

Advances

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Education Conference Celebrates Milestone 10th Anniversary

Nearly 1,200 people—some from as far away as Australia, Nigeria, and Canada—flocked to Chicago in mid-July for the 10th National Alzheimer's Disease Education Conference at the Hyatt Regency Chicago. The conference began with in-depth preconference intensive sessions discussing such crucial topics as comfort care at the end of life and creating a community dialogue to discuss ethical issues in Alzheimer's disease.

In keeping with the conference theme—*New Directions in Alzheimer Care*—more than 250 speakers offered their best-practice advice in a wide variety of education sessions on virtually every topic important to family and professional caregivers. The conference focused on groundbreaking directions in four key areas:

...serving diverse populations, providing innovative programs and practices, building and supporting the dementia care workforce, and enhancing care delivery.

New programs included peer-facilitated interest groups, poster sessions showcasing research and program initiatives from around the world, film viewing and discussion, and site visits to innovative local care facilities. It was also smooth sailing on the Lake Michigan boat cruise for over 700 attendees.

Visionaries Create Education Conference

At the opening plenary session, Orien Reid, chair of the Association's national board of directors, warmly welcomed attendees to a milestone 10th anniversary education conference. "This education conference is a

(Continued on page 11)



Photo By Larry Dermody

Sally Callahan, faculty presenter of "A Daughter's Dilemmas," left, and former conference co-chair Dorothy Seman are all smiles.

Beta-Amyloid: Investigating a Prime Suspect in Alzheimer's Disease

In July 2001, the makers of the experimental drug AN-1792 announced the opening of Phase II clinical trials. These studies will test the drug's effectiveness in treating people recently diagnosed with Alzheimer's disease. AN-1792, which is often referred to as the Alzheimer "vaccine," is designed to prompt an immune system response to a protein fragment called beta-amyloid (A β). A β is the primary component of amyloid plaques, abnormal structures that are characteristic of Alzheimer's.

The study, which will last about two years, is designed to assess whether AN-1792 can prompt the immune system to form antibodies to A β . Researchers will also monitor the effect of the treatment on memory and thinking skills.

These clinical trials will also help scientists answer one of the fundamental questions in Alzheimer research: Are plaques the primary cause of cell damage in Alzheimer's?

Although evidence suggests that plaques may be key to the disease process, their role is difficult to assess.

In previous studies, AN-1792 prevented plaque formation in the brains of young mice genetically engineered to produce human A β . The treatment also reduced the numbers of existing plaques in older mice. Mice do not, however, provide a complete model for assessing the benefits of clearing plaques from the brain of a person with Alzheimer's. The results of the upcoming human trials may help scientists understand the significance of plaques in the progression of the disease.

While these Phase II trials are in progress, researchers will be investigating other questions about the role of A β in Alzheimer's. Scientists have much to learn about how plaques form, how they contribute to cell damage, what other factors contribute to Alzheimer's, and what other treatments may be necessary.

The Fundamentals of A β

Researchers have identified several steps in the formation of amyloid plaques, starting with the production of amyloid precursor protein (APP). The normal function of this protein in the brain is still being investigated. Scientists have determined, however, that it is normally broken down into harmless, soluble fragments.

In Alzheimer's disease, certain enzymes clip APP to create a form of A β that tends to form insoluble, thread-like structures called amyloid fibrils. These fibrils, in turn, combine to form plaques.

