

Advances

Progress in Alzheimer Research and Care

Groups Provide an Oasis of Support

*no man is an island,
no man stands alone.
each man's joy is joy to me,
each man's grief is my own.*

*Alex Kramer and Joan Whitney,
"No Man is an Island," 1950*

The above song lyrics, based on English poet John Donne's *Meditation XVII*, may perhaps form the core belief behind Alzheimer support groups. The idea that we're not isolated from one another—that, instead, we're interconnected—is exemplified in the coming together of people with Alzheimer's and their care partners and family members to face the rigors of the disease.

"When people are allowed to express themselves in a safe setting, they learn to divide problems into a series of issues to be addressed, such as diagnosis, treatment, family issues, planning for the future, loss of intimacy, and needs for connection," says Sharon Shaw, a consultant to the Alzheimer's Association's New York City Chapter. "By participating in a well-run session, with a leader trained in group skills and sensitive to the disease's emotional impact, members learn to cope more effectively by changing the way they feel about their experience."



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The Alzheimer's Association Newsletter

Published quarterly for individuals affected by Alzheimer's disease and their care partners.

Vol. 23 No. 2 Summer 2003

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To find the date and location of your local Memory Walk and to register:

www.alz.org/memorywalk
800.272.3900

*Special thanks to our official
2003 Memory Walk
sponsors GE Financial Advisors
and Creative Memories.*

Memory Walk

Memory Walk 2003 will kick off across the country this fall when thousands of people participate in their local 5K walk to support the fight to end Alzheimer's. Individual walkers and teams of families, friends, and coworkers participate to honor someone they love and to celebrate the strides being made in research and care.

"I'm gung-ho about the walk because I lost an angel to Alzheimer's in May 2002," said Larry Fargher, of Santa Clara, California, who raised \$18,000 last year. "My wife's progression was slow and my family experienced 20-plus years of what Alzheimer's does. Last year my daughter, Laure, and her daughter, Vanessa Camille, joined me. We will have family participation in Memory Walk for many years to come."

Launched in 1989, Memory Walk is the signature fund-raising event of the Alzheimer's Association and walkers have collected more than \$120 million to support our mission. This year's fund-raising goal is \$22.5 million. All funds raised locally stay in your community to help create and maintain vital services, such as Alzheimer's and related disorders helplines, support groups, and education programs.

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Working toward an Alzheimer's cure

research



Open Hearts, Open Minds: “Vaccine” Trial Autopsy Advances Science

The first autopsy on a participant in the 2001–2002 clinical trial of the “Alzheimer vaccine” shows that the drug produced powerful effects throughout the brain, according to scientists in the March 16 on-line edition of *Nature Medicine*. In the most striking finding, significant regions of the 73-year-old woman’s brain lacked the amyloid plaques targeted by the vaccine—a phenomenon not seen in the brains of seven “unvaccinated” individuals with Alzheimer’s who were also included in the autopsy study. In addition to shedding light on the vaccine’s impact, these results highlight the critical contribution that postmortem brain examination makes to Alzheimer research.

Developed by Elan Corporation, plc, and Wyeth under the investigational name AN-1792, the vaccine is a synthetic form of beta-amyloid, the protein fragment that accumulates into plaques, a hallmark Alzheimer pathology. Scientists reasoned that inoculation with beta-amyloid might mobilize the immune system to generate anti-amyloid antibodies. Preliminary studies in mice genetically engineered to produce human amyloid suggested that the inoculations not only reduced plaques, but also improved the animals’ ability to remember their way through mazes. Based on these promising results, the vaccine moved from animal studies to human trials in near-record time.

Excitement turned to heartache for the Alzheimer community during Phase II human tests when 15 of 360 participants—including the woman in this study—developed symptoms of brain inflammation and researchers had to stop administering the vaccine. Results of this autopsy confirm the woman’s brain showed widespread ongoing inflammation and other abnormalities.

In other potentially cautionary results, the autopsy found no evidence that AN-1792 reduced beta-amyloid deposits

found in the brain blood vessels of most individuals with Alzheimer’s or that it affected neurofibrillary tangles, the other hallmark Alzheimer pathology.

