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2004



Media Training Workshop Held. Media expert Kelly Burke, left, coaches Karen Bell, M.D., Columbia University Alzheimer's Disease Center, in a mock television interview, during a media training workshop focused on outreach recruitment of African-Americans.

Neuroimaging Initiative to begin recruiting in spring 2005

The National Institute on Aging (NIA) in conjunction with other Federal agencies, private companies, and organizations is launching a \$60 million, 5-year public-private partnership—the Alzheimer's Disease Neuroimaging Initiative—to test whether serial magnetic resonance imaging (MRI), positron emission tomography (PET), other biological markers, and clinical and neuropsychological assessment can be combined to measure the progression of mild cognitive impairment (MCI) and early Alzheimer's disease (AD).

The study could help researchers and clinicians develop new treatments and monitor their effectiveness as well as lessen the time and cost of clinical trials. The project is the most comprehensive effort to date to find (see Neuroimaging, page 3)

ADCS recruiters gain media expertise during workshop

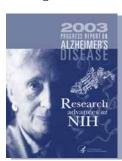
New treatments for Alzheimer's disease depend on clinical trials. Increasing the number of people who participate in clinical trials is a major goal of the NIA and the Alzheimer's Disease Cooperative Study (ADCS) at the University of California, San Diego. Recruitment of minorities is of particular interest because of low participation rates and high relative incidence of AD among African-Americans.

Recognizing that clinical trial recruiters need help developing key messages to the minority community, the NIA and ADCS recently (see Media Training, page 2)

AD Research Update

New Progress Report on AD published

Important AD research advances by NIA-supported scientists and other investigators funded by the National



Institutes of Health are summarized in the newly published 2003 Progress Report on Alzheimer's Disease. This year's report provides information on the

impact of AD, current understanding (see Report, page 4)

NIA welcomes new ADC in San Francisco



The NIA is pleased to announce funding of the University of California, San Francisco (UCSF) as an Alzheimer's Disease Center (ADC). In addition to offering a full complement of AD research, treatment, and diagnostic services, UCSF also provides expertise on diagnosis and treatment of frontotemporal dementia (FTD), conducts advanced research in prion diseases, and provides unique outreach services to the Chinese-American community.

(see UCSF, page 3)





Media Training

(from page 1)

sponsored a communications and media outreach training session. The NIA and the ADCS continue to look for ways to enhance minority participation in large nationwide studies such as: CLASP (Statin Study), VITAL (Homocysteine Study), VALID (Valproate Study), and the Huperzine Study.

The media training workshop was conducted at the NIA's Alzheimer's Disease Education and Referral (ADEAR) Center by the ADCS. Participants at the training session included several representatives from individual ADCS study sites at university hospitals and research clinics, including Washington University in St. Louis, Boston University, Columbia University, Medical University of South Carolina, University of Alabama, Rush University Medical Center, and the Mayo Clinic at Jacksonville, Florida.

The representatives met with media experts to discuss ways in which to involve African-Americans in large-scale trials. Attendees got tips and coaching on how to be spokespersons for their respective clinical trial sites, which are located in areas with large African-American populations. Participants developed key messages for their audiences and talking points for interviews and media presentations.

Trainers briefed workshop participants on various skills and tactics to use during media interviews and



Media Training Participants. From left, Floyd Willis, M.D., Mayo Clinic at Jacksonville; Chanta Witlow, University of Alabama, Birmingham; Consuelo Wilkins, M.D., Washington University in St. Louis; Lisa Barnes, Ph.D., Rush University; Mary Darling, Boston University; Warachal Faison, M.D., Medical University of South Carolina; and Karen Bell, M.D., Columbia University.

community presentations. Videotaped media interviews gave participants the opportunity for immediate feedback, as well as practice handling tough situations with reporters.

Karen Bell, Associate Clinical Professor of Neurology at Columbia University, appreciated the "on the spot" interview training she received. "The illustrations were very effective in pointing out the pitfalls of being unprepared. All of us can benefit from more time spent practicing our interviewing skills," she said.

Armed with their new media and interview expertise, the participants were asked to do four to six media interviews, either for radio, TV, or print, and to make three to four targeted presentations to local groups. Their efforts have already resulted in several news articles and interviews, as well as numerous community events.