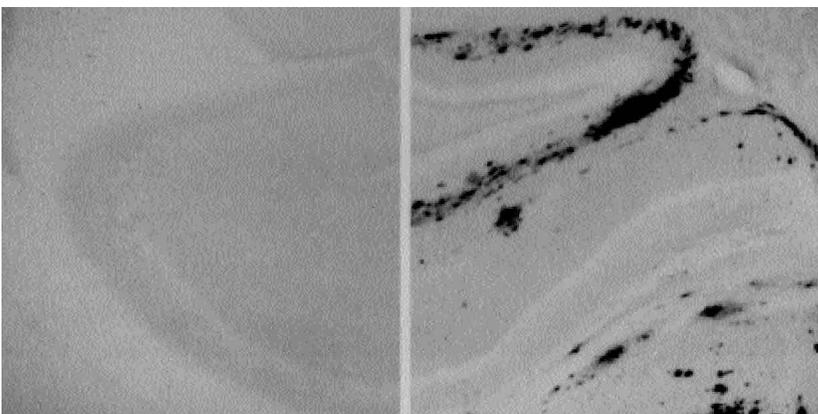
Understanding the details of this process is important in Alzheimer research. Each stage of the process may be a potential target for therapies intended to interrupt the chain of events that lead to plaques.

Supporting A β Research

In 2001, the Alzheimer's Association research program awarded more than \$5 million in grants to investigations of A β . These studies are designed to answer a number of questions about A β processing, A β toxicity, and plaque formation. The following research summaries highlight three of more than 20 grant recipients who are contributing to our understanding of A β in Alzheimer's disease.

Jordan Tang, PhD: Pioneer Award

In 1999, researchers identified beta-site APP-cleaving enzyme (BACE), one of the enzymes responsible for



These microscopic images show healthy brain tissue, left, and tissue with accumulations of amyloid plaques.

clipping A β from its parent protein. BACE is, therefore, considered a potential target for an enzyme-inhibiting treatment to prevent A β processing. Researchers do not know, however, what BACE does in a healthy brain and what will happen if it is deactivated by drugs.

Jordan Tang, PhD, and his colleagues at the Oklahoma Medical Research Foundation in Oklahoma City are investigating both the normal and pathologic roles of BACE and a related enzyme called BACE 2. They will also develop BACE and BACE 2 inhibitors to assess the consequences of blocking these enzymes in cell cultures and in mice. In related experiments with mice, they hope to determine if BACE and BACE 2 inhibitors help reduce the formation of A β . Results from this research will help scientists determine if these enzymes are possible targets for Alzheimer treatment.

Nelson J. Arispe, PhD **Investigator-Initiated Research Grant**

Although much has been learned about A β , researchers have not determined how it might cause damage to cells and why certain cells in the brain are susceptible to toxic factors in Alzheimer's. Nelson J. Arispe, PhD, and his team at the Uniformed Services University of the Health Sciences in Bethesda, Maryland, are investigating these questions.

Arispe's group has hypothesized that the brain cells targeted by Alzheimer's disease have a particular lipid content that changes properties of the cell membrane. They believe that these properties and certain characteristics of A β prompt harmful interactions. The researchers will test this hypothesis by assessing modifications they

make to the lipid content of cell membranes. The project may lead to the development of agents for preventing cell death or treating already damaged cells.

Virginia Lee, PhD **T. L. L. Temple Foundation Award**

Virginia Lee, PhD, and her colleagues at the University of Pennsylvania in Philadelphia are investigating strategies for preventing the formation of A β fibrils, an intermediary step in the formation of amyloid plaques. In laboratory studies, certain compounds have been shown to inhibit fibril formation. The compounds are too large,

however, to cross the blood-brain barrier, the brain's defense system against foreign substances.

Lee's research team is developing new compounds capable of crossing the blood-brain barrier and will test them in cell cultures and in mice. These investigations may help them identify substances for experimental drug therapies to delay or inhibit the onset of Alzheimer's disease. ♦

Association Funds Promising Research

Since 1982, the Alzheimer's Association—the largest private funder of Alzheimer research—has contributed nearly \$120 million to two general fields of investigation:

- research on interventions to manage behavioral symptoms, improve quality of care, and support individuals with dementia and their families.
- research on the biology of Alzheimer's disease that may lead to interventions for preventing, delaying, or arresting the development of Alzheimer's.

The Association's research program offered five different awards in 2001:

- The Pioneer Award, which offers \$1 million over five years, is awarded to scientists who have made groundbreaking contributions to Alzheimer research.
- The T. L. L. Temple Foundation Discovery Awards, worth \$250,000 over two to three years, support investigations into the causes of Alzheimer's and potential treatments.

