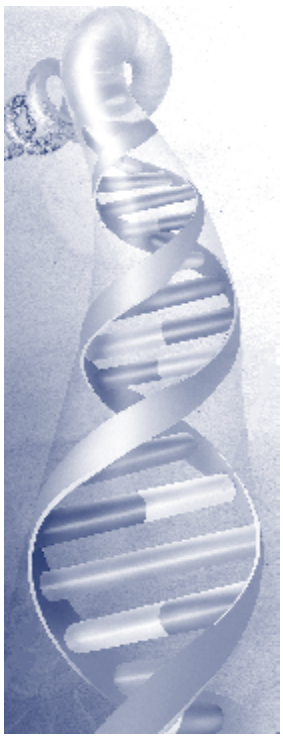
CONNECTIONS

NIA Expands Genetics Research

Families with Multiple AD Cases Sought



The National Institute on Aging (NIA) is accelerating the pace of Alzheimer's disease genetics research with a major new initiative to speed the process of creating a large repository of DNA and cell lines from families with multiple AD cases. The NIA's AD Genetics Initiative will intensify sample collection and encourage data sharing by providing access to the repository to qualified investigators. This new initiative is the result of a series of recommendations made by a team of AD geneticists during a spring 2002 workshop, to speed discovery of risk factor genes that may contribute to late-onset AD. Discovery of these genes is essential for understanding the causes of late-onset AD and for developing appropriate treatments and prevention strategies.

One Late-Onset Risk Factor Gene

Late-onset AD is the most common form of the disease, accounting for 90–95 percent of all cases. It usually strikes people 65 years of age and older. Late-onset AD shows no obvious inheritance pattern. However, researchers have identified an increased risk of developing late-onset AD related to the apolipoprotein E (apoE) gene found on chromosome 19. This gene comes in several different forms, or alleles, but three occur most frequently: apoE2 (E2), apoE3 (E3), and apoE4 (E4).

People inherit one apoE allele from each parent.

(Continued on page 2)

Unraveling the Mystery Better Than Ever!

An updated version of one of the ADEAR Center's most popular free publications, *Alzheimer's Disease: Unraveling the Mystery* is now available. With detailed color illustrations and a companion CD-ROM, *Unraveling the Mystery* is a concise and readable description of recent research advances and how the brain changes as the disease progresses.

Take a "Walking Tour"

Special fold-out sections take the reader on a "walking tour of the brain." Medical illustrations and PET scan images provide comprehensive background information on how and where the disease causes destruction. Illustrations include:

- neurons at work
- formation of beta amyloid plaques
- formation of *tau* tangles
- genetics and oxidative damage
- brain shrinkage and damage as the disease progresses to its end stages

Unraveling the Mystery goes on to describe current thinking on possible causes of AD, recent findings on genetics, cardiovascular risk factors, oxidative stress, brain inflammation,

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News From the ADEAR Center
Alzheimer's Disease Education and Referral Center
A Service of the National Institute on Aging
National Institutes of Health
U.S. Department of Health and Human Services

Genetics Initiative

(from page 1)

Having one or two copies of the E4 allele increases a person's risk of getting AD, but it does not mean that AD is certain. Some people with two copies of the E4 allele (the highest risk group) do not develop the disease, and others with no E4s do. The rarer E2 allele appears to be associated with a lower risk of AD. The E3 allele is the most common form found in the general population and may play a neutral role in AD. Scientists cannot determine the exact degree of risk of AD for any given person based on their apoE status.

Early-Onset Genes

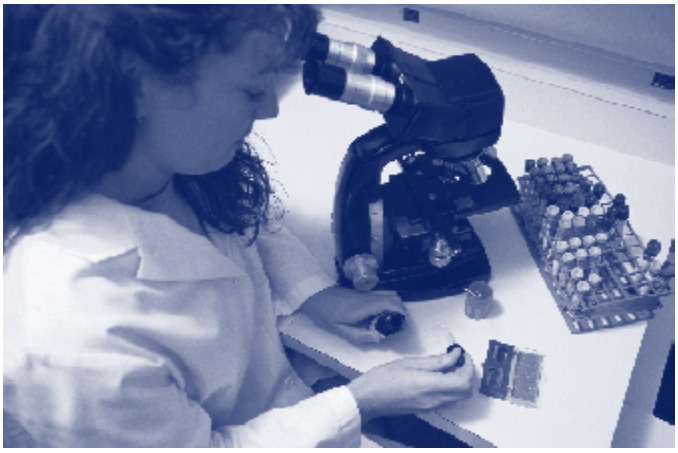
Early-onset AD, or familial AD, is much rarer and has been conclusively linked to mutations in three genes – the APP gene on chromosome 21, the PS1 gene on chromosome 14, and PS2 on chromosome 1. If only one mutation on one of these genes is present, early-onset AD will almost certainly occur. Early-onset AD is the result of an autosomal dominant inheritance pattern, meaning that all offspring in the same generation have a 50/50 chance of developing AD if one of their parents had the genetic mutation. Early-onset AD strikes people as young as age 30.

Late-Onset Gene Search

Scientists have made great progress in the 10 years since apoE4 was identified as a risk factor gene, in narrowing the search for other risk factor genes that may have links to late-onset AD. They have drawn significantly closer to identifying at least four regions of chromosomes where other risk factor genes might be. Intriguing evidence has been uncovered during recent studies, but further analysis of larger sample sets is needed.

