

CONNECTIONS

*Alzheimer's Association
Conferences in July3*

*What's Your
Aging IQ?4*

*Genetic Influence on
Memory Performance6*

*Low Free Testosterone
Level Linked to AD7*

*Vital Visionaries
Program Launched10*

Using marketing principles to improve clinical trial recruitment

Successfully recruiting participants for clinical trials is a challenge that crosses all medical disciplines, but is particularly difficult in the field of Alzheimer's disease (AD) research. The nature of the disease, the need to recruit a caregiver in addition to the person with AD, the changing nature of clinical prescribing practices, and a climate of misunderstanding and misperceptions about AD all contribute to these recruitment challenges.

A growing body of published literature is focusing on consumer attitudes toward participation in clinical trials and benefits and barriers perceived by participants and the public. Articles report on the relative effectiveness of various recruitment tactics and methods. The value of the AD recruitment experiences reported in the published literature could be increased by the use of a framework for systematically planning and evaluating recruitment methods and approaches.

Social marketing is one such framework. It is a discipline introduced in the 1970s that seeks to apply marketing principles and expertise to address social and health problems. Social marketing is defined as a process for influencing human

(see Social Marketing, page 2)

ADEAR services and audience are expanding

In its 14 years, the Alzheimer's Disease Education and Referral (ADEAR) Center has helped millions of people with information on AD and caregiving, updates on research, referral services to community-based resources, publications support for conferences, health fairs, and exhibits, and help with clinical trial recruitment.

How people contact the Center has changed significantly since the early years, when telephone and postal mail represented the primary way people requested information.



Information Specialists respond to phone calls and e-mails from people requesting AD information and other NIA materials. From left are Isela, Max, Lillibet, and Vijay.

Today, growing numbers of caregivers and people with AD are seeking reliable, web-based information, and the ADEAR Center is responding. In its first year on the Internet (1996), ADEAR had just 20,000 visitors.

(see ADEAR Center, page 4)

Clinical Trials Update

New AD trial tests Chinese herb

Huperzine A, a natural cholinesterase inhibitor derived from the Chinese herb *Huperzia serrata*, demonstrates both neuroprotective and antioxidant properties. Studies suggest that the supplement—currently approved for AD treatment in China and available in the U.S. as a nutraceutical—may be more effective and

safer than the four AchE inhibitors approved for use in the U.S. to treat AD (tacrine, donepezil, galantamine, rivastigmine).

The Huperzine Study is a 24-week, Phase II clinical trial to investigate the effect on cognitive function of two different dosages of huperzine A among people with mild to moderate AD. The study, funded by the NIA and coordinated by the Alzheimer's

(see Clinical Trials Update, page 6)



News From the Alzheimer's Disease Education and Referral (ADEAR) Center

*A Service of the National Institute on Aging
National Institutes of Health*

U.S. Department of Health and Human Services



Social Marketing

(from page 1)

behavior, using marketing principles for the purposes of societal benefit rather than commercial profit.

According to Michael Siegle and Lynn Doner, it is a “disciplined, audience-focused, research-based process to plan, develop, implement, and assess interventions designed to influence the behavior of target audiences to improve their personal welfare or that of society.” Like other science-driven disciplines, social marketing relies on thoughtful program design, careful implementation, sufficient documentation, and systematic evaluation to assess success and failure.

Five fundamental principles of social marketing make it particularly relevant for recruiting participants to AD clinical trials:

1. Know exactly who your audience is and look at everything from that group’s point of view. Most clinical trial recruiters can describe the audience they are attempting to reach, but may begin to have trouble when it comes to adopting the group’s point of view. Social marketing is a consumer-oriented and audience-focused approach to program planning. Marketers recognize that they are probably very different from the population they are seeking to recruit, and they seek to understand the world from their audience’s point of view. Understanding the specific internal and external factors of the target audience and how they influence an individual’s decision to participate in a clinical trial is a key to successful recruitment.

2. Be clear about the actions you want your audience to take. Marketing plans are designed with the end goal—behavior change—in mind. Often this end goal involves a series of steps, decisions, or actions. Commercial purchase decisions, for example, involve the following stages:

- awareness,
- evaluation and assessment of

- options,
- purchase, and
- post purchase assessment.

As applied to clinical trial participation, these stages are:

Stage 1—Awareness or problem recognition. The participant or caregiver associates clinical trials with meeting a personal need and seeks information about the trial.

Stage 2—Information search and assessment of alternatives. The potential participant or caregiver searches for information about trials and begins to weigh the alternatives. Alternatives for AD families include continuing with current care or participating in a competing trial.