- The Zenith Fellows Awards, providing \$250,000 over two years, are supported by a group of individuals and organizations who have committed \$1 million each to support investigations that are likely to make significant contributions to Alzheimer research.
- The Investigator-Initiated Research Grants, worth \$240,000 for up to three years, are the backbone of the program, supporting research into interventions for treatment and care.
- New Investigator Research Grants provide \$100,000 over two years to young scientists, allowing them to conduct preliminary research that can lead to funding from federal agencies and other organizations.

Easing the Stress of Balancing Work with Caregiving Responsibilities

Balancing a full- or part-time job with caring for a family, household demands, paying bills, social engagements, volunteer commitments, and commuting to and from work can make the average person tired and overwhelmed. Add to the mix caregiving responsibilities for a loved one with Alzheimer's disease and one begins to put a different spin on the word "stress."

In the spring and summer issue of *Advances*, we asked readers to share the problems they've faced—and solved—balancing work and caregiving responsibilities. Several readers responded with touching stories of their struggles, first to continue working, then to balance the many other facets of their lives with caring for a loved one who sometimes doesn't remember their name.

A working caregiver for 18 months to her 83-year-old mother, Julie Baker says one of the major obstacles she faced was time—or lack thereof. "Work requires a time schedule and care recipients don't always want to or are unable to honor time constraints," she says. "I'd have to miss work to take mom to doctor appointments and then she would be unable to articulate her various aches and pains. She would become confused and disoriented with time, going to bed unreasonably early or late. She never took naps. I couldn't get a decent night's sleep and would be grouchy the next day."

Flexible Hours and Telecommuting Can Help Alleviate Stress

One way Baker solved this problem was by arranging with her employer to work flexible hours. She set up a home office, using voice mail, her computer, and e-mail to do her job more efficiently—with no commute.

She also found resources in the community, including a senior day center staffed by nurses and aides who planned activities and provided care. Baker also received respite care in the evening twice a week.

Even with some necessary outside help, Baker says she feared for her own sanity. "I felt like I was giving up my life to care for someone who wasn't in her right mind," she says, eventually placing her mom in a full-time care center specializing in dementia and Alzheimer's disease. Baker still maintains responsibility for her mom's care, visiting often and hiring others to go on the days she is unable.

Ann Hershman, who lives with her husband John on a farm in rural Lebanon, Indiana, shares that her husband was just 57 when he was diagnosed with frontotemporal dementia in 1996—the date of their fifth wedding anniversary.

Now married 10 years, the couple has found help and support through church activities and by regularly attending support groups of the Central Indiana Chapter of the



Ann and John Hershman with devoted companion, Skyles.

Alzheimer's Association. "John is very aware of what's going on around him. He can fix his breakfast in the microwave and takes responsibility for our animals. Yet, he and I both know he's declining. The other day he didn't paint the bottom part of the wall. I'm more concerned about leaving him alone, but we need my income."

A teacher for 35 years, Hershman says she is facing the new school year with some trepidation. Not only does she have a 50-minute commute one way, but she'll have a new department chair. "In the past, John would occasionally come to work with me to help out with the teenagers in special education. That was good, but I don't know whether it'll work out this year. He's getting more frustrated and angry."

Mom Grapples with Demanding Job, Kids, and Sick Parent

In 1990, when her father Bob was diagnosed with Alzheimer's, Laurie Swanson Gribskov, PhD, was executive director of a nonprofit organization that managed job training programs for low-income people. She oversaw a \$5 million budget and 45 staff members and worked for a 22-member board of directors. "I didn't have one boss," she notes.