Genetics Experts Meet

Recognizing that much larger sets of AD samples is key to continuing the progress made to date and speeding up late-onset AD genetics research, science administrators in the NIA's Neuroscience and Neuropsychology of Aging Program (NNA) brought together leading experts for a workshop. Their discussions centered on how to expand DNA sample collection, standardize data collection, improve access to that data for funded and commercial researchers, and how to rapidly share data to identify and corroborate new risk factor genes.



Workshop participants agreed that an important component of the NIA's genetics initiative will be a new emphasis on recruiting large families with two or (preferably) more members – known as multiplex families – who have late-onset AD. Collecting blood samples from affected and unaffected family members, to create and maintain cell lines for DNA analysis will aid in the hunt for new genes. This will allow researchers to spend more time on experiments, and less time on the expensive and arduous task of collecting appropriate samples.

"If the search for risk factor genes is successful, then there are broad implications for future treatments and therapies."

"This is extremely important research and we are very pleased to be in a position to recruit subjects to organize sample collection, and to offer well-characterized samples to many of the world's leading AD genetics experts. If the search for risk factor genes is successful, then there are broad implications for future treatments," said Dr. Richard Hodes, NIA Director.

National Cell Repository

A centralized repository at Indiana University – the National Cell Repository for AD (NCRAD) – is expanding its collection facilities as part of this new initiative. Ten Alzheimer's Disease Centers (ADCs) have been provided with supplemental funding to recruit new individuals for genetics research and deposit their blood samples with NCRAD. NIA hopes to gather between 1,000 and 2,000 samples for study.

NCRAD has been banking DNA and cells and building a database of family histories and medical records for qualified researchers since 1989. The Repository was established to provide genetic researchers with cell lines and/or DNA samples from people with well-documented AD and from controls. Many researchers working to identify genetic defects associated with AD have used genetic material stored in the Repository.

Because supplies of DNA are finite and cannot be regenerated, NCRAD makes "immortalized" cell lines – cells continuously regenerated in the laboratory from the blood samples – in order to provide samples for the exhaustive studies needed to identify risk factor genes. NNA Associate Director Marcelle Morrison-Bogorad, PhD, commented, "The process of identifying these risk factor genes is incredibly complicated and time consuming.

(Continued next page)

This new initiative on genetics research has great potential to revolutionize early diagnosis and target better drug treatments. It is an important component of the NIA's AD research efforts."

National Case/Control Samples Set

In 2003, AD genetics researchers are planning a national case-control sample set, in which the genes of individuals with AD (case) are compared to those who have no symptoms of the disease (control). Workshop participants arrived at consensus that creating such a sample set, against which potential candidates for risk factor genes for late-onset AD can be evaluated, is also essential.

Population Studies also Useful

Existing population-based datasets, such as the Framingham study, the Honolulu Heart study, the Nurses study, and the Baltimore Longitudinal Study of Aging, could also help scientists evaluate gene-environment interactions. In addition, researchers have access to the valuable AD genetics database maintained by the National Institute of Mental Health.

New Data Sharing Policy

To enhance diversity of analysis, promote new research, and permit creation of new datasets from previously collected data, the National Institutes of Health is adopting a scientific data sharing policy. This policy encourages a freer flow of information among NIH-supported researchers and will help in exchange of information. Further information on the draft policy can be found at: http://grants.nih.gov/grants/policy/data_sharing/index.htm.

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Genes and Their Functions

A gene provides the code, or blueprint, for the type and order of amino acids needed to build a specific protein. Everything in the body is made up of proteins. Bones and teeth, muscles and blood, for example, are formed from different proteins. Genes direct almost every aspect of the construction, operation, and repair of all living things. For example, genes carry information that determines eye and hair color and other traits inherited from our parents. Genes also ensure that we have two hands and can use them to do things, like play the piano.

A healthy body depends on the proper interaction of thousands of proteins (as well as other molecules such as lipids and carbohydrates), in just the right place, and in just the right amount. Malfunctions in proteins are sometimes caused by an alteration, or mutation, in the gene that directs the creation of the protein. As many as 5,000 diseases, such as early-onset Alzheimer's disease, cystic fibrosis, Huntington disease, and sickle cell anemia, are believed to result from mutated genes inherited from either biological parent.

Human cells usually contain 46 chromosomes, which are individual strands of deoxyribonucleic acid (DNA), 23-from each parent. A chromosome is a threadlike structure which can carry hundreds, sometimes thousands, of genes. The number of genes in human beings is still not known, but is probably between 30,000 and 100,000.