One question of vital importance that this study didn’t help answer is whether the vaccine has any impact on the symptoms or progression of Alzheimer’s disease. Cognitive tests of trial participants are ongoing and investigators have not yet made testing data public.

“The current case highlights not only the risks awaiting future attempts at Alzheimer immunotherapy, but also the considerable promise for the potential effectiveness of this approach,” commented Alzheimer’s Association 2000 Pioneer research grant awardee Bradley T. Hyman, MD, PhD.

A Critical Window to the Brain

“There really is still no substitute for looking directly at the human brain,” explains Deborah C. Mash, PhD, founder and director of the University of Miami’s Brain Endowment Bank in Miami, Florida. “All of our current knowledge correlating Alzheimer pathology with clinical symptoms and degree of impairment is based on direct brain observation.”



Emerging techniques are now enhancing these correlations by enabling scientists to identify every gene and every protein expressed in brain tissue. This comprehensive analysis has the potential to link pathology and symptoms with cellular and molecular processes—connections that will provide vital insights into the mystery of Alzheimer’s and related disorders.

One observation of ongoing interest to Alzheimer researchers is that a number of brains with significant plaque deposits come from older individuals with no memory or thinking impairment. “One of the biggest questions in Alzheimer research, and one that the vaccine trial may help us answer, is whether amyloid is really our prime suspect,” adds Mash.

The Brain Endowment Bank currently contains hundreds of specimens and maintains close relationships with 800 prospective donors from across the country. “Anyone, anywhere who decides to donate his or her own brain or the brain of a loved one to research becomes part of our extended family,” says Mash. Nurses and social workers work with future donors and their health care professionals to update a detailed medical and personal

history documenting everything that might conceivably affect brain health and aging.

A donor’s death activates part of a nationwide volunteer network of medical examiners, pathologists, and other professionals who follow a standardized protocol for collecting the brain. Participation in the program is free to donors and each donor’s family receives a detailed neuropathology report. Tissue specimens are provided free to researchers across the United States after the brain becomes part of the collection.

“Our brain bank is under armed guard because our donors’ legacies are literally priceless,” Mash points out. “These are bequests for which we should all be thankful.” For her tireless work in creating and sustaining this vital resource, Mash was recognized as the medical honoree at the 2002 Chicago Rita Hayworth Gala.

Brain Donation Making a Difference, Changing the Future

The University of Miami Brain Endowment Bank would always like to hear from potential donors. Donations are sought from older individuals with and without Alzheimer’s and other brain disorders as well as from younger individuals and especially from African Americans, Latinos, and members of other ethnic minorities.

