewarding process**

Successful outreach to American Indians involves both innovative uses of proven technology and hard-won respect and trust through face-to-face contact, meetings, conferences, and careful preparation of educational materials. Raising awareness, providing diagnoses, and offering treatment evolve slowly as ADC staff work to build interpersonal relationships. Staff find that sometimes it can be a painstakingly slow process (particularly as measured by today's performance standards). Even though progress is sometimes measured in very small steps, staff are striving to foster partnerships with American Indians in their local communities. As these partnerships grow stronger, researchers, clinicians, and educators are overcoming significant barriers in order to both learn from and provide information and state-of-the-art health care to American Indians.



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#### **Frontotemporal dementias conference scheduled**

The 5th International Conference on Frontotemporal Dementias (FTDs) will be held September 6-8 in San Francisco. Hosted by the University of California at San Francisco (UCSF), the conference will devote one full day to caregivers, family members, and interested laypersons. The conference will also feature 3 days of scientific sessions, which will cover topics, such as the molecular basis of FTD, animal models, behavioral manifestations, diagnostic testing, and biomarker assessments, including neuroimaging, and genetics.

Course directors include leading FTD researchers Bruce L. Miller, M.D., Professor of Neurology and Director, Memory and Aging Center, UCSF, and Howard J. Rosen, M.D., Assistant Professor of Neurology, UCSF.

Visit [www.ucsfcmc.com/frontotemp.htm](http://www.ucsfcmc.com/frontotemp.htm) for more information on the conference and registration.

**[Studies show intervention can improve caregiver skills, quality of life](#)**

Community-based dementia care-giver interventions can reduce caregiver depression, teach effective behavior management skills, improve caregiver-care recipient relationships, and positively affect general quality of life for caregivers, according to researchers who have conducted several randomized controlled clinical trials. Summaries of these studies were presented recently at the Gerontological Society of America conference in Orlando, Florida.

During a symposium, Mary Mittelman, Dr.P.H., of New York University, Rebecca Logsdon, Ph.D., of the University of Washington, Ann Steffen, Ph.D., of the University of Missouri - St. Louis, and Lisa Gwyther, M.S.W., CCSW, of Duke University, discussed the results of three successful caregiver intervention studies conducted in community-based settings. They concluded that interventions for family caregivers have made significant strides in the research arena and can be adapted to larger programs in community settings.



*Participating in a recent caregiver intervention symposium were, from left: Lisa Gwyther, M.S.W., CCSW, of Duke University; Rebecca Logsdon, Ph.D., of the University of Washington; and Ann Steffen, Ph.D., of the University of Missouri-St. Louis.*

In a study funded by NIA and the National Institute of Mental Health (NIMH), Dr. Mittelman and her colleagues conducted a randomized trial that included 406 caregivers and their families, who were randomly assigned to enhanced counseling and support or usual care. This study began in 1987 and is still ongoing. The multicomponent psychosocial intervention was designed to help improve caregiver well-being. Care-givers regularly

completed a battery of structured questionnaires. Previous reports showed that the intervention reduced caregiver depression, improved reactions to patient behavior, strengthened the care-giver's social support network, helped with family relationships, and enabled spouse caregivers to keep their husbands and wives out of nursing homes significantly longer. The report that was part of this symposium, entitled "Physical Health Effects of the NYU Spouse Caregiver Intervention," discussed the effects of the intervention on the self-rated health of caregivers over a 5-year period. Dr. Mittelman and her team determined that the self-rated physical health of caregivers receiving counseling and support was better than that of caregivers in the control group. The difference in the two groups occurred within the first year of participating in the study. While differences between the control group and the experimental group diminished over time, the improvements remained statistically significant for 4 years.