Participants needed for clinical trials!

Nationwide, ADCS clinical trials to test potential AD treatments continue to seek volunteers. Contact the ADEAR Center at 1-800-438-4380, or www.alzheimers.org/trials for more information.

- CLASP—Cholesterol Lowering Agent to Slow Progression of AD Statin Study, investigating the safety and effectiveness of simvastatin (a cholesterol-lowering drug or statin) to slow the progression of AD.
- VITAL—VITamins to slow

Alzheimer's (homocysteine study), to determine whether reduction of homocysteine levels with high-dose folate (folic acid), B₆, and B₁₂ supplementation will slow the rate of cognitive decline in people with AD.

- TAP/DAP—Treatment of Agitation/ Psychosis in Dementia/Parkinsonism, to determine the safety and efficacy of quetiapine for the treatment of psychosis and/or agitation in patients with primary dementia complicated by coexistent parkinsonism, or patients with Parkinson's disease with dementia who have episodes of agitation or psychosis.
- VALID—VALproate in Dementia,

to demonstrate whether valproate therapy slows the progression of AD or delays the emergence of agitation and/or psychosis in outpatients with probable AD who have not experienced agitation and psychosis in their illness.

• HUPERZINE A—to determine whether treatment with *huperzine A*, a natural cholinesterase inhibitor derived from a Chinese herb, improves cognitive function in people with AD.

These studies are sponsored by NIA and the Alzheimer's Disease Cooperative Study at San Diego (http://adcs.ucsd.edu).

UCSF

(from page 1)

"UCSF is a leader in both basic science research and in exploring many important aspects of dementia and memory disorders. Its work has added significantly to our growing body of knowledge. We welcome this distinguished group of investigators and clinicians to the ADC program," said Richard J. Hodes, M.D., Director, NIA.

UCSF ADC Director Bruce Miller, M.D. will head the Clinical Core. His research is focused on the differential diagnosis of dementia and brain/behavior relationships, and he is an expert in FTD. He heads up a team that includes Stanley Prusiner, M.D., Nobel-prize winning researcher in prion diseases such as Creutzfeldt-Jacob disease; Mike Weiner, M.D., an authority in magnetic resonance imaging; Lennart Mucke, M.D., who has extensively studied proteinopathies; and

Stephen DeArmond, M.D., Ph.D., who is accomplished in both clinical and experimental neuropathology.

UCSF staff have a long history of working closely with many local San Francisco organizations, including the Veterans Administration, the Alzheimer's Association, and the Family Caregiver Alliance. "With the funding of our institution as an ADC, we hope to expand our basic research and outreach services. Our focus on both AD and non-AD dementias will also help us continue to explore the heterogeneity of dementias," said Dr. Miller.

A dementia program integrating this level of research and clinical effort has not existed in San Francisco previously. Now, a well-regarded medical school and skilled basic scientists will be able to increase the focus on aging and dementia issues. "A comprehensive dementia program will strengthen outreach into local communities to help elderly patients suffering from



Bruce Miller, M.D., UCSF ADC Director

cognitive disorders," said Creighton Phelps, Ph.D., Program Director, Alzheimer's Disease Centers, Neuroscience and Neuropsychology of Aging Program, at NIA.

Along with the clinical and education and outreach cores, the ADC structure includes a data management and biostatistical core, a neuropathology core, and an imaging core. Researchers hope to produce novel structural, chemical, and physiological data that will be used to study brain-behavior relationships and the role of MRI in the differential diagnosis of dementias.

Neuroimaging

(from page 1)

neuroimaging and other biomarkers for the cognitive changes associated with MCI and AD.

The NIA is joined in this partnership by the National Institute of Biomedical Imaging and Bioengineering (NIBIB) and by the Food and Drug Administration (FDA). The Foundation for NIH is managing corporate and other private participation, and has received commitments totaling more than \$20 million in contributions from the following companies and organizations: Pfizer Inc., Wyeth Research, Eli Lilly and Company, Merck & Co., Inc., GlaxoSmithKline, AstraZeneca AB. Novartis Pharmaceuticals Corporation, Eisai Global Clinical Development, Elan Corporation, plc, the Institute for the Study of Aging, and the Alzheimer's Association.