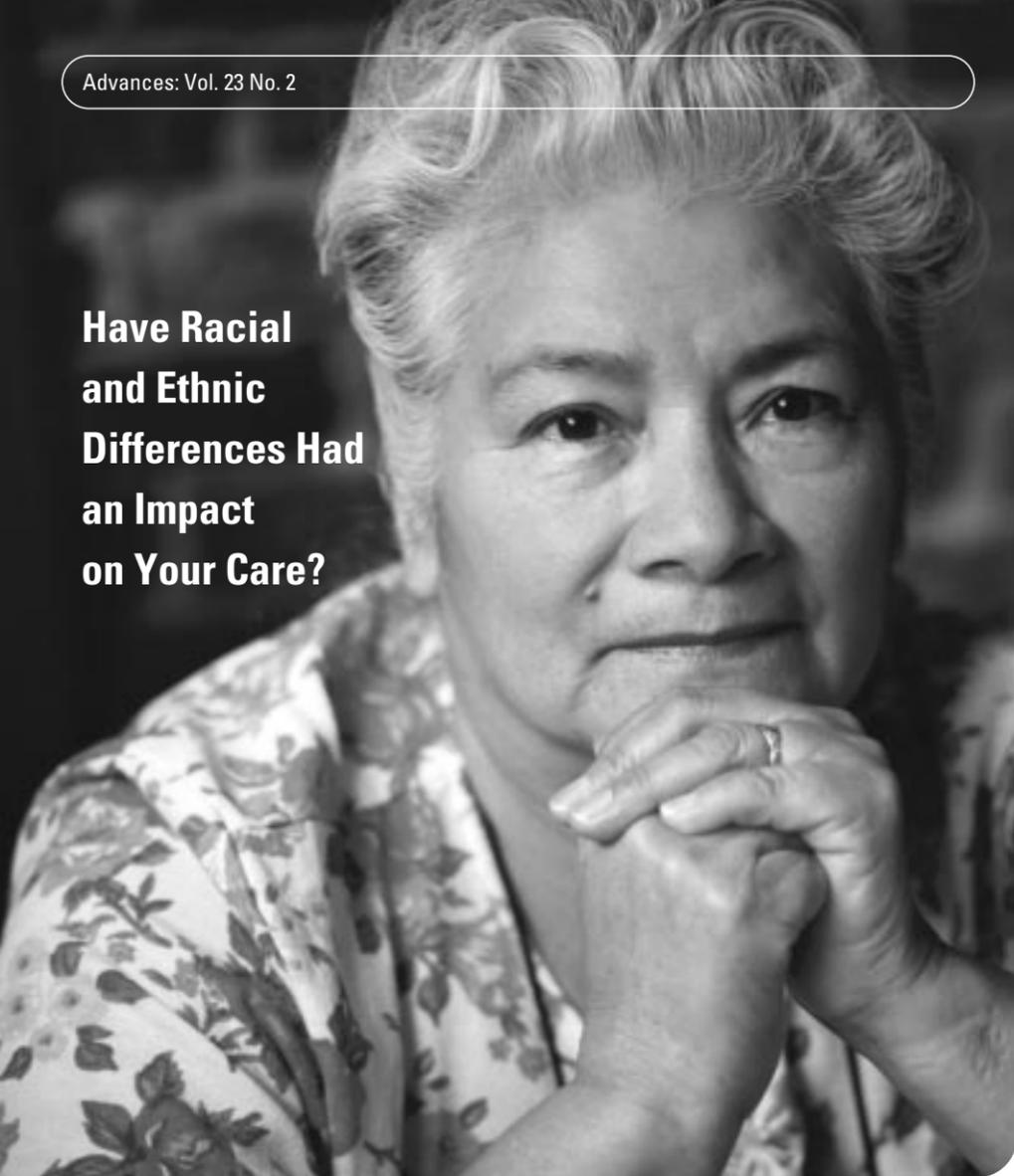
For More Information

800.UM.BRAIN

brainendowmentbank@yahoo.com



Have Racial and Ethnic Differences Had an Impact on Your Care?



Some individuals from diverse ethnic communities view Alzheimer's as a spiritual test, punishment, or mental illness that extends beyond the diagnosed individual to the entire family. Others believe dementia is "normal" aging, while others who have emigrated from another country may be afraid to ask for help.

Reader Feedback

None of the caregivers *Advances* talked to felt that racial and ethnic differences impacted their loved ones' care.

While many of her African American friends are in denial about Alzheimer's disease, Evelyn Proctor, 79, candidly

tells them "to get over it." Although her husband Willie died in 1994 after 13 years with the disease, Proctor still keeps Alzheimer literature and freely passes out the Association's toll-free number. Friends of friends call the Oklahoma hairdresser for advice. "This disease can kill the caregiver emotionally. You can't do it alone."

At the University of Oklahoma Health Sciences Center, Vicki Lampley-Dallas, MD, MPH, and colleagues held focus groups with 13 African Americans impacted by Alzheimer's disease to address barriers to care and to provide health care professionals with a better understanding of what caregivers expect.

dialogue

"Caregivers did not believe the physician's race made a difference. They expected the doctor to have a working knowledge of dementia, make the correct diagnosis, and explain the disease process. Some doctors understood; others did not," said Lampley-Dallas, in a 2001 study published in the *Journal of the National Medical Association*.

Finding the right doctor is crucial. Patricia Schwarzmann, a Latina from Los Angeles, California, initially had difficulty grasping the enormity of her husband's disease, and her Harvard-educated internist was not helpful. "He turned to me and said, 'Patricia, I know nothing.' He referred us to a neurologist who was condescending. We walked out." Like many people, Schwarzmann, 66, found resources through her priest.

Breaking Down Barriers

Through its coast-to-coast chapter network, the Alzheimer's Association is breaking down barriers and ensuring that culturally sensitive programs, services, and resources are available to everyone victimized by Alzheimer's disease.