Dr. Logsdon presented "An Interdisciplinary Approach to Community Care: Training Community Consultants to Incorporate Behavioral Interventions into Clinical Practice." This study, funded by an Alzheimer's Association Pioneer Award to Linda Teri, Ph.D., focused on implementing a behavioral intervention for dementia caregivers which can be delivered by community home health providers. Dr. Teri and her research team based the intervention on the Seattle Protocol, a manual-based, behavioral approach to problem solving in dementia. They trained community home health

providers to deliver the treatment and studied its impact on caregivers' mood and behavior. Compared to caregivers in the control group, those who received the behavioral intervention had significantly reduced depression, burden, and reactivity to care recipient behavior problems. Care-givers in the treatment condition also reported decreased frequency of targeted problem behaviors and overall improvement in quality of life of the care recipient. Results were maintained at 6-month follow-up. Dr. Logsdon and colleagues concluded that these results demonstrate that training community home health providers to deliver the Seattle Protocol behavioral intervention provides a practical approach to translating research-based AD caregiving tactics into usable clinical settings.

“Reducing Distress in Dementia Family Caregivers Through a Distance-Based Intervention,” a study presented by Dr. Steffen, examined the effectiveness of a distance-based intervention for female caregivers (ages 35 to 85) of dementia patients. Caregivers were randomly assigned to a 14-week telehealth intervention course or to a basic education course. The intervention course used videos, a workbook, and weekly telephone coaching sessions. The basic education course involved a caregiving manual and biweekly phone checkups. Caregivers who participated in the “telehealth” intervention demonstrated reduced stress shortly after the study completed. However, while positive results were maintained after 3 months, they were not maintained after 6 months. This study was originally funded by NIMH, and the current longitudinal phase is now funded by the Alzheimer’s Association.

These studies provide a range of strategies for providing dementia caregiver support. Noted AD caregiving expert Lisa Gwyther concluded that teaching caregivers communication skills and engaging psychiatric interventions are generally very successful. Gwyther also stressed that it is necessary to have a clinically meaningful outcome to each study that also entails a randomized control group. She commented that in order to make a translational research study successful, it must also be fundable and sustainable. For future caregiver intervention studies assessing effectiveness of specific strategies, she suggested that researchers adopt multicomponent interventions with various steps and frequent checkups from professionals. Studies must be flexible, Gwyther said, to adapt to the stressful nature of caregiving and deliver interventions based on individual caregivers' and patients' needs.

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### **New Staff at NIA**

The NIA's lead program for AD research—the Neuroscience and Neuropsychology of Aging (NNA) Program—recently welcomed three new health science administrators (HSAs). Each new staff member brings a wealth of scientific and administrative expertise to the NNA as the program continues to foster a variety of research programs exploring the normal course of aging in the neuronal system and the dementias of aging.

“We are delighted to welcome Nina Silverberg, Ph.D., Laurie Ryan, Ph.D., and Suzana Petanceska, Ph.D. They have impressive research experience and excellent science administration skills. We have truly strengthened our abilities to serve the scientific community and continue the quest to find the causes of age-related cognitive, motor, and sensory



decline and of dementias such as AD,” said Marcelle Morrison-Bogorad, Ph.D., Director, NNA.

As the Assistant Program Director for the Alzheimer’s Disease Centers (ADCs), Dr. Silverberg will be responsible for assisting Dr. Creighton (Tony) Phelps with the Centers. Specifically, she will be involved with cognitive assessment in normal aging and dementia, education cores, and minority outreach programs in the ADCs.



*From left, Nina Silverberg, Ph.D.,  
Laurie Ryan, Ph.D.,  
and Suzana Petanceska, Ph.D.*

Dr. Silverberg received her Ph.D. from the University of Arizona and was most recently a clinical research scientist at the Sun Health Research Institute (Arizona ADC). At the ADC, she was involved in grant development and extracting and analyzing data from the brain donation program database. Dr. Silverberg also coordinated the ADC’s American Indian outreach program. She was the principal investigator on a New Investigator Research Grant from the Alzheimer’s Association to assess the usefulness of culturally adjusted neuropsychological tools in an American Indian population. She worked closely with a neurologist and neuropsychologist in designing, carrying out, analyzing, and interpreting various investigations of AD, mild cognitive impairment (MCI), Parkinson’s disease, and normal aging.