"This is an extraordinary pooling of talent and resources toward a common goal—delaying or preventing Alzheimer's disease," says Richard J. Hodes, M.D., Director of the NIA. "The initiative should become a landmark study in the development of neuroimaging and other biomarkers, helping us to find biological changes early so that we can identify the people at highest risk of the disease and test the effectiveness of new therapies more quickly and efficiently."

The study will take place at approximately 50 sites across the U.S. and Canada. In April 2005, investigators will begin recruiting about 800 adults, ages 55 to 90, to participate in the research—approximately 200 cognitively normal older individuals to be followed for 3 years, 400 people with MCI to be followed for 3 years, and 200 people with early AD to be followed for 2 years.

The study will compare neuroimaging, biological, and clinical information from these participants, seeking correlations among the data that will track the progression of memory loss from its earliest stages. Neuroimaging research has suggested that PET or MRI may serve as a more sensitive and consistent measure of disease progression than the neuropsychological and cognitive assessments now typically used in research and clinical practice. As MCI and AD progress, for example, areas of the brain involved with memory shrink. Researchers will evaluate the best ways of measuring this volume loss in the hippocampus and other brain structures.

PET scans assess brain function by measuring the rate of metabolism of glucose. PET scans of people with AD show that glucose in certain parts of the brain is metabolized at lower levels than in healthy people, and previous studies have shown that low glucose metabolism can be seen in some people even before noticeable symptoms of memory loss occur. The Initiative will seek to identify additional biological factors from blood, cerebrospinal fluid (CSF), and urine samples.

"Today, imaging is used to rule out other causes of memory problems, still not leaving the researcher or the clinician with a very clear idea of what is going on. By the end of this study, we should be able to use imaging and other biomarkers to accurately monitor disease

(continued on page 4)

Kit for Community Presentations on AD Now Available on CD-ROM

ALZHEIMER'S DISEASE

Families, patients, health care professionals, and the general public all need accurate and up-to-date information about Alzheimer's disease. To help volunteers, health educators, program directors, and other community speakers convey

basic information about AD, diagnosis, treatment, and current and future research, the ADEAR Center has developed a Speaker's Kit.

The Speaker's Kit
contains a PowerPoint
slideshow, Alzheimer's
Disease: Unraveling the
Mystery, based on the ADEAR
Center's popular booklet of the
same name.

A detailed *Speaker's Notes* document allows the speaker to expand on the information contained in each slide, and speakers can tailor the talk for their own audience. Additional files, including the booklet in PDF format, and low

and high resolution medical illustration files, are also on the CD-ROM.

The kit is designed for presenters speaking to lay audiences, such as community groups or clubs, volunteers, members of senior citizens' centers, and residents of retirement

communities. Presenters are also encouraged to adapt the presentation to address particular aspects of the disease, or to feature local resources.

The slideshow and accompanying support files are now available on

CD-ROM, and can be down-

loaded at the ADEAR Center's website: www.alzheimers.org/unraveling/speak_kit.html.

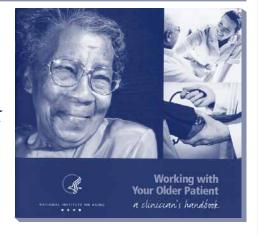
Copies of the CD-ROM and print copies of the booklet can be ordered directly from the ADEAR Center website at www.alzheimers.org, or by calling 1-800-438-4380, or by using the order form on the back page of the newsletter.

New NIA Publication

Working with Your Older Patient: A Clinician's Handbook

The NIA has updated and reprinted a free booklet called Working with Your Older Patient: A Clinician's Handbook. The Handbook provides practical tips to promote adherence to treatment and lists resources for more information. Primary care providers and health professionals who work with older people in an outpatient setting will find the Handbook useful. In addition, it is a helpful training tool for students and new practitioners. It also addresses difficult-to-discuss issues, such as driving, abuse, end-of-life care, incontinence, and sexuality.

Since older people may face



multiple illnesses, hearing and vision impairments, or cognitive problems, good communication techniques help both the patient and the health care professional. You can order a copy in several ways:

- go to www.niapublications.org/ pubs/clinicians2004/index.asp
- call the NIA Information Center at 1-800-222-2225.
- use the order form on the back page of the newsletter.