"We're committed to actively fostering diversity, inclusion, and cultural competency through our programs, public policy, research, development, and operational efforts," says Miriam Brewer, the Association's associate director of diversity and inclusion outreach.

The Association is reaching out to community groups to increase awareness of Alzheimer's. These

"I will never place my mother in a nursing home!"

include the African American Outreach Initiative, comprised of 200,000 members of Delta Sigma Theta Sorority, Inc., and the National Caucus and Center on Black Aged. A partnership with the National Medical Association is also being established.

Recognizing the need to "speak the language" of the seniors we serve, the Association's Greater Illinois Chapter has partnered with Northwestern University, the Coalition of Limited English-Speaking Elderly (CLESE), the Illinois Department of Public Health, and the Illinois Department on Aging to identify, screen, diagnose, and treat Russian, Chinese, Polish, Korean, and Spanish elderly.

Rate of Minority Elders Increasing

The U.S. population of all minority seniors is increasing faster than that of Caucasian elders. Minorities are expected to double to two in 10 by 2050. "The number of elderly African Americans is expected to triple in this period, while the size of the elderly Latino population, which is growing even faster, may exceed that of the elderly African American population within 30 years," according to *Geriatrics Review Syllabus*.

More than six million Latinos live in the Greater Los Angeles area. Through 10 years of leadership with the El Portal program, the Association developed a coalition of service providers in East and Southern Los Angeles. The coalition assessed community needs and developed a system of care built of the strengths of each participating agency, including

support groups, diagnostic centers, a legal clinic, care management services, day care centers, and a Spanish helpline.

"The El Portal model is a proven strategy," says Meyling Eliash Daneshfar, manager of Latino Services, Los Angeles, Riverside, and San Bernardino Counties Chapter. "We've consulted with chapters nationwide, as well as providers from Puerto Rico, Mexico, and Costa Rica."

Like many Latino care partners, Rosa Meza is reluctant to seek outside help to care for her mother, Maria Salazar, who suffers from moderate Alzheimer's disease. She says she will never put her mother in a nursing home even though Maria, 73, has difficulty walking and talking, and also suffers from incontinence.

"I clean up my mom and she says, 'thank you, thank you.' Sometimes my mom is happy and I do not want to miss any of those moments," says Rosa, 48, one of nine children and her mother's sole caregiver. The Huntington Park, California, resident works nights as a seamstress so she can care for her mother during the day. She is more relaxed now due to the support of the Alzheimer's Association.

Rosa attends a bilingual support group twice a month. The chapter also helped her find a Spanish-speaking doctor for her mother. She advises, "Get help, there is help."

For More Information

800.272.3900 / www.alz.org

A Loved One Has Dementia: How Do You Help Children and Teens Cope?

A child or teen may feel neglected and resentful when parents become caregivers and they have less time to spend with them. Teens may become angry when they have to repeat the same question over and over to a loved one who no longer recognizes them.

We Want to Hear From You!

How do you discuss Alzheimer's with younger family members? What is their reaction? What resources, books, or videos are helpful in addressing this topic? What activities do your children participate in with the Alzheimer-affected family member? For example, they look at photo albums together or perhaps they've written a poem or story to express their emotions. We encourage adults and children (with a parent's permission) to share their experiences and advice for coping and interacting strategies.

Your experiences could be included in a future "Dialogue" article. Please send your stories to us no later than July 3.

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Treating the Whole Person, Part II

Medication Management

Older people are likely to have a number of long-term medical conditions, such as diabetes or high blood pressure, and are particularly vulnerable to infections. If each possible medical condition is considered a single problem that requires a single medical solution, the result is often the use of multiple medications. The results may cause more harm than good.

If we think about treating the whole person, rather than individual conditions, we can make medical decisions that meet overall health goals. In the spring issue of *Advances*, we discussed the importance of the relationship between the person with dementia, the care partner, and the primary care physician who can coordinate all treatment decisions. In this second part, we will focus on medication management when treating coexisting medical conditions.