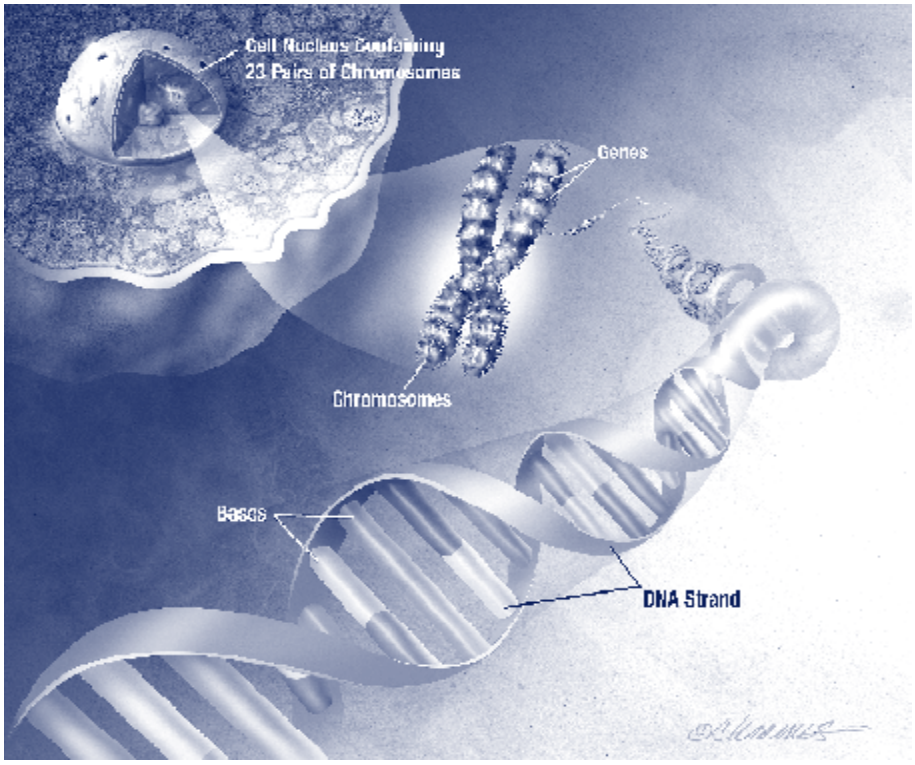


Illustration from *Alzheimer's Disease: Unraveling the Mystery.* Illustrator: Christy Krames

DNA consists of chemical bases called nucleotides. Each nucleotide contains one chemical base, one phosphate molecule, and the sugar molecule deoxyribose. Each strand of DNA is made up of millions of sequences of nucleotides.

The bases in DNA nucleotides are

(Continued at bottom of next page)

Informed Consent in Genetic Research

Genetic research is often the only way scientists can pin down the root causes of a disease, but genetic research also presents unique problems for obtaining informed consent. Informed consent is the process by which a fully informed patient or research subject can make choices related to participation in health care and/or medical research. In genetics research, benefits and risks of the research may affect the individual, his/her family, or the community in which the individual lives. Therefore, potential research participants should be given sufficient information about the implications and limitations of the research to allow them to make an informed choice of whether to participate or not. Using plain language they understand, they should be told the purpose of the research, procedures to be used, possible outcomes, potential benefits to the participants and others, any discomfort expected from participation, how the resulting information will be communicated, and how confidentiality will be maintained. Subjects should be informed about the collection and disposition of blood and tissue samples, storage of data and samples, sharing with other investigators, and potential commercial implications. For genetics research there are risks that disclosure of results could influence life choices, affecting the individual directly, disrupting family dynamics and leading to social stigmatization and possible discrimination that may influence insurability. Therefore, protection from disclosure is very important and "firewalls" should be established to guard against disclosure. These procedures should be outlined during the consent process. Since participation in research is voluntary, subjects should be given the opportunity to withdraw at any time.

Samples From Minority Populations

Of particular interest to genetics researchers is the collection of samples from ethnic/minority populations and other special populations, including African Americans, the Amish, Hispanics, Asians, Japanese-Americans, and Africans. NIA staff plan to develop community outreach programs and collaborate with institutions and investigators who have close ties to minority communities, professional societies and institutions.

Dr. Richard Mayeux, Co-Director, Columbia University ADC, has investigated AD genetic risk factors in specific populations in New York and the Caribbean and has been appointed as the Genetics Initiative Study Coordinator. He commented, "We're very pleased by the extent to which NIA is supporting genetics research. We're looking forward to working with the ADCs and the Alzheimer's Association to educate the public on the value of participating in sample collection. We hope that people with AD will want to share their blood and data to help in the search for causes, treatment, and prevention."

Families interested in participating can contact the National Cell Repository for Alzheimer's Disease at 1-800-526-2839 or 1-317-274-7360. Jamalynne Stuck, MS, is the Genetic Counselor and Research Coordinator, and she can be reached via e-mail at jastuck@iupui.edu. Their Internet address is http://medgen.iupui.edu/research/alzheimer/.

Genes and Their Functions

(from previous page)

adenine, thymine, guanine, and cytosine, hence the letter sequence A, T, G, C. The order – combinations and repeats – in which these bases occur determines the genetic code that directs the construction of a specific protein. A single misspelling in a sequence can cause a hereditary disease. Changes in a person's DNA can also occur during his/her lifetime, through mistakes in cell division, or influences of environmental toxins or radiation, as well as by inheriting the change from one or both parents.

The search to identify the genes that may be linked to late-onset AD will present many challenges. Long stretches of DNA strands appear to have no function, at least as far as scientists can tell presently. Some genes only have a particular function at a particular time of a person's life. The only known risk factor gene for late-onset AD is a form (allele) of the apolipoproteinE (apoE) gene. Scientists are studying several regions in chromosomes that have shown potential for links to late-onset AD, but they will need many more DNA samples to achieve positive identification.

The potential benefits of finding these other AD risk factor genes are numerous. They will aid in diagnosis, prognosis, prevention, and targeted drug treatments.

Until more is known about late-onset AD, both the NIA and the Alzheimer's Association support apoE testing for diagnostic purposes only in conjunction with other tests to evaluate people who have symptoms of AD. People who learn that they have an increased risk of AD may experience emotional distress and depression about the future because there is not yet an effective way to prevent or cure the disease.