Stage 3—Enrollment. The third stage represents the actual decision to enroll and the enrollment process. It is closely linked to Stage 2 and it may occur at the same time as Stage 2 or many weeks and months later if the participant and caregiver need time to weigh the options.

Stage 4—Marketers recognize that their job does not end at the initial purchase. The same is true for clinical trials, where patient and caregiver satisfaction with the care and services provided influence retention in the current trial. Participant satisfaction may also affect the institution’s reputation, which may influence future recruitment efforts.

Participating in an AD clinical trial will almost always be a high-involvement decision with multiple consequences. For example, participating may require inconvenient and difficult hospital or clinic visits and increased time or transportation demands for a caregiver. Participants may have to stop taking current medications and switch to new drugs. Understanding the basis of high-involvement decisions can help trial planners develop recruitment strategies that are tailored to groups of participants and specific to each stage.

3. To succeed in getting people to do something you want them to do, you must offer them something they value in return. In a commercial transaction an exchange of value is

easy to identify—a consumer gives money in exchange for a product. Social marketers must make a special effort to design and position their service so that it provides benefits that are valued by the target audience. This is particularly true in the field of clinical trial recruitment, where although most people endorse the need for clinical trials, they remain suspicious about the safety and value of the personal care offered. Marketing efforts should stress quality of care, support for caregivers, and feelings of contributing to scientific advancements as the value participants will receive.

4. Be aware of and plan for the competition. People with AD and their caregivers can choose a clinical trial offered by an academic research institution or a research protocol offered by a drug company. Or, they can choose neither. A clinical trial must not only provide value to that individual or family—but must provide value that exceeds the value of their other available choices. For example, providing access to support services for caregivers, easing transportation barriers to getting to appointments, or having staff who speak the participants’ language might tip the balance of decision-making and make participation in a trial a better alternative to other options.

5. Address all elements of the “marketing mix” in developing recruitment strategies. A successful marketing strategy will incorporate a range of tactics and approaches—known as the “marketing mix.” Four sets of variables should be considered in designing clinical trial recruitment strategy:

Product—the composite of all the services and benefits a patient or caregiver receives in a clinical trial.

Price—might include costs of transportation, extra visits to doctors, procedures and tests, and other barriers to participation such as lack of knowledge about AD, skepticism, and mistrust.

Place—the doctor’s office, clinic, or research institution the participant must visit periodically, and which

includes other elements such as availability of trained staff to answer questions and provide support, accessibility, and availability of parking.

Promotion—activities should include:


- Community networking
- Radio and newspaper advertising
- Media placements in magazines or direct mail
- Public relations efforts, such as making community presentations
- Use of patient registries to contact potential participants
- Individual counseling
- Interpersonal support

Conclusion

The growing field of AD research depends on a sufficient number of human volunteers, including those with AD, their caregivers, and healthy older men and women. Social marketing can provide a useful framework for designing, carrying out, and evaluating successful AD clinical trials recruitment and retention efforts. Social marketing principles can help investigators meet their recruitment and retention goals, thereby helping to ensure success of this critically important area of research.

Adapted from : *Using a Social Marketing Framework to Improve Alzheimer's Disease Clinical Trial Recruitment*, Schechter, C., et. al., Academy for Education Development (in press).

Suggested Reading

- Andreason, A. *Marketing social change: changing behavior to promote health, social development, and the environment*. San Francisco: Jossey-Bass Publishers, 1995.
- Kotler P., Armstrong G. *Principles of marketing*. Upper Saddle River (NJ): Prentice Hall, 2001.
- Siegel, M., Doner, L. *Marketing public health: strategies to promote social change*. Gaithersburg (MD): Aspen Publishers, Inc., 1998.
- Smith, W. *Social marketing: beyond the nostalgia*. In: Goldberg, M., Fishbein, M., Middlestadt, S., eds. *Social marketing: theoretical and practical perspectives*. Mahwah (NJ): Lawrence Erlbaum Associates, Inc., 1997. 

Alzheimer's Association Education and International Conferences to be held in Philadelphia in July

Education Conference, July 16-18

The Alzheimer's Association 12th National Alzheimer's Disease Education Conference will be held July 16-18, 2004 at the Philadelphia Marriott, Philadelphia, Pennsylvania. Presentations will focus on:

- The Changing Profile of AD
- Person-Centered Care
- Quality Care and Care Access
- Empowering Programs for People with Dementia and Their Care Partners

Plenary Highlights

- *Alzheimer's Disease Genetics Initiative*—Marcell Morrison-Bogorad, Ph.D., Director, National Institute on Aging Neuroscience and Neuropsychology of Aging Program.
- *Brain Health Across the Lifespan*—Paul Nussbaum, Ph.D., Philadelphia.
- *The Voices of Alzheimer's Disease*—Debra Cherry, Ph.D., Alzheimer's Association, Los Angeles.
- *Medical and Scientific Update*—Samuel Gandy, M.D., Ph.D., Farber Institute for Neurosciences at Thomas Jefferson University, Philadelphia.
- Cornelia Beck, Ph.D., R.N. F.A.A.N., University of Arkansas for Medical Sciences, Little Rock.