Neuroimaging (cont. from page 3)

progression and detect the effects of treatments which can slow that progression," says Michael W. Weiner, M.D., the study's Principal Investigator.

In September 2004, the Centers for Medicare and Medicaid Services decided to expand Medicare coverage of PET on a limited basis to include beneficiaries who meet the diagnostic criteria for both AD and frontotemporal dementia, who have been evaluated for specific alternate causes of dementia, and for whom the cause of the clinical symptoms remains uncertain, and for patients in certain large clinical trials. Studies such as the AD Neuroimaging Initiative and other research should help determine the value of PET scans for the broader Medicare population.

Recruitment for the study will begin in the spring of 2005. Questions and answers about the study and a list of participating sites are available by contacting the ADEAR Center (www.alzheimers.org, 1-800-438-4380).

Report (from page 1)

of the possible causes of AD, diagnosis, and treatment.

The *Progress Report* presents a detailed discussion of studies of the transformation from healthy aging to AD and the earliest cognitive and pathological changes in development of AD.

Recent studies involving biological markers and oxidative stress, beta-amyloid, presenilins, genetics, lifestyle, diet, inflammation, and additional AD risk factors are discussed. The *Report* also describes ongoing AD prevention and treatment clinical trials.

The final section highlights NIA's initiatives in neuroimaging, genetics, prevention, and cognitive and emotional health. You can order a copy in several ways:

- go to www.alzheimers.org/pr03/ index.asp
- call the ADEAR Center at 1-800-438-4380
- use the order form on the back page.

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.nlm.nih.gov/ medlineplus/databases.html.

Early Stage AD

Alzheimer's Early Stages: First Steps for Family, Friends and Caregivers. 2nd ed. 2003

Kuhn, D.

Available from Hunter House Publishers, P.O. Box 2914, Alameda, CA 94501-0914. Tel.: 1-800-266-5592 or 510-865-5282; Fax: 510-865-4295. Website: www.hunterhouse.com. PRICE: \$15.95 paperback, \$27.95 hardcover.

This book offers information and support to the families and friends of people in the early stages of AD. The book begins with a discussion of the medical aspects the disease, the need for an accurate diagnosis, symptoms of early AD, risk factors, and progress in treatment and prevention. The following section centers on caring for the loved one with AD, with information on the changes in relationships and roles that take place, and offers advice on making practical decisions, improving communication, planning for the future, and keeping the person with AD active and healthy. A chapter explores the experience of AD from the perspective of people with the disease. Suggestions to keep the caregiver healthy and positive include individual and family counseling, exploring spiritual resources, keeping a journal, and maintaining a sense of humor. Community resources such as support groups, respite care, and adult day care are also suggested. A resource section contains listings of AD Centers funded by the NIA.

AD Hospice Treatment

Living With Grief: Alzheimer's Disease. 2004

Doka, K.J., ed.

Available from the Hospice Foundation of America, 2001 S Street, Suite 300, N.W., Washington, DC 20009. Tel.: 202-638-5419; Fax: 202-638-5312. Website: www.hospicefoundation.org. PRICE: \$24.95.

Hospice principles can improve care for patients with AD and their families, according to Living with Grief: Alzheimer's Disease. The book provides background information about AD and related dementias, including the impact of dementia on society, the biology of AD, promising therapies, dementias other than AD, cultural influences, and dementia in older adults with intellectual disabilities. The book then presents personal accounts of the experience of AD from both patients and family members. How to help patients and caregivers cope with loss in AD is the focus of another discussion. Grief issues associated with the disease itself as well as the mourning that follows death, grief counseling for people with cognitive impairment, assessing grief in family caregivers, caregiving styles, and spiritual issues are among the topics. A look at the future of dementia care is presented, along with a discussion of the challenges of providing hospice care in dementia, ethical issues in end-of-life care, quality-of-life concepts in AD. Resources for family members and caregivers are included.

Palliative Care

Palliative Care: Complete Care Everyone Deserves. 2004

National Alliance for Caregiving

Available from the National Alliance for Caregiving, 4720 Montgomery Lane, Bethesda, MD 20814. Tel.: 301-718-8444. Website: www.caregiving.org. PRICE: free for 1 to 10 copies; over 10 copies, pay postage.