Unraveling the Mystery

(from page 1)

advances in diagnosis, and the search for new treatments. The book also features a section on participating in clinical trials and improving support for caregivers. A glossary provides definitions of words key to understanding the basic science involved in AD. Finally, a list of reading materials for further information is provided, along with a list of organizations that provide help.

While this new version of *Unraveling the Mystery* was in development, staff at the NIA also decided to update an older version of an animation showing the progression of AD. Simultaneous completion of both projects allowed a copy of this helpful animation to be placed on a CD-ROM found in the book's back page pocket. The CD-ROM also contains:

- text files of the book
- high and low resolution copies of the various illustrations found in the book
- a PDF (Portable Document File) copy of the book
- contact information for the ADEAR Center

Anyone interested in understanding AD and current research will find *Unraveling the Mystery* useful. Educators can use the booklet as a teaching guide to present complex science in an approachable way. Health care professionals will find it is a good source for families to learn more about AD (along with the many other publications offered by ADEAR such as the *Caregiver Guide* and *Home Safety for People with AD*). Support group organizers may want copies of the book to use as handouts.

To order *Alzheimer's Disease: Unraveling the Mystery,* use the form on the back of the newsletter or call ADEAR toll-free at 1-800-438-4380. *Unraveling the Mystery* is available in both PDF and HTML versions at www.alzheimers.org/unraveling/index.htm.

New Alzheimer's Association CEO Welcomed

The Alzheimer's Association has named long-term care advocate Sheldon Goldberg president and Chief Executive Officer. Goldberg, 55, joined the association Dec. 1, 2002. Goldberg assumed the position held on an interim basis by Stephen McConnell, who has served the Association for the past 13 years in a variety of roles, most notably as its Vice President for public policy in the Association's Washington, DC, office.

Goldberg, who most recently was President and CEO of the Jewish Home and Hospital in New York has a 30-year career in association leadership and healthcare management. A psychologist by training, Goldberg's expertise includes business, advocacy, fund-raising and management in large, urban, multi-site settings.

"Sheldon Goldberg is an exceptionally dynamic, innovative, charismatic and visionary leader who is passionate about the potential of the Alzheimer's Association," said Orien Reid, chair, Alzheimer's Association's national board of directors, in an Association press release. "He believes consensus is built when all parties are beneficiaries, and he recognizes that it takes creativity to find as many win-wins as possible."

"Working together, the NIA and the Association have made great strides in research and assisting caregivers. We look forward to continuing our strong relationship with the Association and welcome Mr. Goldberg to his new position," said NIA Director Dr. Richard Hodes.

Through its national network of chapters, the Association offers programs and services for people with the disease, their families, and caregivers. The Association has committed $136 million toward research into the disease.

NIA Down Syndrome Study Gets Underway

The first ever large-scale study of the effects of vitamin E on rate of cognitive decline in older people with Down syndrome is now underway. The NIA-sponsored Multi-Center Trial of Vitamin E in Aging Persons with Down Syndrome plans to enroll 400 people with Down syndrome age 50 or older at approximately 25 trial sites.

It is well-known that people with Down syndrome are vulnerable to Alzheimer's disease, with symptoms of dementia evident after age 50. Almost all people with Down syndrome who die after age 40 show the characteristic brain lesions of AD at autopsy.

The goal of this 3-year trial is to determine whether the administration of vitamin E, which has been shown to delay the progression of AD, will slow the rate of cognitive/functional decline in older people with Down syndrome. A vitamin E regimen (1,000 international units twice daily, plus a multivitamin) will be compared to a multivitamin alone in a two-arm parallel group design.

Individuals with Down syndrome 50 years of age or older, with or without a diagnosis of Alzheimer disease, will be eligible for enrollment. The treatment period is 3 years, with study visits at 6-month intervals. The primary outcome measure is a measure of cognitive functions expressed as performance of simple, short sequences of voluntary movements.

This trial will serve as a model for future efforts at applying treatments developed for sporadic Alzheimer disease to the population of at-risk people with Down syndrome.

For more information please visit www.alzheimers.org/trials/index.htm or contact the Principal Investigator, Arthur J. Dalton, Ph.D., Center for Aging Studies, 1050 Forest Hill Road, Staten Island, New York 10314, telephone: 718-494-5309.

ADCS Kicks Off Homocysteine Trial

Following up on a growing body of evidence linking high levels of the amino acid homocysteine with increased incidence of Alzheimer's disease, the Alzheimer's Disease Cooperative Study (ADCS) has initiated new research to determine whether high-dose vitamins to reduce homocysteine levels may slow the progression of AD.

Widely reported earlier in 2002, an NIA-sponsored study by Phillip A. Wolf, MD, and colleagues at Boston University found that people with elevated levels of homocysteine in the blood had nearly double the risk of developing AD. The findings, in a group of people participating in the long-running Framingham Study, were the first to tie homocysteine levels measured several years before with later diagnosis of AD and other dementias.

Higher-than-normal levels of homocysteine have also been identified in other studies as risk factors for heart disease, blood clots, and hardening of the arteries.

Scientists still do not know how elevated homocysteine contributes to the development of AD. However, we do know that high doses of folate and vitamins B_6 and B_{12} act to lower its levels in the blood.