Symposia Highlights

Symposia highlights will include panel discussions and presentations on:

- Lessons Learned from Family Care Plans
- Differential Diagnosis
- Alzheimer's Caregiving: Enhancing Conceptual Learning Through Interactive Strategies

While attending, stop by the ADEAR Center exhibit booth and NIA poster session.

9th International Conference, July 17-22

More than 5,000 NIA grantees and other researchers will share information and resources on the etiology,

pathology, and treatment of AD and related disorders at the 9th International Conference on Alzheimer's Disease and Related Disorders. The conference, to be held July 17-22, in Philadelphia, is part of the Alzheimer's Association research program for generating new knowledge about dementia. While attending, stop by the NIA's Neuroscience and Neuropsychology of Aging exhibit. Register for the conference online at www.alz.org/education conference or call 312-335-5790.

Also in Philadelphia

Frontotemporal Dementia: Clinical, Genetic, Biomarker, and Pathological Perspectives

International experts will discuss state-of-the-art approaches to fronto-temporal dementia (FTD) in a satellite meeting to be held on July 15-16, 2004 at the Meyerson Auditorium on the campus of the University of Pennsylvania in Philadelphia.

Penn faculty will be joined by other international and national FTD experts, who have selected topics to discuss, including:

- clinical overviews of progressive aphasia and social/personality disorder
- structural, functional, and biochemical imaging
- CSF *tau* and other biomarkers
- animal models of *tauopathies*
- genetic studies of FTD
- effects of FTDP-17 mutations on *tau* structure and function.

For more information contact Gayle Joseph, Center for Neurodegenerative Disease Research, telephone: 215-662-4708, or fax: 215-349-5909, or e-mail: viale@mail.med.upenn.edu.



What's Your Aging IQ?

Find Out with a Free Booklet from the NIA

Popular culture perpetuates myths about older people as frail, forgetful, and depressed. Much of the health decline associated with aging is, in fact, related to lifestyle factors such as the lack of regular exercise and a poor diet. To help you distinguish aging facts from fiction, the NIA has created a free booklet called *What's Your Aging IQ?*

You'll read eight short stories about fictional older people who are dealing with a variety of issues like weight training and bone density, smoking cessation, sexuality, hypothermia, and vision problems. The stories are followed by multiple-choice, true/false, and yes/no questions about growing older. You can record your answers on the pullout answer sheet and compare them to the correct answers, accompanied by explanations, in the back of the booklet.

If you would like more information on the subjects raised in the *Aging IQ* booklet, please call the NIA Information Center at 1-800-222-2225 or preview and order the booklet at www.niapublications.org/pubs/agingiq/index.asp. You may also view and order other NIA publications at www.niapublications.org.

ADEAR Center

(from page 1)

By 2003, ADEAR had more than 1,500,000 visitors. Web-based information services are also improving. The ADEAR Center offers online publication ordering, a clinical trials database, and an online, real-time live chat service (M-F, 2-4 p.m., Eastern Time).

At first, ADEAR focused on communicating research advances to scientists and health professionals. Demand for credible, objective information to help growing numbers of AD caregivers has enlarged the ADEAR Center's focus and audience outreach. Staff work continuously to improve resources, such as enhancing the website, expanding the clinical trials database, and adding new materials to the reference library (CHID). Recently, another bilingual Information and Referral Specialist was added to the team.

What We Do

ADEAR services include:

- responding to requests for caregiving and research information about AD and related disorders
- referring requesters to community-based resources, including the 29 NIA-funded Alzheimer's Disease Centers nationwide
- providing background on clinical trials
- filling publication orders

In 2003, Information Specialists responded to more than 8,600 telephone calls and 6,200 e-mails.


CHID

The ADEAR librarian maintains the Combined Health

Information Database (CHID) Alzheimer's subfile, containing more than 7,700 items. The CHID reference library features books, videos, articles, and many other AD resource materials that are not found in any other bibliographic database.

Clinical Trials Database

The ADEAR website contains a clinical trials database with 26 trials currently displayed, sponsored by NIA, the National Institute on Neurological Disorders and Stroke (NINDS), the National Institute on Mental Health (NIMH), the National Cancer Institute (NCI), the National Institute on Nursing Research (NINR), the Alzheimer's Association, and several private organizations. Each record provides information about the trial, contact information for recruitment and recruitment status, the trial's protocols, the principal investigator, inclusion/exclusion criteria, and a list and map of trial sites.