Dr. Petanceska is a new HSA whose portfolio spans the Neurobiology of Aging and the Dementias of Aging branches at NNA. Her duties are to manage and develop a portfolio of grants addressing aspects of normal aging related to AD pathogenesis and to assist in developing the NNA’s translational initiatives.

Dr. Petanceska received her Ph.D. from the Sackler Institute for Graduate Biomedical Studies at New York University. Prior to coming to NNA, Dr. Petanceska was an Assistant Professor of Psychiatry and Pharmacology at the Nathan Kline Institute/New York University. She has extensive research experience in AD pathogenesis and has had a long-standing interest in AD therapeutics. Her most recent research focused on the role of disrupted sterol metabolism in the development of AD amyloidosis and the mechanisms by which estrogens and cholesterol-lowering drugs might exert neuroprotection.

Dr. Ryan will be involved in the AD clinical trials program, which includes managing current AD clinical trials and further developing the clinical trials program by identifying goals, research questions, and appropriate investigators. She will also be responsible for helping to stimulate research in the clinical trials portfolio, including pilot and large-scale clinical trials for AD treatment, modification of disease progression, and prevention.

Dr. Ryan received her Ph.D. in clinical psychology with specialty training in neuropsychology at Louisiana State University in Baton Rouge. Her professional interests as a neuro-psychologist center on the neurocognitive and behavioral manifestations of disorders affecting central nervous system function such as AD and traumatic brain injury. She was most recently the Assistant Director for Research and Senior

Neuropsychologist for the Defense and Veterans Brain Injury Center, Department of Neurology, at the Walter Reed Army Medical Center in Washington, DC, where she was responsible for overseeing clinical research development and implementation in particular clinical trials. Dr. Ryan has also served as an Assistant Professor of Neurology, Uniformed Services University of the Health Sciences in Bethesda, Maryland.

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### **Web redesigns, integration improve access**

Finding NIA health and Alzheimer's disease information and publications just got easier. The ADEAR website and the Health Information section on the NIA website have been substantially redesigned and moved to Federal web addresses. The new address for the ADEAR website is: [www.alzheimers.nia.nih.gov](http://www.alzheimers.nia.nih.gov); the new address to preview and order NIA publications is: [www.nia.nih.gov/HealthInformation](http://www.nia.nih.gov/HealthInformation).

Moving the websites and their online ordering systems to the new ".gov" addresses is in response to Federal guidelines aimed at creating more web portals to help users find and use information quickly. In addition, the Federal government wants users to be confident that they are accessing websites that are legitimate and accurate, updated consistently, and accessible to those with disabilities.

"The project also presented us with an opportunity to redesign and reorganize our web information and publications for both websites to enhance access and navigation. Repeat users will find improvements, and first-time visitors will be able to quickly locate key health information," said Vicky Cahan, Director, NIA Office of Communications and Public Liaison. Although the ADEAR website has always been maintained by the NIA (on a contractor's web server), the consolidation project also repositions the ADEAR website as part of NIA's unified series of web resources available to both the public and scientific community, says Cahan.

Each website continues to feature an online ordering system in which users can preview publications and place orders in a shopping cart to receive printed copies. Each also continues to offer a number of services, including e-mail alerts, contact with clearinghouse staff for help on AD and aging issues, comprehensive listings of current clinical trials, and links to literature, bibliographic, and resource databases.

The ADEAR website has been operating since 1995 and has won numerous awards. It currently attracts more than 2.5 million visitors annually with up-to-date, factual information on AD and related dementias.