This brochure discusses palliative care for people with advanced illnesses, including those with AD and other types of dementia. The brochure explains the purpose and characteristics of palliative care and describes the elements of good palliative care, including advance care planning, care coordination, pain management, psychological counseling, spiritual help, and flexibility. It also suggests strategies for obtaining palliative care and working with nursing homes and other long-term care facilities. The brochure includes case examples of the types of patients who could benefit from palliative care and a list of resources.

Reducing Caregiver Distress

Innovative Interventions to Reduce Dementia Caregiver Distress: A Clinical Guide. 2003

Coon, D.W.; Gallagher-Thompson, D.; Thompson, L.W.

Available from Springer Publishing Company, 536 Broadway, New York, NY. Tel.: 212-431-4370; Fax: 212-941-7842. Website: www.springerpub.com. PRICE: \$46.95.

Emerging themes in dementia caregiving research and a broad array of practical strategies for reducing caregiver distress are presented in this book. Background issues related to the family caregiving experience, the monitoring and assessment of interventions, and the development of services for diverse cultural and ethnic groups are discussed in Part 1. Then, an array of practical interventions for relieving caregiver distress, including several novel approaches such as the use of technological advances and partnering with primary care physicians, are listed. Interventions for specific populations such as ethnic minority caregivers, male caregivers, and caregivers with diverse sexual orientation are discussed, as well as recommendations for future directions in dementia caregiving intervention research and practice.

Treating Disturbing Behaviors

Dementia Practice Guideline for Recreational Therapy: Treatment of Disturbing Behaviors. 2003

Buettner, L; Fitzsimmons, S.

Available from the American Therapeutic Recreation Association, 1414
Prince Street, Suite 204, Alexandria, VA 22314. Tel.: 703-683-9420; Fax: 703-683-9431.
Website: www.atra.org. PRICE: \$179.00 for nonmembers; \$99.00 for members.

This practice guideline for recreational therapists provides protocols for the treatment of disturbing behaviors in older patients with dementia. The first section discusses evidence-based practice and defines key terms, followed by an overview of disturbing behaviors in dementia, the different types of dementia, and risk factors for behavior problems. Need-Driven Dementia-Compromised Behavior (NDB) Model, which is a conceptual framework for understanding the

behaviors associated with dementia, is then described. A review of the literature supporting the use of recreational therapy as an intervention for disturbing behaviors in dementia, plus details of the steps in the recreational therapy process for treating disturbing behaviors, are contained in sections 4 and 5. General principles to follow for all recreational therapy protocols and precautions to take for common comorbid medical conditions are provided. Next is a graph to guide the recreational therapist in selecting protocols to use with patients and detailed descriptions of the protocols, including the staff requirements, client participation criteria, group size, duration, safety considerations, and facility and equipment requirements. The final sections contain appendices and references.

Recognizing Pain

Guide for Providing Quality of Life for Alzheimer's Patients: Recognizing Pain. 2003

Video Press

Available from Video Press, University of Maryland School of Medicine, 100 North Greene Street, Suite 300, Baltimore, MD 21201-1563. Tel.: 1-800-328-7450; Fax: 410-706-8471. Website:

www.videopress.org. PRICE: \$150.00 purchase; \$75.00 rental.

Unlike other long-term care residents, in many cases patients with AD are incapable of describing their pain to the health care provider. Part of a three-videotape series on providing quality of life for patients with AD, this tape focuses on the recognition of pain in AD patients. The first two tapes concentrate on communication and maintaining independence and involving the AD patient. In an interactive discussion with staff, Dr. Peter V. Rabins explains how caregivers can determine if a resident with AD is experiencing pain. He emphasizes that knowing the patient well is key because a change in behavior is the most common indicator that a patient is in pain. The nursing assistant is most likely to notice such a change and trigger a pain assessment.

Non-AD Dementias

Caregiver's Guide to Dementia. 2003

Radin, L. ed.; Radin, G., ed.

Available from Prometheus Books, 59 John Glenn Drive, Amherst, NY 14228-2197. Tel.: 1-800-421-0351 or 716-691-0133; Fax: 716-691-0137. Website:

www.prometheusbooks.com. PRICE: \$22.00.