The ADCS study, dubbed "VITAL" (VITamins to slow ALzheimer's), seeks to discover whether lowering homocysteine with high-dose supplements of folate, B_6, and B_{12} will slow cognitive decline in people with AD. Paul Aisen, MD, of Georgetown University will direct the study.

Approximately 40 sites will enroll a total of 400 volunteers age 55 or older with mild to moderate AD for this 18-month trial. Researchers plan to randomize 60 percent of participants into the active treatment group and 40 percent into the placebo group. Previous studies have shown that people are more willing to volunteer if their chances of being in the active treatment group are greater.

CLASP, TAP/DAP Studies Underway

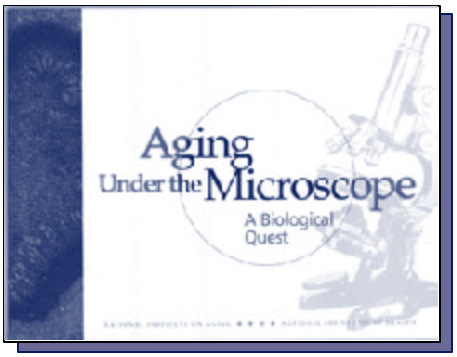
Two other ADCS-coordinated studies, CLASP (Cholesterol Lowering Agent to Slow Progression of AD) and TAP/DAP (Treatment of Agitation/Psychosis in Dementia and Parkinsonism) continue to recruit participants.

▼ CLASP, which will determine the effectiveness of the statin simvastatin (Zocor) in slowing AD, seeks 400 volunteers age 50 or older with mild to moderate AD and not requiring lipid-lowering treatment according to current public health guidelines. More than 40 sites nationwide are conducting the 2-year study.

▼ TAP/DAP is a 10-week study to test the safety, effectiveness, and influence on parkinsonism of quetiapine (Seroquel) and donepezil (Aricept), used separately and in combination. Twenty sites are seeking volunteers age 50 or older with all of the following: primary dementia (AD or dementia with Lewy bodies); psychosis or agitation; and parkinsonism or extrapyramidal motor features.

The NIA-funded Alzheimer's Disease Cooperative Study (ADCS), based at the University of California, San Diego, is leading these and other upcoming major clinical trials to investigate mechanisms for potentially slowing or preventing Alzheimer's disease.

Interested in volunteering?
Want more information?
Call the ADEAR Center at 1-800-438-4380 or visit our online clinical trials database at www.alzheimers.org/trials.



NIA Introduces Aging Under the Microscope

Why do we age? Why do cells die? Is aging programmed into our biological clock? Is aging the gradual and inevitable result of wear and tear, gene mutations, or environmental stress?

A new publication from the National Institute on Aging called *Aging Under the Microscope* offers discussions of current scientific theories on aging. *Aging Under the Microscope* explores fundamentals of the aging process, presenting the latest genetic, biochemical, and physiological research. Topics include:

- Longevity genes
- Oxygen radicals and antioxidants
- Hormones and hormone replacement
- DNA repair and synthesis
- The immune system and normal aging
- Caloric restriction
- Normal aging
- Role of exercise
- Stem cell research in aging

To order your copy of *Aging Under the Microscope*, call the National Institute on Aging's Information Center at 1-800-222-2225 or 1-800-222-4225 (TTY), e-mail the Information Center at niaic@jbs1.com, or use the order form on the back of the newsletter.

Training Improves Cognitive Abilities of Older Adults

Training sessions for 2 hours a week for 5 weeks improved the memory, concentration, and problem solving skills of healthy independent adults 65 years and older who participated in the nation's largest study of cognitive training. The training not only improved participants' cognitive abilities, but the improvement persisted for 2 years after the training, according to initial findings from the multi-site trial of Advanced Cognitive Training for Independent and Vital Elderly, or ACTIVE.*

"The trial was highly successful in showing that we can, at least in the laboratory, improve certain thinking and reasoning abilities in older people," says Richard M. Suzman, Ph.D., Associate Director for the Behavioral and Social Research Program at the NIA. "The findings here were powerful and very specific. Although they did not appear to make any real change in the actual, daily activities of the participants, I think we can build on these results to see how training ultimately might be applied to tasks that older people do everyday, such as using medication or handling finances. This intervention research, aimed at helping healthy older people maintain cognitive status as they age, is an increasingly high priority."

The study, published in the November 13, 2002, issue of the *Journal of the American Medical Association,* was funded by the NIA and the National Institute of Nursing Research (NINR).

According to Dr. Patricia A. Grady, Director of the NINR, "The ACTIVE trial provides encouraging preliminary findings that we may be able to conserve or improve some cognitive abilities in older adults not currently having problems in these areas. How this training may affect those who later experience cognitive deficits is a tantalizing question waiting to be answered."

The study looked at several types of cognitive training and then assessed, in the laboratory and in "real world" measures, whether the training was effective. At the outset, certified trainers conducted 10 sessions of 60 to 75 minutes over a 5- to 6-week period. The 2,802 participants were divided into four groups — three groups received either memory training, reasoning training, or speed of processing training, and a fourth group received no training. The three types of training were chosen because they showed the most promise in small laboratory studies and were related to tasks of daily living such as telephone use, shopping, food preparation, housekeeping, laundry, transportation, medication use, and personal finances. For all three groups, the training focused on developing strategies as well as providing exercises using these new strategies. All participants were assessed prior to training, immediately after training, and again 1 and 2 years later.