On the homefront, Swanson Gribskov and her husband Pete had two adopted children, Kristina, 3, and Erik, 10 weeks. Things began to unravel when Pete's father died unexpectedly, leaving Pete to run the family-owned printing company single-handedly. "We were all stressed to the max, but I felt that my workplace had already accommodated my instant maternity needs. I didn't tell anyone about my dad's illness," recalls Swanson Gribskov, then 39. "It wasn't socially acceptable for a woman in an executive position to discuss why she couldn't do a job—the proverbial 'glass ceiling.'"

In her poignant 2000 book, *Where Did My Father Go? Coping and Caring When a Parent Has Alzheimer's*, Swanson Gribskov expresses in narrative and journal form her many emotions concerning her sick father. These included the heart tugging role reversal, sibling issues, the tough choices, and the anger, frustration, sadness, and, ultimately, peace and closure when her dad died in 1993.

Swanson Gribskov, now in her late 40s, says her life was transformed after dealing with her father's illness. She left her career at the nonprofit agency, earned her PhD in education,

and started her own company, New Work Designs, which emphasizes elder care issues and workplace impact. She leads workshops and offers her now 20/20 hindsight on how to help others cope with loved ones who have dementia.

Tips for Working Caregivers

Like Swanson Gribskov, many of the *Advances* readers who wrote stressed that working caregivers needed to take care of themselves. "You can't give to others if you don't give to yourself," wrote one survey respondent.

Other suggestions included:

- Take advantage of the Family and Medical Leave Act (*see sidebar, page 8*),
- Enlist the support of your employer for flexible, reduced or part-time hours,
- Work at home/telecommute,
- Take advantage of employee assistance programs (EAP) at your workplace,

- Access public senior service programs and check out resource and referral services for elder care on the Internet and in books,
- See if employer can set aside pre-tax dollars to pay for elder care,
- Have a support network of alternative caregivers,
- Seek out professional counseling and/or use support groups, and
- Learn about Alzheimer's so you know what to watch for and how to react.

More Companies Support Employees with Elder Care Needs

As the population ages, employers who want to retain good employees are going to have to implement strategies to help employees address work/life balance. Margaret Neal, PhD, of the Portland State University Institute on Aging in Oregon, recently published a work-family sourcebook for employers entitled *Supporting Employees with Child and Elder Care Needs*.

(Continued on page 8)

Laurie Swanson Gribskov with her father Bob.



Communication Gap Separates Caregivers and Physicians

A nationwide survey reveals that substantially less than half of caregivers surveyed feel they are receiving all the information they want from primary care physicians as they deal with the challenges of caring for a loved one with Alzheimer's. Yet, most physicians are convinced that they are offering the necessary advice and recommendations.

The survey, commissioned by the Alzheimer's Association, involved 376 caregivers and 500 primary care physicians and the differences in their responses are significant. For example, only 38 percent of caregivers said that they received guidance about what to expect as the disease progressed, although 83 percent of doctors reported that they provided information about disease progression.

Similarly, 28 percent of caregivers said that doctors told them about Alzheimer's impact on a person's ability to cope with and perform daily tasks, while 91 percent of physicians claimed that they discussed these issues. Furthermore, although only 31 percent of caregivers said they received information about where to find help and services, 88 percent of doctors surveyed felt they had provided recommendations. Only 22 percent of caregivers said that doctors recommended caregiver support groups, but 74 percent of physicians responded that this was advised.

The survey did find some common ground—80 percent of caregivers felt



Orien Reid, chair of the Association's national board of directors, shares a loving moment with her mother, Octavine Alexander, during Christmas 1991. Mrs. Alexander was diagnosed with Alzheimer's in 1988.

that physicians are knowledgeable about the disease and wanted to hear about their concerns and questions. Physicians also understand the need for a comprehensive approach to disease management—84 percent said that the best treatment plan includes a combination of medication, lifestyle changes, and support services.

The results of the survey, which was supported by Janssen Pharmaceutica and Ortho-McNeil Pharmaceutical, were presented at a June media briefing on Alzheimer's disease held by the American Medical Association in New York City.

What Explains the Gap?