Problems With Too Many Drugs

The age 65-and-older community, which comprises about 13 percent of the U.S. population, consumes an estimated 30 percent of the drugs prescribed in the U.S. This figure does not include over-the-counter drugs, vitamins, herbal remedies, and other supplements, all of which essentially function as medications that affect how our bodies work.

Taking multiple medications can cause problems for any individual, especially for older adults and, in particular, for people with dementia.

- Taking several medications may increase the number of errors in following appropriate guidelines.
- An increase in medications will increase the likelihood of unwanted or harmful interactions.
- Physical changes associated with age may affect how a medication is distributed, used, or excreted by the body.
- A person with dementia may be particularly sensitive to the side effects of medications that have an impact on alertness, mood, or thinking abilities.

Simplify, Simplify, Simplify

When medications are not managed by a single physician or pharmacy, there is risk of starting a cascade effect with one drug being used to treat symptoms that are side effects of another. This cascade can cause more health problems, reduce quality of life, and waste financial resources.

The best use of medication is the simplest regimen that meets the overall treatment goals agreed upon by the person with dementia, the care partner, and a primary care physician.

“Simplifying the treatment program is my target,” says Eric Tangalos, MD, an internist at the Mayo Clinic in Rochester, Minnesota.

One strategy for checking medication use is to conduct an occasional “brown bag” survey with the primary care physician. This includes a review of any prescription drug, over-the-counter drug, herbal remedy, vitamin, or other supplement that the individual may be taking. This exercise can help the physician discuss the risks and benefits of the different medications, identify potential problems, and recommend the simplest, most appropriate regimen.

Care Partner’s Role

The care partner’s role in decisions about medication and proper use of medication increases significantly as dementia symptoms progress. Geri R. Hall, PhD, ARNP, associate clinical professor at the University of Iowa College of Nursing, encourages people to be actively involved in medication decisions and ready to ask questions.

Hall recommends that the care partner keep the following issues in mind:

- Make sure you have a clear explanation of the purpose of each medication. It is all right to ask, “Is this medication necessary?”

- Ask whether a new medication is being started at the lowest dose possible.
- Be sure that new medications are introduced one at a time, if possible, in order to monitor effect more accurately.
- Ask if a new medication is meant to replace another, so that the other should be stopped.
- Ask for written explanations about how and when the drug should be taken, what side effects to watch for, and when you should call about adverse effects.
- Ask about the desired treatment outcomes: How long might it be before we know if it is effective? When will we reevaluate the treatment? Under what conditions might we consider stopping or changing the medication?

Double-check about potential drug interactions with your pharmacist, most of whom have access to large databases of drug information.

Following Prescribed Drug Plan

Compliance, or following the prescribed drug regimen, is important. Taking a drug as prescribed may have a significant impact on its effectiveness. For example, it may matter whether it is taken at a certain time of day, with or without food, or at the same time as another drug. If a person repeatedly stops and

starts taking a medication, it may not work safely or effectively.

Noncompliance, a relatively common problem among older adults, is a significant concern when a person has dementia. The individual may not remember to take medication, forget that he or she has already taken the medication and repeat a dosage, or not understand why taking the drug is important. The care partner, therefore, plays a critical role in ensuring the regular and appropriate use of drugs.

Noncompliance can also disrupt medication management. If the physician is unaware that the individual has not taken the prescribed course, he or she may prescribe a higher dosage in order to achieve the therapeutic goal.

Talking About When to Stop

As the disease progresses and treatment goals evolve, it may be necessary to discontinue treatments. Lisa Gwyther, MSW, director of Duke University Alzheimer’s Family Support Program, notes that the care partner should not hesitate to question the necessity of a drug even if it met a desired treatment goal at one time. Appropriate questions include the following:

- What changes over what period of time can we expect if we end a treatment?

- If there are withdrawal symptoms, how long might they last?
- How will these effects align with our overall treatment goals?
- Should we end the treatment all at once or gradually?

In the final stages of Alzheimer’s disease, the guiding principle of simplifying the drug regimen usually focuses decisions on very narrow goals. The decisions about treatment near the end of life should be driven by an effort to alleviate pain and discomfort. Tangalos notes, “As we reach the end, we want to ensure as much comfort and dignity as possible.”

Receive a copy of the first part of “Treating the Whole Person.”