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### **Alzheimer's Disease Neuroimaging Initiative Maya Angelou asks adults ages 55 - 90 to join study**

The Alzheimer's Disease Neuroimaging Initiative (ADNI)—a project developed by the National Institutes of Health (NIH)—is seeking 800 older



adults to participate in a study aimed at identifying biological markers of memory decline and AD. Ultimately, scientists hope that brain and biological changes can be detected before memory decline and other symptoms appear, allowing the effectiveness of drugs to be evaluated at the earliest possible time.

The \$60 million, 5-year ADNI study is the most comprehensive effort to date to identify brain and other biological changes associated with memory decline. The project was begun by NIA and is supported by more than a dozen other Federal agencies and private-sector companies and organizations. Investigators at 58 local study sites across the U.S. and Canada will be asking people ages 55 to 90 to become a part of this landmark research.

“We encourage people to participate in this important study because it will help us to identify needed biological markers of memory decline and Alzheimer’s disease. These biomarkers could become comparable to the cholesterol measures now used as biomarkers for heart disease,” says Susan Molchan, M.D., program director for the ADNI project at the NIA. “In addition, using what we learn from the brain scans and other tests, we hope to lessen the time and cost of testing drugs and to bring treatments to patients much sooner.”

Scientists are looking for new ways to measure changes in the brain that occur with normal aging and with the progression of mild cognitive impairment (MCI), a subtle but measurable transitional state between the cognitive changes of normal aging and very early AD. People with MCI have memory impairments but otherwise function well and do not meet clinical criteria for dementia.

The ADNI researchers will employ serial magnetic resonance imaging (MRI); positron emission tomography (PET) scans; measurement of various biological compounds in blood, cerebrospinal fluid, and urine; and clinical and neuropsychological assessments to track MCI and early AD progression. MRI and PET scans are used in both medical practice and research to produce images of the brain.

The study’s principal investigator (PI) is neuroimaging expert Michael W. Weiner, M.D., of the San Francisco Veterans Affairs Medical Center and the University of California, San Francisco. The Northern California Institute for Research and Education, a foundation affiliated with the U.S. Department of Veterans Affairs, has been awarded the multi-center ADNI grant.

Dr. Weiner explains that the 800 adults ages 55 to 90 sought for the study will be divided into three groups: approximately 200 cognitively normal older people will be followed for 3 years, 400 people with MCI will be followed for 3 years, and 200 people with early AD will be followed for 2 years. At the end of the study, the researchers will compare neuroimaging, biological, and clinical information from the participants, looking for correlations among the data to develop standards for tracking progression of memory decline.

A unique feature of the project is the development of an imaging and biomarker database that can be tapped by researchers in both the public

and private sectors as they develop and test drugs for memory decline.

A special aspect of the project is the support of Dr. Maya Angelou, the eminent poet, author, educator, and historian. Dr. Angelou, a professor at Wake Forest University in Winston-Salem, NC, is working with the researchers to ask the public to take part in the study through the national ADNI recruitment outreach campaign, "Imagine Stopping the Progression of Alzheimer's Disease," in which she will appear in radio and print public service announcements. She has a number of dear friends who have suffered the effects of AD.

ADNI is the largest public-private partnership on brain research underway at the NIH, part of the U.S. Department of Health and Human Services (DHHS). In addition to the NIA, the Federal ADNI partners are the National Institute of Biomedical Imaging and Bioengineering, also part of NIH, and the U.S. Food and Drug Administration, another DHHS agency.

Partnership with private-sector funders is managed through the not-for-profit Foundation for the NIH, established by the U.S. Congress to support NIH's mission by facilitating private-sector organizations' support of and involvement with NIH programs. Corporate and nonprofit participants are: Pfizer Inc; Wyeth Research; Bristol-Myers Squibb; Eli Lilly and Company; GlaxoSmithKline; Merck & Co., Inc.; AstraZeneca AB; Novartis Pharmaceuticals Corporation; Eisai Global Clinical Development; the Alzheimer's Association; Elan Corporation, plc; and the Institute for the Study of Aging.