Although the survey didn't explain the gap, Orien Reid, chair of the Association's national board, offered

some insights based on her personal experiences. "I know what it's like to hear a doctor say that your mother has Alzheimer's, because it happened to me 13 years ago," Reid said. "At first I was at a complete loss. I desperately needed information about the disease, about how to manage my mother and myself."

At the same time, Reid observed, "When the diagnosis is first given, caregivers can't hear everything at once. Information needs to be given in appropriate doses—the right amount at the right time—just like medication. It's important to establish patterns of communication that will help all three parties—the doctor, the affected individual, and the caregiver—through the experience of Alzheimer's disease."

Pamela Saunders, PhD, assistant professor of neurology at Georgetown University in Washington, D.C., agrees that the stress of hearing an Alzheimer diagnosis may affect a caregiver's ability to absorb information. "It can be overwhelming," Saunders says. "The emotional impact can severely disrupt a caregiver's capacity to comprehend and process what the physician is saying."

Focus Groups Offer Additional Insight

Vicki Lampley-Dallas, MD, MPH, assistant professor in the Donald W. Reynolds Department of Geriatric Medicine at the University of Oklahoma, has held focus groups to explore African American caregivers' satisfaction with physician communications and other topics. Some of her discoveries echo survey findings. For example, her groups expressed a need for general information on dementia and services as well as referrals for respite care, and financial and legal advice.

Most participants, however, felt that their physicians lacked knowledge of these services and failed to make appropriate referrals.

Many participants also felt that physicians should take a stronger lead in providing caregiver education. Says Lampley-Dallas, "Reassurance from the physician goes a long way in helping the caregiver accept and manage the needs of the person with dementia. Understanding that memory and behavior problems are not under affected individuals' control can lessen stress significantly."

Lampley-Dallas's research also suggests that minority caregivers face additional hurdles, including cultural biases in mental state assess-

ment tools. Many participants also encountered troubling assumptions about their ability to pay for medical services.

Lampley-Dallas's caregivers reported low participation in support groups. Many described difficulty finding a group nearby. Another factor stems from the fact that older African Americans have frequently experienced past racial prejudice that makes them reluctant to seek support outside their established, reliable networks. As one participant said, "We are not used to talking about our business. We just go on and deal with it. We don't realize we have to talk, and I think we do need to talk."

"Services and information on dementia and its management must be available locally and tailored toward demographic differences among and within ethnic groups," Lampley-Dallas stresses. She recently presented her findings at the Association's 10th Education Conference.

The Impact of Medical Economics

Medical reimbursement rules may pose a barrier to physician effectiveness in communicating and managing Alzheimer's and other chronic illnesses. Medicare does not currently allow physicians to bill for care coordination and management unless a beneficiary is in a hospice or receiving home health services. Medicare also fails to cover telephone calls. In addition, physicians cannot bill for office time spent speaking to caregivers unless the person with Alzheimer's is also present. All of these restrictions create a barrier to unpressured, effective communication. ♦

The National Institute on Aging publishes the pamphlet "Talking with Your Doctor: A Guide for Older People." Single copies are available free at (800) 222-2225. The full text is also available on-line at www.nih.gov/nia/health/pubs/talking/index.htm.

How Can Caregivers Aid Communication?

Experts suggest these strategies for enhancing your satisfaction when you talk to your loved one's physician:

- 1) Realize that doctors vary in their ability to communicate. If you are very dissatisfied, consider changing doctors.
- 2) Try to choose a doctor whose staff includes a nurse or physician's assistant. These professionals may be more accessible than physicians for answering routine questions.
- 3) Try to schedule appointments when the office is least busy.
- 4) Write down your questions and prioritize them so you can ask the most important question first.
- 5) Be sure to bring glasses, hearing aids, or any devices you need to communicate effectively.
- 6) Consider asking a friend or relative to accompany you to help you remember everything.
- 7) Bring a notepad and ask the doctor to jot down key instructions, names, or telephone numbers.