For More Information

800.272.3900 / www.alz.org

Partnering With Physicians

Beginning this fall, Alzheimer’s Association chapters in 26 states will offer a 90-minute workshop and guide for individuals experiencing memory loss and their care partners titled “Partnering With Your Doctor: A Workshop for Persons With Memory Problems and Their Care Partners.”

For More Information This Fall

800.272.3900 / www.alz.org



Savor Summer, Keep Alzheimer Special Needs in Mind

The summer sun, the smell of fresh-cut grass and brightly colored flowers, and picnics and barbecues are just a few reasons to savor summer. Summer is also the start of a high travel season, with all of us feeling the need to “get away,” whether it’s to a neighborhood park or on a vacation.

As care partners, it’s important to consider the extra care needed for the Alzheimer individual who enjoys summer activities. Uncovered swimming pools or bodies of water can present challenges from accidental drowning so it’s important that the person affected by Alzheimer’s be supervised at all times. The same precaution should be taken around barbecue grills, campfires, or lawn candles. Unfamiliar surroundings, like airports, ballparks, or hotel rooms, can also put a person with Alzheimer’s disease at greater risk of wandering. This common and potentially life-threatening behavior affects nearly 60 percent of people with Alzheimer’s who wander off and become disoriented and lost in their own neighborhoods or far from home.

In 1993, more than 100,000 individuals have been registered in the nationwide safety identification program, and nearly 8,000 individuals have been found and safely returned to their families and caregivers. Safe Return’s one-time enrollment cost is \$40, which includes registration in a national database to assist law enforcement agencies and others in the search; access to a 24-hour, toll-free telephone number; and identification products including jewelry and wallet cards.

Summer Safety Tips

Whether your loved one is traveling away from home or enjoying outside activities at or near home, there are simple modifications that can help to create a safer and supportive environment for people with dementia. Consider the following:

Avoid overexposure to warm weather, as a person may be overly sensitive or unable to ask for a drink of water or break from the weather. Coach him or her to drink fluids to avoid dehydration.

Stick to an individual’s daily routine as much as possible. For example, have the person eat and take prescribed medicines at regular times. Modify the environment by locking gates to fences and all doors to houses and hotel rooms.

Ensure grills, lawn mowers, weedwackers, power tools, drills, axes, and saws are out of reach and secure. Disconnect gas grills when not in use.

Visit airports and public venues at less busier times to cut down on noise and confusion. Make sure facilities are accessible to people with disabilities.

Involve the person in activities such as packing, folding clothes, or watering flowers.

Take along familiar and comforting items such as scrapbooks, photo albums, or old magazines when traveling by car, train, or plane. Build in time for stretch breaks.

Choose hotel rooms with showers/tubs that offer grab bars, shower seats, and textured decals.

Diffuse bright light/reduce glare; close window shades or draperies to block bright sunlight.

Remove electrical appliances like hairdryers and window fans, to reduce the risk of electrical shock.

For More Information

800.272.3900 / www.alz.org

Safe Return Program

888.572.8566 / www.alz/safereturn

“While wandering is always potentially dangerous, the hot summer weather can prove fatal, putting wanderers at greater risk of dying from exposure or dehydration. If not found within 24 hours, nearly half of those who wander may die,” says Brian Hance, associate director of the Alzheimer’s Association’s Safe Return Program. Since the program’s founding in April

Association Advocates \$1 Billion Research Goal

“There is a disaster looming on the horizon that only President Bush and Congress can prevent,” said Sheldon L. Goldberg, president and CEO of the Alzheimer’s Association, testifying before the Senate HHS Appropriations Subcommittee on April 1. “The U.S. health care system is about to implode, and Alzheimer’s disease will be the detonator. Congress must act to prevent the economic disaster and human tragedy that Alzheimer’s will cause.”

Aided by powerful testimony from nationally recognized leaders, the Alzheimer’s Association is actively advocating for \$1 billion in federal funding for Alzheimer research to fund more vital research into the causes, treatment, and prevention of Alzheimer’s disease.