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### **Popular NIA booklet now available!**



The NIA has updated its popular booklet, Talking with Your Doctor, A Guide for Older People. Many important doctor-patient communication topics are covered in this colorful, easy-to-read update, including choosing a doctor, getting ready for an appointment, asking the right questions, and discussing sensitive subjects. It can be ordered:

- on the NIA website at [www.nia.nih.gov/HealthInformation](http://www.nia.nih.gov/HealthInformation),
- by calling the NIA Information Center at 1-800-222-2225, or
- using the order form on the back page of the newsletter

### **Progress Report on Alzheimer's Disease 2004-2005 published**

The NIA is pleased to announce publication of the Progress Report on Alzheimer's Disease 2004-2005. This 80-page book offers an intriguing inside look at the latest AD research, and uses highly detailed, computer-

enhanced illustrations to help readers identify some of the more complex molecular aspects of normal aging and the AD process.

Topics discussed in the Progress Report include:

- the impact of AD on individuals and the Nation,
- the main characteristics of AD,
- research advances and discoveries,
- whether certain factors can protect against AD, and
- future research innovations.



A detailed discussion explains how scientists are making enormous progress in characterizing the disease process. New and exciting discoveries about how amyloid precursor protein is cleaved, the toxic effects of beta-amyloid, the role of presenilin, effects of AD on mitochondria, cell death, genetics, and inflammation are all described in this report. Highlights of research by a number of NIH Institutes are presented.

Copies are available by contacting the ADEAR Center at 1-800-438-4380 or by visiting the ADEAR website at [www.alzheimers.nia.nih.gov](http://www.alzheimers.nia.nih.gov). Both a PDF and the medical illustrations are also available for downloading from the website.

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### **New NIA booklet has tips for long-distance caregivers**

Approximately 7 million adults are long-distance caregivers, mostly caring for aging parents who live an hour or more away. Anyone, anywhere can be a long-distance caregiver. Many long-distance caregivers act as information coordinators, helping with home health, insurance benefits, medical care, and legal issues.



So Far Away, Twenty Questions for Long-Distance Caregivers, organized in a question-and-answer format, features some of the most commonly asked questions about long-distance caregiving and includes detailed information and tips about:

- how to know if help is needed,
- things to do to feel less frustrated,
- geriatric care managers,
- visiting with the doctor,
- home safety and AD,
- moving to long-term care,
- future health care preferences,
- advance directives and living wills,
- and dealing with a terminal illness.

Many helpful government and nonprofit organizations are listed as resources in the back of the booklet. So Far Away can be previewed and ordered on the NIA website at: [www.nia.nih.gov/HealthInformation](http://www.nia.nih.gov/HealthInformation). You

can also order copies by:

- calling the NIA Information Center at 1-800-222-2225, or
- using the order form on the back page of the newsletter.

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## CHID Highlights

CHID Highlights describes materials recently added to the Alzheimer's disease file of the Combined Health Information Database (CHID). 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. CHID is accessible on the Internet at [www.chid.nih.gov](http://www.chid.nih.gov), by following the link at [www.alzheimers.nia.nih.gov](http://www.alzheimers.nia.nih.gov) or by following the National Library of Medicine's link to CHID at [www.nlm.nih.gov/medlineplus/databases.html](http://www.nlm.nih.gov/medlineplus/databases.html).

## Behavior Management

*Caring for People With Challenging Behaviors: Essential Skills and Successful Strategies in Long-Term Care. 2005*

Long, S.W.

Available from Health Professions Press, P.O. Box 10624, Baltimore, MD 21285-0624. Phone: 1-888- 337-8808 or 410-337-9585; Fax: (410) 337-8539. Website: [www.healthpropress.com](http://www.healthpropress.com). PRICE: \$32.95.