"... training focused on the ability to identify and locate visual information quickly for use in tasks such as looking up a phone number, finding information on medicine bottles, and responding appropriately to traffic signs."

Those in the memory-training group were taught strategies for remembering word lists and sequences of items, text material, and main ideas and details of stories. Participants in the reasoning group were taught how to solve problems that follow patterns. Such strategies can be used in tasks such as reading a bus schedule or filling out an order sheet. Speed of processing training focused on the ability to identify and locate visual information quickly for use in tasks such as looking up a phone number, finding information on medicine bottles, and responding appropriately to traffic signs.

Immediately following the 5-week training period, 87 percent of participants in speed training, 74 percent of participants in reasoning training, and 26 percent of participants in memory training demonstrated reliable improvement on their respective cognitive ability. The training effects continued through 24 months, particularly for the participants who received "booster" training. "The improvements in memory, problem solving, and concentration following training were sizeable," noted Karlene Ball, Ph.D., of the University of Alabama at Birmingham, the study's corresponding author. "These roughly counteract the degree of cognitive decline that we would expect to see over a 7- to 14-year period among older people without dementia."

The analysis did not find, however, that participants' improvements in thinking and reasoning also improved their ability to perform everyday tasks like preparing food or handling medications. "Since all participants were living independently, and most were functioning quite well at the outset of the study, it will be interesting to see if those who received training experience less decline in their daily living skills over time," Ball said.

*For a complete list of ACTIVE investigators, please go to www.alzheimers.org/pubs/conv10n3and4.html

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, by following the link at www.alzheimers.org, or by following the National Library of Medicine's link to CHID at www.nlm.nih.gov/medlineplus/databases.html.

Caregiver Assistance

Caregiver Survival Kit

National Family Caregivers Association. 2000
Available from the National Family Caregivers Association, 10400 Connecticut Avenue, Suite 500, Kensington, MD 20895-3944,1-800-896-3650, Fax: 301-942-2302, Internet: www.nfcacares.org. PRICE: Free.

This multimedia kit contains a video, booklet, 4 brochures, and a newsletter about caring for a loved one with Alzheimer's disease. The video *Alzheimer's Disease: What Everyone Should Know* discusses warning signs, diagnosis, treatment, research, and caregiving tips. Personal experiences of family caregivers appear throughout the video. The booklet *Caregiving: What Everyone Should Know* gives an autobiographical account of the actress Linda Dano's experiences of caring for her father who had AD. Brochures include:

- *Understanding Alzheimer's Disease,* which presents answers to frequently asked questions about AD, such as definition, causes, signs, diagnosis, stages, heredity, and treatment.
- *AD Caregiver Recognition Program* explains a monthly recognition program for caregivers, and includes criteria and a nomination form.
- *Defining the Help You Need* lists 10 steps to caring for the caregiver.
- *Share the Caring* contains a checklist of services that the caregiver may need or that a friend of the caregiver might offer.

The quarterly newsletter, *Take Care*, provides caregiving information.

Moving a Relative With Memory Loss: A Family Caregiver's Guide

White, L., Spencer, B. Whisp Publications. 2000. 50 p.
Available from Whisp Publications, P. O. Box 5426, Santa Rosa, CA 95402, 707-525-9633. PRICE: $8.80 plus $4.00 shipping and handling fee for 1-4 copies.

This booklet is designed to help families think about the issues involved in moving a relative with memory loss to residential care. It offers practical suggestions for making the move easier. The first section discusses the decision to move, including the reasons why a loved one might need residential care, the advantages and disadvantages of moving, why moving is hard, locating residential care homes, planning for a visit, questions to ask and things to look for, what to do after the visit, and taking the relative for a visit before the move. The second section focuses on the move itself. It includes tips for talking to the relative about the move, planning for moving day, and moving in. The third section offers suggestions about what to do after the move, including building relationships with staff, visiting, and coping with common emotional reactions.

Caregiver Self-Assessment Questionnaire (Auto-evaluación de Cuidadores)

American Medical Association. 2001.
Available from the American Medical Association, Program on Aging and Community Health, 515 North State Street, Chicago, IL 60610, 312-464-5355, fax: 312-464-5841, Internet: www.ama-assn.org/ama/pub. PRICE: Free printed packet, and free online.

This caregiver self-assessment questionnaire has been developed for distribution to physician offices. It is to be completed by caregivers when they accompany the patient for an office visit or when the physician identifies that the patient is providing long-term care to a family member. The caregiver completes the 16 yes/no items and 2 global scale items designed to measure levels of emotional and physical well-being. By using the self-assessment score as an index of caregiver distress, the physician can determine the need for supportive services and make referrals to community resources. The questionnaire is available in English and Spanish versions and includes instructions for scoring and interpreting the instrument, suggested actions, and a list of resources. The printed kit includes copies of both versions as well as background information on the purpose and development of the questionnaire.