The Association’s advocacy efforts have centered around a few key messages. If our elected officials are serious about saving our health care system and controlling Medicare and Medicaid costs, they must substantially increase our nation’s investment in Alzheimer research before 14 million baby boomers succumb to the disease. There is a narrow window of time to prevent the devastating impact of Alzheimer’s on families, businesses, and the U.S. economy.

As a result of the Association’s increased focus on advocacy, federal support for Alzheimer research funding has grown

to approximately \$650 million this year. The Association is currently calling on Congress to increase that amount by \$200 million in 2004 as the next step toward the billion-dollar goal.

Taking the Message to Congress

Rallying around the theme, “Many Voices One Message,” nearly 400 Alzheimer advocates nationwide converged on Capitol Hill March 29–April 1 for the Association’s 15th Public Policy Forum in Washington, D.C.

The Association’s Capitol Hill day April 1 was passionate and inspiring. A standing-room only hearing before the Senate Labor, Health and Human Services Appropriations Subcommittee featured powerful testimony from Dr. Richard Hodes, head of the National Institute on Aging, and Dr. Marilyn Albert, chair of the Association’s Medical and Scientific Advisory Committee.

Compelling testimony came from two courageous individuals who spoke about their own fight with Alzheimer’s. Dubuque, Iowa resident Mary Jean Uptegraph, whose husband Dwayne was diagnosed with early-onset Alzheimer’s one week before his 53rd birthday, urged the Senate to provide a \$200 million increase in research funding. “Dwayne’s father died of Alzheimer’s, my grandmother and an aunt suffered from dementia. We worry that we have passed this disease on to our children and grandchildren,” she said.



Donald Kurtz, 59, of Blue Bell, Pennsylvania, told lawmakers that increasing research funding should be one of the nation’s top priorities. “I participated in 51 missions in Vietnam. Today I am on a single mission—to urge Congress to increase the federal government’s investment in Alzheimer research. I’m here to send the message that we cannot abandon our most urgent priorities at home, including the fight against Alzheimer’s.”

Become an Alzheimer Advocate

Make your voice heard! Write to Congress and help educate your legislators about Alzheimer’s issues. Visit the Association’s Web site to find your Senators and Representatives by typing in your zip code. Sample letters and talking points are provided to help you compose an e-mail message or letter to your elected officials.

For More Information

www.alz.org/advocates/overview.htm
Click on “Write Congress” button.



Several hundred people attended the inspirational Candlelight Vigil.

Photos by R. Langan, Green Bay, Wis.

around the association

Association Partners with Kaiser Permanente to Address Dementia Needs

The Association has entered into a multiyear collaboration with Kaiser Permanente on the managed care industry's first program designed specifically to address the special needs of those with Alzheimer's disease and other dementias. Developed by Kaiser Permanente's Care Management Institute (KP-CMI), the program is a culmination of a 10-year working partnership between the Association and Kaiser, the nation's largest nonprofit health maintenance organization with more than 8.4 million enrollees. The breakthrough KP-CMI Dementia Care Program provides guidelines and tools to primary care providers, nurses, and social workers on the proper screening, diagnosis, treatment, and management of behavioral symptoms, as well as linkage to the Association and other community services.

For More Information

www.kpcmi.org/products/programs/dementia/Dementia_GL_Summary.pdf

Thank You for Your Generosity

Donors are the lifeblood of the Alzheimer's Association. From a single dollar to a million dollars and beyond, each donation gets us closer to achieving our mission: a world without Alzheimer's. We appreciate the recent generosity of the following people:

- Since 1985, the National Association of Retired Federal Employees (NARFE) has been a leading partner in advancing Alzheimer research. NARFE will soon complete its pledge to raise **\$5 Million by 2005**—approximately two years ahead of schedule. NARFE has also extended its successful campaign and will raise an additional \$2 million, bringing its cumulative fundraising to **\$7 Million in 2007**.
- Marshall Gelfand has initiated a \$1.5 million campaign to establish The Judy Gelfand Alzheimer Research Fund (The Judy Fund), in honor of his beloved wife. The Judy Fund will support leading scientists launching vital investigations that strive to prevent and cure Alzheimer's disease. As of this printing, Mr. Gelfand's efforts have raised \$955,000 in gifts and pledges.
- John Osher, of Palm Beach Gardens, Florida, has become a member of the Zenith Fellows program with a commitment of \$1 million. The Zenith Awards support some of the most significant scientific investigations aimed at unlocking the secrets of Alzheimer's disease.