A caregiver's guide to frontotemporal dementia (FTD), this book is designed to be both a resource and reference. It contains 25 chapters with practical information for health care professionals and families. Focusing on the medical aspects of FTD, it includes basic information about different types of dementia as well as specific information about FTD, including its clinical presentation and management, genetics, the health care team, drug treatments and other therapies, rehabilitation interventions, disease progression, the importance of autopsy, and future directions in FTD research. Part 2 discusses the management of daily care, including communicating, swallowing and eating, exercise and mobility, activities and socialization, hygiene and dressing, creating a safe environment, adapting to social and emotional changes, general medical care issues, and end-of-life care. Part 3, on caregiver resources, describes home health care and adult daycare services, nursing home and assisted living options, support networks, and financial and legal issues in FTD care. The final section discusses caring for the caregiver, including getting respite and coping with loss. The book includes a list of resources, suggested reading, and an index.



2005

March 3-6, 2005

American Association of Geriatric Psychiatrists Annual Meeting, San Diego, CA

Contact:

American Association for Geriatric Psychiatry

7910 Woodmont Avenue, Suite 1050

Bethesda, MD 20814 Telephone: 301-654-7850 Fax: 301-654-4137

Website: www.aagponline.org

March 9-13, 2005

7th International Conference on Alzheimer's and Parkinson's Disease, Sorrento, Italy

Contact:

Kenes International 17 Rue du cendrier P.O. Box 1726 CH-1211 Geneva 1

Switzerland

Telephone: +41 22 908 0488 Fax: +41 22 7322850 E-mail: adpd@kenes.com

Website: www.kenes.com/adpd

March 10-13, 2005

NCOA/ASA Joint Conference on Aging, Philadelphia, PA

Contact:

ASA-NCOA Joint Conference 833 Market Sreet, Suite 511 San Francisco, CA 94103-1824 Telephone: 415-974-9600

Fax: 415-495-6509

E-mail: jc05@asaging.org

Website: www.agingconference.org

April 9-16, 2005

American Academy of Neurology Annual Meeting, Miami Beach, FL

Contact:

American Academy of Neurology 1080 Montreal Avenue Saint Paul, MN 55116 Telephone: 1-800-879-1960 or

651-695-2717 Fax: 651-695-2791

Website: http://am.aan.com

May 19-20, 2005

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

Contact:

Alzheimer's Disease Research Center

UC San Diego

Telephone: 858-622-5850 E-mail: jcollier@ucsd.edu Website: http://cme.ucsd.edu/

events.cfm?cat_id=1

June 9-12, 2005

American Association of Neuropathologists Annual Meeting, Arlington, VA

Contact:

Office of Secretary-Treasurer Dr. George Perry Institute of Pathology Case Western Reserve University

Cleveland, OH 44106 Telephone: 216-368-2488

2095 Adelbert Rd

Fax: 216-368-8964 E-mail: aanp@cwru.edu

Website: http://www.aanp-jnen.com/

June 18-21, 2005

International Conference on Prevention of Dementia, Washington, DC

Contact:

Alzheimer's Association 225 N. Michigan Avenue

Suite 1700

Chicago, IL 60601

Telephone: 1-800-272-3900 Website: www.alz.org

E-mail: prevention@alz.org

June 20-22, 2005

Dementia: Molecules to Management, Brisbane, Queensland, AUSTRALIA

Contact:

Australian Society for Geriatric Medicine

c/o Organisers Australia PO Box 1237

Milton, Queensland 4064

AUSTRALIA

Telephone: 61 7 3371 0333 E-mail: asgm@orgaus.com.au Website: www.asgm.org.au

July 26-29, 2005

13th Annual Dementia Care Conference, Chicago, IL

Contact:

Alzheimer's Association 225 N. Michigan Avenue Suite 1700

Chicago, IL 60601

Telephone: 1-800-272-3900

Website: www.alz.org

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□ Unraveling the Mystery of Alzheimer's Disease booklet			
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Or, you may order these materials by mail or fax to:

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You also may call our toll-free telephone number: 1-800-438-4380,

or contact us via e-mail: adear@alzheimers.org



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