Caring for You, Caring for Me: Education and Support for Caregivers

Participant's Manual and Leader's Guide
Haigler, D.H., Mims, K.B., Nottingham, J.A. Rosalynn Carter Institute. 1998. 101 p. (Participant's Guide), 125 p. (Leader's Guide)
Available from University of Georgia Press, 330 Research Drive, Athens, GA 30602-4901. 1-800-266-5842, fax: 706-369-6131, Internet: www.uga.edu/ugapress. PRICE: $10.00 (User's Guide), $30.00 (Leader's Guide)

The Caring for You, Caring for Me: Education and Support for Caregivers program is designed to address the information and support needs of formal and informal caregivers. It consists of five 2-hour modules: (1) what it means to be a caregiver,

(2) taking care of yourself, (3) building cooperative relationships, (4) preventing and solving problems, and (5) accessing and developing resources. The Participant's Manual provides course materials, class exercises, and reference materials for program participants. It is organized into five sections, one for each module. Each section contains the informational guides, which support the presentation by the program leader, and pages to be completed in class exercises. The manual includes a suggested reading list and a list of national sources of help for caregivers. The Leader's Guide provides an overview of the course content, guidelines for setting up and conducting the program, instructions for using the guide, and all instructional materials and visual aids needed for the program. Lesson plans for the five modules include the session objectives, topic outline, materials list, script for presenting content, recommended methods of instruction, and references.

Safe Return

Safe Return and Law Enforcement: Saving Lives Together

Alzheimer's Association. 2001. Available from the Alzheimer's Association, P. O. Box 930408, Atlanta, GA 31193-0408, 1-800-272-3900, Internet: www.alz.org. PRICE: $15 (video, nonlooped) or $25 (video, looped).

This videotape describes Safe Return, a program offered by the Alzheimer's Association to assist in the safe return of people with dementia who wander and become lost or endangered. Started in 1993 with the Department of Justice, Safe Return is a nationwide network of local police officials and Alzheimer's Association chapters. The Association maintains a national database of information on people with dementia who wander. Participants wear or carry identification which provides an ID number and the toll-free telephone number to the Safe Return program. Police officers who find a wandering Safe Return participant can call the program to find out who that person is and where he or she lives. In addition, Safe Return notifies local police departments and provides identifying information when a participant is reported missing. This videotape also offers advice to police officers about how to handle a wandering person with dementia.

Pain Assessment

The PADE (Pain Assessment for the Dementing Elderly) User's Guide

Villaneuva, M.R., Smith, T.L., Lee, A.C. Behavioral Assessment Resources. 2001. 25 p. Available from Behavioral Assessment Resources, 955 Town Centre Drive, Suite C, Medford, OR 97504, 1-800-851-9585, fax: 541-608-3880. PRICE: $145 plus shipping.

This document is a user's guide for the Pain Assessment for the Dementing Elderly (PADE). The PADE is a caregiver rating tool for assessing pain in nursing home residents with Alzheimer's disease or related dementias, who cannot reliably report pain. It measures both physical and functional expressions of pain, and does not require the patient to be an active participant in the assessment. It takes approximately 5 minutes to administer and score, and can be completed in the normal course of caregiving duties. In multi-center psychometric testing, the PADE was found to have good reliability, temporal stability, internal cohesiveness, and construct and criterion validity. The guide includes an overview of the instrument, and instructions for administration and scoring.

Staff Training

Dementia 101

Villanueva, M.R., Smith, T.L., Lee, A.C. Behavioral Assessment Resources. 2001. 32 p. Available from Behavioral Assessment Resources, 955 Town Centre Drive, Suite C, Medford, OR 97504, 1-800-851-9585, fax: 541-608-3880. PRICE: $24.95 plus $4.00 shipping and handling for first copy; $2.00 for each additional copy.

This training guide is designed to provide new caregiving staff, private caregivers, and family members with basic information about dementia. It consists of a series of fact sheets and transparencies on the symptoms and causes of dementia, Alzheimer's disease, the effects of AD on the brain, memory and memory loss, aphasia (problems with language), apraxia (problems with movement), agnosia (problems recognizing common objects), behavior changes, and hallucinations and delusions.

Brains and Aging

Keep Your Brain Young: The Complete Guide to Physical and Emotional Health and Longevity

McKann, G., Albert, M. John Wiley and Sons, Inc. 2002. 296 p. Available from John Wiley and Sons, Inc., 111 River Street, Hoboken, NJ 07030, 201-748-6000, fax: 201-748-6088, Internet: www.wiley.com. PRICE: $24.95.

This book explains methods that may keep your brain working at the highest possible level for the longest possible time. It is based on current research findings and supplemented with case examples from the authors' patient files. It describes the normal changes that occur in the aging brain and shows how to minimize them while enhancing mental and physical functioning. The book discusses steps a person can take that may reduce the risk for serious diseases such as Alzheimer's or Parkinson's, and explains how to recognize the symptoms of these diseases. It also discusses the brain-body link for other diseases, including heart disease and cancer and highlights the progress being made in the treatment of brain disorders with explanations of the latest techniques for maintaining memory, managing stress, and coping with sleep disorders. A list of organizations, books, and Web sites for further information is provided.

Spanish and English Caregiver Kits Available

The ADEAR Center has developed a *Caregiver Kit* featuring new and popular English and Spanish caregiving publications, and basic information about AD.

The kit is designed to provide easy-to-read information on the latest developments in AD research and possible causes of AD, and the currently approved AD treatment medications. Symptoms of AD, diagnostic advances, and bilingual resource lists for additional assistance are also provided.