This book helps professional caregivers find effective ways to prevent, reduce, or eliminate the disruptive behaviors of residents in long-term care settings. Using vignettes of readily recognizable resident types, including those with dementia and mental disorders, this guidebook helps staff understand what triggers and reinforces challenging behaviors. Solutions are derived by identifying the "ABCs" of behavior (antecedents, behaviors, and consequences), and using practical communication techniques and other effective psychological approaches to encourage positive behavior. The book includes advice to help staff recognize and manage on-the-job stressors; avoid common intervention mistakes; respond to obstacles to effective intervention; promote teamwork and improve interpersonal relations; set and execute realistic, achievable goals in treatment planning; and encourage residents' autonomy. Written in easy-to-understand language, the book can be used as a self-help tool, a curriculum for in-services, or a training guide for students. It includes numerous handouts and displays, exercises, blank forms, bibliography, and an index.

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## Staff Dementia Training

*Copper Ridge Institute Dementia Care Certification Course. 2005*

Available from Lippincott Williams and Wilkins, 351 West Camden Street, Baltimore, MD 21201. Phone: 1-800-399-3110. Website: [www.lww.com](http://www.lww.com).

PRICE: \$199 for one work station. \$399 for multi-set.

Copper Ridge Institute is a nursing home and assisted living facility affiliated with the Johns Hopkins School of Medicine (an NIA-funded Alzheimer's Disease Center). Staff have developed this Dementia Care Certification Course, which instructs caregivers and clinical workers on the most appropriate ways to treat people and patients with dementia. The accompanying CD-ROM uses video clips, photos, and narration to demonstrate key points and review material. The module uses real-life scenarios to show caregivers and experts what to expect when working with someone with dementia and the best strategies to deal with these issues. Helpful quizzes follow each module to test comprehension of the information provided. The modules include these topics:

- normal aging and dementia,
- dementia explained,
- approaches to dementia care,
- daily activities,
- managing behavior problems,
- types of behavior problems, and
- medications.

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### **Lewy Body Disease**

*Lewy Body Disease: LBD*

Available from the Lewy Body Dementia Association, Inc., P.O. Box 11390, Tempe, AZ 85284. Phone: 1-800-539-9767; Fax: 480-422-5434, Website: [www.lewybodydementia.org/services.php](http://www.lewybodydementia.org/services.php). PRICE: Free

Published by the Lewy Body Dementia Association, this comprehensive pamphlet gives an overview of Lewy body dementia, also known as dementia with Lewy bodies (DLB), Lewy Body Disease, Diffuse Lewy Body Disease (DLBD), or Cortical Lewy Body Disease (CLBD). A progressive brain disorder, LBD is a leading causes of degenerative dementia in older people, who are at the greatest risk for diagnosis. Topics included in the brochure include the history of the disease, the prognosis of LBD and various associated risk factors , including advanced age, genetics, and gender. The brochure also discusses in detail the diagnosis of LBD and the symptoms linked with the disease. Various medications and treatments are suggested as well.

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### **Reminiscing Strategies**

*Past in the Present: Using Reminiscence in Health and Social Care. 2004*

Gibson, F.

Available from the Health Professions Press, P.O. Box 10624, Baltimore, MD 21285. Phone: 1-888-337-8808; FAX: 410-337-8539. Website: [www.healthpropress.com](http://www.healthpropress.com). PRICE: \$32.95.

Written by a professor of social work, Past in the Present discusses the health benefits and well-being gained through reminiscing. The author

states that reminiscing can help people find meaning in their lives with positive health effects. This book contains reproducible forms and charts, case studies, a historical U.S. timeline, and an international resource list. These and additional tools can help case workers and clinicians work with older patients using both formal and informal methods of reminiscing in group and individual sessions. Divided into three main sections, (1) Reminiscence Theory and Values, (2) Reminiscence Practice, and (3) Reminiscence in Dementia Care, the book discusses using a variety of reminiscence techniques.