The ADEAR Center is a service of the National Institute on Aging, and has been in operation since 1990. This year, NIA combined its Information Center with the ADEAR Center, creating a unified clearinghouse distributing materials on AD and healthy aging. Public access to each center by toll-free telephone, mail, fax, and e-mail remain the same, however. The Clearinghouse is operated under contract with a private company, Maryland-based Johnson, Bassin, and Shaw, Inc. 



ADEAR Center Teams: Helping People Get the Information They Need



● *Who is processing your order?*

When you contact the ADEAR and NIA Centers, a dedicated support team processes publication orders by mail and fax, e-mail requests, and funds sent in to pay for items. The team also answers phone calls, monitors inventory, and keys data for mailing publications to requesters.

Fulfillment Specialists, from left, Wendy Nunez, Allison Henderson, Kisha Thompson, and Administrative Assistant, Debbie Koster.



● *Who is mailing your publication?*

The Warehouse Team fills as many as 400 requests for AD and aging information from ADEAR and NIA Clearinghouse customers every day. Staff retrieve publications, package them for mailing, manage inventory space, ship special orders, and manage ADEAR and NIA exhibit and conference materials.

Warehouse Team, from left, Raymond Euell, TaShane Elder, Gerry Chambers, Ernie DePaz, Anthony White, and Matthew Lloyd (Warehouse Manager).



● *Who takes care of publications, CHID, the website, outreach and promotions, and databases?*

Publications such as the annual *Progress Report on Alzheimer's Disease* and various fact sheets, brochures, booklets, and this newsletter are managed, researched, and/or written by ADEAR staff. The web content manager configures these products for online viewing. The librarian catalogs CHID items and maintains the Clinical Trials Database. The outreach and promotions specialist determines how best to serve the various ADEAR audiences.

Team Members, from left, Nancy Clark, Assistant Writer/Editor, Jennifer Watson, Outreach and Promotions Specialist, Trammell Maury, Librarian, Fran Gillen, Project Director, Lenita Gray, Assistant Manager, Janiré Hopkins, Web Content Specialist, David Burton, Publications Coordinator, and Mike Nescot, Computer Specialist.

visit www.alzheimers.org

Clinical Trials Update

(from page 1)

Disease Cooperative Study, is led by Georgetown University, under the direction of Principal Investigator Paul Aisen, MD.

Beginning this Spring, the randomized, double-blind, placebo-controlled trial will be conducted at approximately 20 sites nationwide, enrolling a total of 150 subjects. Study participants will be age 55 or older, with mild to moderate AD, and cannot have been taking cholinesterase inhibitors within 3 months prior to screening.

"We are excited about the possibility of adding a new option for the treatment of Alzheimer's disease," said Dr. Aisen. "Participation in the trial may be appropriate for people who have not found currently approved


cholinesterase inhibitors effective or tolerable, and for those who are interested in natural therapies."

Participants will be randomly assigned to three equal groups: 1) 200 micrograms (μg) huperzine A, twice daily 2) 400 μg huperzine A, twice daily, and 3) placebo. All subjects will receive huperzine A during the last 8 weeks of the 24-week trial. Efforts are underway to add an open-label extension study which would provide huperzine A to all participants for at least an additional 6 months.

The primary outcome, slowed progression of AD, will be measured by the cognitive portion of the Alzheimer's Disease Assessment Scale. Secondary outcomes will include measures of clinical global change, mental status, functional ability, behavioral disturbances, and quality of life.

VALID Study continues to seek participants

The VALID (VALproate In Dementia) Study, launched last fall by the AD Cooperative Study (UC San Diego), is continuing to recruit volunteers. This 2-year trial is investigating whether low-dose valproate, an anti-convulsant drug, can help delay the emergence of agitation and psychosis and slow the clinical progression of AD. To be eligible for this study, volunteers must be age 55 or older, diagnosed with AD, and have not experienced agitation or psychosis since the onset of AD.

For more information on these and other AD studies, visit ADEAR's clinical trials database at www.alzheimers.org/trials or call the ADEAR Center at 1-800-438-4380. 

Researchers find genetic influences on memory performance in familial AD

Genetics may influence memory performance in families with a history of Alzheimer's Disease according to researchers writing in the February 10, 2004 issue of *Neurology*. Previous human genetic studies focusing on memory have been limited primarily to twin studies. In this new study, NIA-supported grantees at Columbia University, Joseph Lee, DrPH, and Richard Mayeux, MD, MSc, examined the heritability of cognitive elements, including memory, in patients with AD and their family members across multiple generations. Their study included data from 1,036 individuals from 266 Caribbean Hispanic families from the Dominican Republic and Puerto Rico.