Each **free** kit contains:

- *Alzheimer's Disease Fact Sheet (La Enfermedad de Alzheimer Folleto Informativo)*
- *Forgetfulness, It's Not Always What You Think (La Mala Memoria no es Siempre lo que se Piensa)*
- *Caregiver Guide: Tips for Caregivers of People with Alzheimer's Disease (Guía Para Quienes Cuidan Personas con la Enfermedad de Alzheimer)*
- *Home Safety for People with Alzheimer's Disease (Protección en el Hogar para las Personas con la Enfermedad de Alzheimer)*

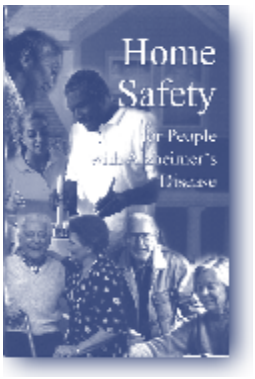
All the publications in the kit can be previewed online by going to www.alzheimers.org and selecting the Publications page. For ordering information, please see the back page, or call ADEAR at 1-800-438-4380.

New Home Safety Publications Introduced

Each is included In Caregiver Kits

Two of the ADEAR Center's newer publications offer practical tips for in-home care of a person with AD. *Home Safety for People with Alzheimer's Disease*, originally written by staff of the Alzheimer's Disease Center at the University of California, San Diego, is now updated and free. The new publication, also available in Spanish, provides safety and environmental design tips on a room-by-room and behavior-by-behavior basis, plus warning signs of unsafe driving, natural disaster safety, and additional resources.

For ordering information, please see the back page, or call ADEAR at 1-800-438-4380.



For a complete listing of upcoming conferences, please visit: www.alzheimers.org/calendar

April 13-16, 2003

Nursing 2003 Symposium: The Conference for Clinical Excellence
Lake Buena Vista, FL

Contact:
Lippincott Williams & Wilkins
1111 Bethlehem Pike
PO Box 908
Springhouse, PA 19477-0908
1-800-346-7844, ext. 7750
Fax: 856-218-0557

April 25, 2003

Today's Caregiver Sharing Wisdom Conference
Fort Lauderdale, FL

Contact:
Caregiver.com
6365 Taft Street, Suite 3006
Hollywood, Florida 33024-5960
1-800-829-2734
Fax: 954-893-1779
www.caregiver.com

April 30-May 2, 2003

Assisted Living Federation of America Spring 2003 National Conference & Expo
Phoenix, AZ

Contact:
Assisted Living Federation of America
11212 Waples Mill Road, Suite 104
Fairfax, VA 22030
1-800-258-7030
www.alfa.org

May 1-3, 2003

2nd International Symposium on Alzheimer's Disease in the Middle East
Istanbul, Turkey

Contact:
World Events Forum, Inc.
5030 N Marine Drive
Suite 2608
Chicago, IL 60640
773-784-8134
Fax: 208-575-5453
meetings@worldeventsforum.com
www.worldeventsforum.com/alzsymposium/IntroAlz2.htm

May 3-7, 2003

American Society for Neurochemistry 34th Annual Meeting
Newport Beach, CA

Contact:
American Society for Neurochemistry
9037 Ron Den Lane
Windermere, FL 34786
407-876-0750 Phone/fax
amazing@iag.net
www.asneurochem.org/ASN2003.htm

May 8-12, 2003

6th International Conference on Progress in Alzheimer's and Parkinson's Disease
Seville, Spain

Contact:
6th International Conference AD/PD 2003
Kenes International
17 rue de Cendrier
P.O. Box 1726
CH-1211
Geneva 1 SWITZERLAND
+41 22 908 0488
adpd@kenes.com

May 12-16, 2003

National Rural Health Association 26th Annual Conference
Salt Lake City, UT

Contact:
National Rural Health Association
One West Armour Boulevard
Suite 203
Kansas City, MO 64111
www.NRHArural.org

May 13, 2003

9th Annual Rural Minority Health Conference
Salt Lake City, UT

Contact:
National Rural Health Association
One West Armour Boulevard
Suite 203
Kansas City, MO 64111
www.NRHArural.org

May 14-18, 2003

American Geriatrics Society Annual Scientific Meeting
Baltimore, MD

Contact:
American Geriatrics Society
350 Fifth Avenue, Suite 801
New York, NY 10118
212-308-1414
Fax: 212-832-8646
www.americangeriatrics.org

May 21, 2003

Alzheimer's Conference: The Jewish Home and Hospital
New York, NY

Contact:
Naim M. Gribaa
The Jewish Home and Hospital Lifecare System
120 W. 106 Street
New York, NY 10025
212-870-4762
ngribaa@jhha.org
www.jewishhome.org

May 22-27, 2003

AAPA's 31st Annual Physician Assistant Conference
New Orleans, LA

Contact:
American Academy of Physician Assistants
950 North Washington Street
Alexandria, VA 22314-1552
703-836-2272
Fax: 703-684-1924
aapa@aapa.org
www.aapa.org

Publications Order Form

- ❑ *Aging Under the Microscope*
- ❑ *Alzheimer's Disease: Unraveling the Mystery*
- ❑ *Caregiver Kit* (English)
- ❑ *Caregiver Kit* (Spanish)
- ❑ *Home Safety for People with Alzheimer's Disease* (English)
- ❑ *Home Safety for People with Alzheimer's Disease* (Spanish)

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❑ NIA News ❑ Clinical Trial Updates ❑ *Connections* Newsletter ❑ New ADEAR Publications

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name:_____ mailing address:_____

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or contact us via e-mail: adear@alzheimers.org,
Web site: www.alzheimers.org

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