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### **Improving Minority Research**

*Alzheimer's Disease and Communities of Color. 2004 (in Closing the Gap: Improving the Health of Minority Elders in the New Millennium, edited by Keith Whitfield, Ph.D.)*  
 Allery, A.J. et al.

Available from the Gerontology Society of America, 1030 15th Street, N.W., Suite 250, Washington, DC 20005. Phone: 202-842-1275. Website: [www.geron.org/gap.htm](http://www.geron.org/gap.htm). PRICE: \$20.

This book from the Gerontology Society of America discusses health disparities among older minorities in a scientific and straightforward way, citing numerous studies and hundreds of references. Chapters include discussions ranging from the diversity of older people in the new millennium to the access and quality of sufficient health care for various racial and ethnic groups. Older minority populations that are specifically identified include Asian Americans, Native Hawaiians, Pacific Islanders, African Americans and American Indians. Chapter 7, in particular, discusses Alzheimer's disease and communities of color. It reviews general information about AD's history and genetic makeup and then addresses the importance of participation of various racial and ethnic groups in studies. The book makes a case for increasing diversity in AD research, stating that the Caucasian middle-class, which dominates most of the participation in AD research today, does not represent all populations at risk. Four major studies funded by the Alzheimer's Association are highlighted.

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### **Preparing Directives**

*About Preparing Your Advance Medical Directives. 2005*

Available from Channing Bete Company. One Community Place, South Deerfield, MA 01373-0200. Phone: 1-800-628-7733; Fax: 1-800-499-6464. Website: [www.channing-bete.com](http://www.channing-bete.com). PRICE: \$1.15 each for 1-99 copies; \$.89 each for 100-499 copies.

This easy-to-read, illustrated booklet explains how to make your health care wishes known through an advance directive and how such a document can protect you, your family, and physicians. An advance medical directive can protect your right to accept or refuse medical treatment if you ever become unable to choose or communicate your wishes due to illness such as dementia or injury. This booklet explains the two types of advance directives: the living will, and the durable power of attorney for health care. The booklet:



- outlines the steps involved,
  - highlights some special issues to consider,
  - answers commonly asked questions, and
  - provides a checklist to help you prepare an advance directive.
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## **Elder Law Attorneys**

*Questions and Answers When Looking for an Elder Law Attorney. 2005*

Available from the National Academy of Elder Law Attorneys, Inc. 1604 North Country Club Road, Tucson, AZ 85716. Phone: 520-881-4005; Fax: 520-325-7925. Website: [www.naela.org/public/index.htm](http://www.naela.org/public/index.htm). PRICE: Free

Elder law attorneys assist senior clients in planning for possible long-term care, including nursing home care, financial and estate planning, guardianships, and other issues relevant to the needs of AD patients and their families. This brochure provides information about elder law and what it covers, and provides tips for finding an elder law attorney, what to do after selecting such an attorney, the discussion of fees, and establishing a contract.

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## **Ethics of Palliative Care**

*Ethical Foundations of Palliative Care for Alzheimer Disease. 2004*

Purtilo, R.B., ed.; Ten Have, H.A., ed.

Available from The John Hopkins University Press, 2715 North Charles Street, Baltimore, MD 21218-4363. Phone: 1-800-537-5487; Fax: 410-516-6968. Website: [www.press.jhu.edu](http://www.press.jhu.edu). PRICE: \$49.95.

This book explores the ethical, policy, and practice issues of palliative care for people with AD or dementia who are near the end of life. Starting with an overview of health care and larger societal challenges related to the diagnosis and prognosis of AD, the book includes descriptions of palliative care as it is administered worldwide. Key philosophical and theological concerns that are central to understanding AD are discussed, along with the clinical ethics issues in end-of-life and palliative care decision-making. The book explores both the need to prepare families and health professionals for the challenges presented by AD, and the need to base allocation decisions for AD on sound ethical principles and practical realities. The book concludes with a look at the ethical aspects of biomedical research involving AD patients and their families.