Neuropsychological tests were given to all family members and those with AD, in Spanish. Study participants were tested for memory, attention, abstract reasoning, language, and visual-spatial ability.


Researchers found that nearly 50 percent of assorted memory abilities among study participants were due

to genetics, while the other half can be attributed to outside factors, such as education. Because traits, such as the genetic mutation that triggers early-onset AD, are dominant, memory performance may have an even higher genetic influence than the test results suggest.

Areas of mental ability that appear to be less influenced by genetics included attention, abstract reasoning, language, and visual-spatial ability. Even after the scores of those participants with AD were removed from analysis, researchers arrived at the same conclusions regarding memory performance. When adjustments for sex, age, education, and general intelligence were made, heritability approximations increased for cognitive tests, especially for those observed for memory. No other cognitive ability was estimated to be as closely linked to genetics as memory.

The relationship between the apolipoprotein E gene (APOE) and the risk of developing AD was tested. The $\epsilon 4$ variant allele of APOE is strongly

associated with AD. The APOE gene, however, appeared to have little influence on memory scores. When researchers controlled for the APOE gene, heritability estimates changed modestly with a slight increase in delayed recall; however, estimates made little to no changes for other memory scores.

More research is needed to establish whether these findings apply to families without multiple family members with AD and those living in the U.S. Because those who lived in the Dominican Republic received limited education between the years 1930 to 1961, the average education of those researched from this area is 6 years. Past research suggests that this group may be more susceptible to AD than those educated in the U.S., because education appears to have AD protective effects. A better grasp of which genetic influences affect memory and memory impairment in AD may shed light on which genetic factors cause this degenerative disease. 

Low Free Testosterone Levels Linked to Alzheimer's Disease in Older Men

Older men with lower levels of free, or unbound, testosterone circulating in their bloodstreams could be at higher risk of developing Alzheimer's disease than their peers, according to new research. This prospective observational study is believed to be the first to associate low circulating blood levels of free testosterone with AD years before diagnosis.

The study appeared in the January 27, 2004 issue of the journal *Neurology*. This work was conducted by NIA investigators and scientists at other institutions supported by NIA grants.*

"Our finding that low free testosterone might be associated with an increased risk of developing AD is a step forward in helping to understand the possible effects of sex hormones on the aging brain and other parts of the body," said Susan Resnick, Ph.D., an investigator in the NIA's Laboratory of Personality and Cognition and corresponding author of the study.

Dr. Resnick, however, cautions that much more research is needed before scientists can establish a causal relationship between low testosterone and AD. "Even if a relationship between AD and levels of free testosterone in the bloodstream is confirmed, we are very far away from knowing if hormonal therapy or any other intervention could safely prevent AD," she said.

Dr. Resnick, Scott Moffat, Ph.D., and their colleagues evaluated the testosterone levels of 574 men, ages 32 to 87, who participated in the Baltimore Longitudinal Study of Aging (BLSA). The investigators examined free and total testosterone levels—measured over an average of 19 years—in relationship to subsequent diagnosis of AD. Based on physical, neurological, and neuropsychological exams, 54 of the 574 men were diagnosed with AD.

The research team found that for every 50 percent increase in the free testosterone index in the blood-

stream, there was about a 26 percent decrease in the risk of developing AD. Although overall free testosterone levels fell over time, these levels dropped more precipitously in those men who later developed AD. In fact, at the end of the study, men who were diagnosed with AD, on average, had about half the levels of circulating free testosterone as men who didn't develop the disease. In some cases, the drop-offs in free testosterone levels associated with AD were detected up to a decade before diagnosis.

Previously, Dr. Resnick and her colleagues found that older men with high levels of circulating free testosterone have better visual and verbal memory and perform spatial tasks more adeptly than their peers.

"It is quite possible that circulating free testosterone has a broad range of influences on the aging brain," Dr. Resnick said. "The effects of some of these influences—such as the role of testosterone in the development of certain types of memory loss and AD—are just beginning to be explored."


In men, testosterone is produced in the testes, the reproductive glands that also produce sperm. As men age, their testes often produce somewhat less testosterone than they did during adolescence and early adulthood, when production of this hormone peaks. Within the body, testosterone tends to bind with sex hormone binding globulin (SHBG). But some testosterone remains freely circulating in the bloodstream. Unlike the SHBG-bound form of the hormone, free testosterone can circulate into the brain and affect nerve cells. In this study, only reduced levels of free testosterone were associated with AD, Dr. Resnick said.