For More Information on Making a Donation

800.272.3900 / www.alz.org

in brief

in the news

Wave of Alzheimer Research Spotlights Scientific Momentum

The recent simultaneous release of seven large-scale studies examining a range of scientific paths in Alzheimer's disease is an exciting reflection of the current momentum in Alzheimer research. The studies, funded by National Institute on Aging, were published in the *Archives of Neurology* (Feb. 2003). The articles span research into risk factors for dementia, such as blood pressure, dietary fat, and antioxidants, to studies comparing Alzheimer's disease incidence among racial groups, the effect of estrogen on cognitive function, and a study on active life expectancy.

Streisand Necklace Nets Thousands for Alzheimer's Research

In February, a Barbra Streisand-designed platinum heart necklace was auctioned at Sotheby's and earned a high bid of \$13,300. Streisand selected the Alzheimer's Association to benefit from the sale of the necklace as part of the Women With Heart™ program, a celebrity design and charity auction campaign sponsored annually by Platinum Guild International USA.

The inspiration for the design was her mother, Diana Streisand Kind, who had Alzheimer's and died last year. "I know the pain of caring about someone who is still alive but is forever beyond any meaningful contact," Streisand said.

Groups Provide an Oasis of Support

continued from page 1

Support groups generally comprise people who gather to discuss a problem, condition, or life situation and who believe that sharing personal details can result in emotional or practical help in coping. Such meetings can serve as an outlet for emotions and frustrations as well as a source of information for people with Alzheimer's and their care partners. The many benefits of support groups include:

- discovering community resources
- understanding the behavior of the individual with Alzheimer's
- hearing validation for negative or ambivalent feelings
- learning specific strategies to handle behavior
- receiving encouragement to maintain or regain personal lives
- increasing self-esteem, as members acknowledge each other's efforts, successes, and growth

The two distinct types of support groups are those open to both the person with dementia and their family members/care partners and those only for care partners. Through its chapter network, the Alzheimer's Association sponsors over 4,000 support groups covering a wide range of issues, topics, and participants, such as early-stage, children/teens, Down syndrome and Alzheimer's, veterans, Spanish-speaking, and gay/lesbian.

In addition to in-person gatherings, telephone and on-line communities exist for people who either find conventional support groups

inconvenient or who live in rural areas. For example, the Association's Los Angeles, Riverside, and San Bernardino Counties Chapter has developed Alzheimer's Supportive Online Services, where care partners interact via Internet message boards and moderated chat sessions.

On-Line Connections

"The benefit of the on-line service is that caregivers can log on, ask questions, or respond to peer inquiries at any time, day or night," says Amy Corwin, the chapter's support group manager. "This provides more control and the opportunity to interact, share, and feel connected."

The Georgia Chapter's Caring Connection is a twice-monthly telephone group developed for family care partners unable to attend in-person sessions. Dialing an 800 number, participants "meet" on the first and second Thursday evenings of each month for one hour. "The program allows for needed support when members are unable to leave their homes due to lack of transportation, caregiving responsibilities, frail health, or living in a rural area," comments John Thames, family and community services director for the chapter's Atlanta office. "Many participants say the group provides them with moral support, encouragement, friendship, decreased isolation, and sympathy from people impacted by Alzheimer's disease."

No matter the format, support groups can be a boundless source of information and sustenance during the many stressful

cover story continued

stages of Alzheimer's. "I felt like I was at the end of my rope with my mom," remarks a member of a care partner support group operated by the East Bay Office of the Northern California Chapter. "I was exhausted from the stress of trying to correct her all the time and trying to keep her as she was before. The group taught me that this wasn't fair to her. Our life together has dramatically improved. I have learned so much from the people in our group."

Adds an individual with Alzheimer's who participates in the chapter's early-stage support group: "I was so frightened when I received my diagnosis. Now I feel like I'll be able to cope for a long time. I've met people (in our group) that have had Alzheimer's disease for a longer period of time, and they're still coping and enjoying life. I can do it, too."

For More Information

800.272.3900 / www.alz.org