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## **Calendar of Events**

**March 13, 2006**

Brain Awareness Week 2006

Contact:

Brain Awareness Week Campaign Clearinghouse  
The Dana Foundation  
745 Fifth Avenue, Suite 900  
New York, NY 10151  
Telephone: 212-401-1680  
Fax: 212-593-7623  
E-mail: [bawinfo@dana.org](mailto:bawinfo@dana.org)  
Website: [www.dana.org/brainweek](http://www.dana.org/brainweek)

**March 16, 2006**

2006 Joint Conference of the National Council on the Aging and the American Society on Aging, Anaheim, CA  
Contact:  
American Society on Aging  
833 Market Street, Suite 511  
San Francisco, CA 94103-1824  
Telephone: 415-974-9600  
Fax: 415-974-0300  
E-mail: [jc06@asaging.org](mailto:jc06@asaging.org)  
Website: [www.agingconference.org](http://www.agingconference.org)

**April 1, 2006**

Annual American Academy of Neurology Meeting, San Diego, CA  
Contact:  
AAN Member Services  
Telephone: 1-800-879-1960  
E-mail: [membership@aan.com](mailto:membership@aan.com)  
Website: <http://am.aan.com>

**April 5, 2006**

Teleconference: Pain Management at the End of Life: Bridging the Gap Between Knowledge and Practice  
Contact:  
Hospice Foundation of America  
Telephone: 1-800-854-3402  
Website: [www.hospicefoundation.org](http://www.hospicefoundation.org)

**April 27-28, 2006**

20th Annual Joseph and Kathleen Bryan Alzheimer's Disease Research Center Conference, Durham, NC  
Contact:  
Center for the Study of Aging and Human Development  
Duke University  
3600 DUMC  
Durham, NC 27710  
Telephone: 1-800-672-4213 or 919-660-7510  
Fax: 919-684-8569  
Websites: [www.dukefamilysupport.org](http://www.dukefamilysupport.org)  
<http://adrc.mc.duke.edu/news.html>

**April 19, 2006**

9th International Geneva/Springfield Symposium on Advances in Alzheimer Therapy, Geneva, Switzerland  
Contact:  
Ann Hamilton  
Southern Illinois University School of Medicine  
P.O. Box 19602  
Springfield, Illinois 62794-9602

Telephone: 217-545-7711  
Fax: 217-545-4413  
E-mail: [ahamilton@siumed.edu](mailto:ahamilton@siumed.edu)

**April 22, 2006**

Train the Trainers, Washington, DC

Contact:

National Council of Certified Dementia Practitioners

Telephone: 1-877-729-5191

E-mail: [nationalccdp@aol.com](mailto:nationalccdp@aol.com)

Website: [www.nccdp.org](http://www.nccdp.org)

Other seminar dates/locations:

October 7, 2006 - Orlando, FL

June 24, 2006 - St. Louis, MO

**April 28, 2006**

University of California, San Diego ADRC Annual Conference:  
Epidemiology of Alzheimer's Disease, San Diego, CA

Contact:

Office of Continuing Medical Education

University of California, San Diego

School of Medicine

9500 Gilman Drive

La Jolla, CA 92093-0617

Telephone: 1-888-229- 6263

Fax: 858-534-7672

E-mail: [ocme@ucsd.edu](mailto:ocme@ucsd.edu)

Website: <http://cme.ucsd.edu>

**May 12, 2006**

3rd Annual Alzheimer's Disease and Dementia Update Conference,  
Phoenix, AZ

Contact:

Minnie Jim

Native American Outreach Coordinator

Sun Health Research Institute

10515 W. Santa Fe Drive

Sun City, AZ 85351

Telephone: 623-875-6524

E-mail: [minnie.jim@sunhealth.org](mailto:minnie.jim@sunhealth.org)

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