Other BLSA studies suggest that many men older than 70 have low levels of free testosterone compared to younger men. But while prescription testosterone replacement therapy is available, it may not be advisable for

most older men because many effects of hormone therapy remain unclear. It is not yet known, for instance, if testosterone replacement increases the risk of prostate cancer, the second leading cause of cancer death among men. In addition, studies suggest that in some men testosterone therapy might trigger excessive red blood cell production. This side effect can thicken blood and increase a man's risk of stroke.

"We still have much to learn," Dr. Resnick said. "For now, testosterone therapy should not be considered an option for older men seeking to reduce their risk of AD or to improve their memory and cognitive performance in general."

A multi-disciplinary panel, led by the Institute of Medicine (IOM) and supported by the NIA and the National Cancer Institute, recently evaluated the pros and cons of conducting clinical trials of testosterone replacement therapy in older men to answer many of the lingering questions about the effects of this hormone in the aging body. The NIA is considering the IOM recommendations very carefully and likely will act on the recommendations to begin small-scale clinical trials to determine the efficacy of testosterone in treating symptomatic older men with low testosterone levels. Until carefully designed and monitored clinical trials are conducted, the risks and benefits of testosterone therapy for most men who do not have extreme deficiencies of the hormone will remain largely unknown.

* Scott Moffat, Ph.D., formerly of the NIA, is now at Wayne State University, Detroit. Claudia Kawas, M.D., now at the University of California, Irvine, collaborated on this study while at the Johns Hopkins University Alzheimer's Disease Research Center in Baltimore. Marc R. Blackman, M.D., collaborated on this study while at Johns Hopkins University; he is clinical director at the NIH's National Center for Complementary and Alternative Medicine. Former NIA investigator S. Mitchell Harman, M.D., Ph.D., is now at the Kronos Longevity Research Institute in Phoenix. 

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.

Better Strategies for Health Communications

Making Health Communication Programs Work. 2002.

Available from the U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health, National Cancer Institute, CANCERLIT, MSC8322 CANCERLIT, 6116 Executive Boulevard Suite 3036A, Bethesda, MD, 20892-8322. 301-496-7406. Website: <https://cissecure.nci.nih.gov/ncipubs>. PRICE: free

This booklet may be of interest to researchers planning recruitment strategies for clinical trials. It describes a practical approach for planning and implementing health communication efforts. The booklet offers guidelines that can be tailored to individual circumstances and situations. Stages of the health communications process are described. It discusses specific steps in the planning process, including planning and developing a strategy; developing and pretesting concepts, messages, and materials; implementing the program; and assessing effectiveness and making refinements. Each chapter also describes common myths and misconceptions. Originally published in 1989, this new version updates communication planning guidelines to account for advances in knowledge and technology that have occurred during the past decade. Sources of additional information are provided at the end of each chapter. A glossary, a bibliography, and other resources are appended.

REACH Program Examined

Resources for Enhancing Alzheimer's Caregiver Health (REACH). Introduction and 4 articles.

Psychology and Aging. 18(3): 357-405. September 2003.

Introduction.

Schulz, R., et al.

This introduction and series provide background information and an overview of Resources for Enhancing Alzheimer's Caregiver Health (REACH), a multi-site intervention trial designed to reduce burden and depression among caregivers of people with AD. REACH involved 1,222 caregiver and care recipient pairs recruited from 6 sites throughout the U.S. The Introduction is followed by four related articles:

1. Effect of Multi-component Interventions on Caregiver Burden and Depression: The REACH Multi-site Initiative at 6-Month Follow-Up
Gitlin, L.N., et al.

2. REACH Project Design and Baseline Characteristics
Wisniewski, S.R., et al.

3. Methodology for Describing and Decomposing Complex Psychosocial and Behavioral Interventions
Csaja, S.J., et al.

4. Using a New Taxonomy to Combine the Uncombinable: Integrating Results Across Diverse Interventions
Belle, S.H., et al.

Exercising Your Brain

Memory Bible: An Innovative Strategy for Keeping Your Brain Young. 2002.

Small, G.

Available from Hyperion, 77 West 66th Street, 11th floor, New York, NY 10023-6298. 212-456-0100. Website: www.hyperionbooks.com. PRICE: \$25.95.

This book is a guide to improving memory performance and keeping the brain young and presents background information on memory and brain aging; tests for rating current memory performance; and the Look, Snap, Connect technique for enhancing memory ability. Effects of stress on memory ability and strategies to reduce stress; brain-teasers and puzzles and exercises for the left brain, right brain, and whole brain; and more advanced strategies for building memory skills, are described. Guidelines for a 'brain diet' of memory-protective foods and supplements; lifestyle factors such as exercise, sleep, smoking, alcohol, and recreational drugs that can affect memory performance; and medicines that can help or impair memory, are discussed. The last chapter explains how to use this information to organize a memory enhancement program.

Physician's Guide to AD

Alzheimer's Disease: A Physician's Guide to Practical Management. 2004.

Richter, R.W., ed.; Richter, B.Z., ed.
Available from The Humana Press,

999 Riverview Drive, Suite 208, Totowa, NJ 07512. 973-256-1699; Fax: 973-256-8341. Website: www.humanapr.com. PRICE: \$99.50 hardcover; \$89.50 eBook.

This book for physicians is a practical guide to the assessment and treatment of AD. First, it reviews the genetics of AD, neuropathology, pathogenetic mechanisms, epidemiology, and risk factors. It then describes the clinical assessment, early changes, and preclinical conditions, including mild cognitive impairment and predementia AD, current treatment options, late-stage care, promising preventive strategies, emerging therapies, and rating scales for measuring treatment response. It also discusses the neuropsychiatric aspects of AD, family and caregiver issues, dental care for AD patients, and management of comorbid medical conditions. A list of resources is included.

Palliative Care

On the Road From Theory to Practice: A Resource Guide to Promising Practices in Palliative Care Near the End of Life. 2003.

Fins, J.J., et al.

Available from *Last Acts*, 1620 Eye Street, N.W., Suite 202, Washington, DC 20006-4017. 1-800-341-0050; Fax: 202-296-8352. Website: www.lastacts.org. PRICE: free

This resource guide describes promising practices in palliative care at the end of life. It identifies key issues relevant to 5 precepts of quality palliative care: (1) respecting patient goals, preferences, and choices; (2) comprehensive caring; (3) utilizing the strength of interdisciplinary resources; (4) acknowledging and addressing family caregiver concerns; and (5) building systems and mechanisms of support. The resource guide examines each issue from the perspectives of hospital, long-term care/home care, and hospice. A three-column matrix identifies barriers to quality care, recommendations for improvement,

and promising practices across health care settings. Selected promising practices are also described.

Health Care Professionals and End-of-Life Planning

Advance Care Planning: Preferences for Care at the End of Life. March 2003.

Kass-Bartelmes, B.L.; Hughes, R.

Available from the *Agency for Healthcare Research and Quality*, 2101 East Jefferson Street, Suite 501, Rockville, MD 20852. 1-800-358-9295.

Website: www.ahrq.gov/research.

PRICE: free.

This guide is designed to show how physicians and other health care professionals can help patients with advance care planning and assess their preferences for care at the end of life. Research findings include: (1) patients need more effective advance care planning; (2) patients with chronic illnesses also need such planning; (3) patients value advance care planning discussions; (4) opportunities exist for advance care planning discussions; (5) patients have preference patterns for hypothetical situations; and (6) patient preference patterns can predict other choices. The guide includes a five-part process that physicians can use to structure discussions on end-of-life care.

Caregiver Decision-making

Eldercare 911: The Caregiver's Complete Handbook for Making Decisions. 2002.

Beerman, S.; Rappaport-Musson, J.

Available from *Prometheus Books*, 59 John Glenn Drive, Amherst, NY 14228-2197. 1-800-421-0351; 716-691-0133; Fax: 716-564-2711. Website: www.prometheusbooks.com. PRICE: \$24.00.

This guide to caregiving for elderly family members, including those with dementia, is designed to help the caregiver make informed decisions

about typical eldercare issues. Topics include: the pros and cons of being a caregiver, knowing when your parents need help, planning for intervention, caregiving realities, long-distance caregiving, finding and using support services, handling burnout, managing medical issues, overseeing medications, managing benefits and insurance, dealing with serious illness, coping with AD, when hospitalization is necessary, detecting and dealing with elder abuse, hiring a home care worker, making decisions about housing, evaluating the move to a nursing home, sexual intimacy and new relationships, and death and dying. The chapter on AD includes information about testing and diagnosis, treatment options, effects on the family, and planning for the future.

Respite Programs

New Look at Community-Based Respite Programs: Utilization, Satisfaction, and Development. 2002.

Home Health Care Services Quarterly. 21(3-4): 1-175.

Available from *The Haworth Press, Inc.*, 10 Alice Street, Binghamton, NY 13904-1580. 1-800-429-6784; Fax: 1-800-895-0582.

Website: www.haworthpressinc.com. PRICE: \$28.13 for an individual; \$60.00 for an institution.

This journal discusses the Alzheimer's Demonstration Program, a demonstration project of the Administration on Aging designed to expand support services for people with Alzheimer's disease and their caregivers. Papers report the initial findings from the evaluation of the Alzheimer's Disease Demonstration Grants to States program in 15 States and present profiles of respite service use for a diverse sample of 4,369 families from 7 States. Effects of cultural factors on clients' attitudes toward caregiving, perceptions of service delivery, and service utilization are examined. Factors related to client satisfaction with community-based respite services are discussed.

National Institute on Aging, American Visionary Art Museum Launch “Vital Visionaries” Collaboration

The National Institute on Aging and the American Visionary Art Museum (AVAM) in Baltimore, MD, are joining forces in the Vital Visionaries Collaboration, a program pairing Baltimore elders with first-year medical students. Concurrent with AVAM's exhibit on late-onset creativity, the two-person teams will embark on a four-part art adventure to learn about the value of creative, self-reliant expression as a healthy aspect of aging.



Johns Hopkins University medical students learn about older people and their artistic and creative capabilities.



Self-portrait techniques are discussed by Baltimore-area older people paired with medical students in the Vital Visionaries program



Old and young converse easily and become friends as they talk about the stereotypes of creativity in older people.

“The program aims to improve medical students’ attitudes towards aging and older people by giving them an opportunity to learn about AVAM's featured senior artists and each other,” said Judith A. Salerno, M.D., M.S., NIA deputy director, who initiated the unique partnership. “We also expect that the program might exert a positive effect on the older people’s attitudes towards aging and awaken them to the creative possibilities still available to them.” She noted that the research-based program reflects findings that:

- Medical students who interact with older people early in their medical training may have better attitudes towards aging,*
- Older people who internalize negative stereotypes of old age may experience heightened cardiovascular response to stress and reduced longevity.**

The NIA hopes to bring together medical students and older people at several other museums in cities across the country, said Jeannine Mjoseh, NIA public affairs specialist. For more information on health and aging, visit the NIA website, www.nia.nih.gov or call the NIA Information Center at 1-800-222-2225.

*Bernard, Marie A. An Evaluation of a Low-Intensity Intervention to Introduce Medical Students to Healthy Older People. *Journal of the American Geriatrics Society*. 2003. Mar;51(3):419-23.

** Levy, Becca. Longevity Increased by Positive Self-perceptions of Aging. *Journal of Personality and Social Psychology*. 2002. Aug; 83(2) 261-270. Reducing Cardiovascular Stress With Positive Self-Stereotypes of Aging. *Journals of Gerontology*, 2000. 55:205-P213. 🇺🇸



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

June 21-23, 2004

Challenges in Dementia Care: Can Technology Help People with Dementia?, Oslo, Norway

Contact:

ENABLE

The Norwegian Centre for Dementia Research

Box 64

N-3107 Sem

Norway

fax: +47 33 33 21 53

post@nordemens.no

www.enableproject.org

June 24-27, 2004

American Association of Neuropathologists 80th Annual Meeting, Cleveland, OH

Contact:

George Perry, Secretary-Treasurer

Institute of Pathology

Case Western Reserve University

2085 Adelbert Rd

Cleveland, OH 44106

216-368-2488

fax: 216-368-8964

aanp@cwru.edu

www.aanp-jnen.com

July 10-14, 2004

N4A's 29th Annual Conference, Atlanta, GA

Contact:

Martin Kleffner

National Association of Area

Agencies on Aging

202-872-0888

202-872-0057

mkleffner@n4a.org

www.n4a.org

July 15-16, 2004

Frontotemporal Dementia (FTD): Clinical, Genetic, Biomarker, & Pathological Perspectives, Philadelphia, PA

Contact:

Gayle Joseph

University of Pennsylvania

Center for Neurodegenerative

Disease Research

215-662-4708

fax: 215-349-5909

viale@mail.med.upenn.edu

www.uphs.upenn.edu/cndr/retreat.html

July 16-18, 2004

Alzheimer's Association 12th Annual Education Conference, Philadelphia, PA

Contact:

Alzheimer's Association

225 North Michigan Avenue

17th floor

Chicago, IL 60601-7633

312-335-5813

www.alz.org/educationconference2004/registration.htm

July 17-22, 2004

9th International Conference on Alzheimer's Disease and Related Disorders, Philadelphia, PA

Contact:

Alzheimer's Association

225 North Michigan Avenue

17th floor

Chicago, IL 60601-7633

312-335-5813

www.alz.org/internationalconference/registration.htm

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Is your organization sponsoring a conference about Alzheimer's disease or related disorders? To be included on the online ADEAR Conference Calendar and listed as an upcoming event in *Connections*, please send details in an e-mail to: adear@alzheimers.org. Be sure to include date, place, and all contact information.

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