Dialogue
(Continued from page 5)

The book discusses the rising number of dual-worker families, increased rates of absenteeism due to caregiving issues, and how to conduct an employee needs assessment. As a tool, the book contains a five-page survey, which employees can take anonymously to ascertain their stress level and the hours they spend caring for an older person.

Says Neal, “Wives generally appeared to be fairing worse than husbands, with a significantly higher level of depression, more worry about work-

ing less effectively due to concerns about their children or aging parents, and a lower level of performance in taking care of themselves.”

Because there are an estimated 14.1 full- and part-time employed caregivers, 73 percent of whom are women balancing work with a demanding “other” profession—caregiving—organizations and human resources departments nationwide are making more effort to give caregivers the flexibility and assistance they need. ♦

Dialogue Survey Question

What Do You Do When a Loved One Begins Wondering?

It’s a scary feeling—you awake in the morning and your loved one with Alzheimer’s disease isn’t in bed. A careful search of the house reveals she isn’t there. Panic-stricken, you call the police and scour the neighborhood, calling your loved one’s name. Several hours later, she is found sitting on a park bench, calmly watching children at play. Relieved but emotionally spent and exasperated, you hope this never happens again.

We Want to Hear From You!

- Share one or two stories about your loved one’s wandering episodes.
- What suggestions do you have for preventing someone with Alzheimer’s from wandering off?
- Has hanging noisemakers, like jingle bells, on the front and back doors deterred wandering?
- To facilitate the safe recovery of missing loved ones, the Alzheimer’s Association established the Safe Return Program. Have you used this program? How has it been helpful?

*Your experiences will be incorporated into the Dialogue article in the winter Advances. Please send your feedback no later than **October 19**, by e-mail to barbara.harfmann@alz.org or by mail to Advances editor, 919 North Michigan Avenue, Suite 1100, Chicago, Illinois, 60611-1676.*

Caregivers Can Take Advantage of the Family and Medical Leave Act

Alzheimer caregivers who need to take time off from work to fulfill caregiving duties may be able to take advantage of the Family and Medical Leave Act (FMLA).

What is the Family and Medical Leave Act?

The FMLA is a federal law that allows caregivers to take up to 12 weeks of unpaid leave a year to care for ill family members, including spouses and parents with Alzheimer’s disease and other serious health problems. The law allows caregivers to take unpaid leave without fear of losing their job.

FMLA Basics

- A caregiver must work for a company with 50 or more employees, have worked for his/her employer for at least 12 months, and worked at least 1,250 hours during the previous year.
- FMLA leave may be taken intermittently or in specified blocks of time, e.g., half-day, full day, one week, etc.

- Employers can require employees to obtain a medical certification of the serious health condition from a physician.

For Additional Information

- One Web site, sponsored by the National Partnership for Women and Families, provides a basic fact sheet on the FMLA, a guide, in both English and Spanish, to frequently asked questions about the FMLA, and a fact sheet on caregiving and the FMLA.

<http://www.nationalpartnership.org/workandfamily/workmain.htm#fammed>

- Sponsored by the U.S. Department of Labor, this Web site provides basic information about the FMLA for employers and consumers, the text of the law, and sample medical certification forms.

<http://www.dol.gov/dol/esa/fmla.htm>

Alzheimer “Vaccine” Moves to Phase II Clinical Trials

On July 23, CNN ran a segment about an experimental drug designed to fight Alzheimer’s disease that is about to move to Phase II clinical trials. (See *Research article, page 2.*) The drug, commonly called the Alzheimer “vaccine” or AN-1792, is designed to stimulate the immune system to wipe out amyloid plaques in the brain. Aired on television and featured on-line, the CNN story extensively quoted the Association’s William Thies, PhD, vice president of medical and scientific affairs.

“I think it’s very exciting to see this product moving forward because it’s going to test one of the fundamental theories of Alzheimer’s disease,” said Thies. “For people who have well-established disease, the vaccine won’t be able to return dead brain cells and certainly can’t return memories, but it could potentially arrest the disease in whatever stage the individual is in.” *USA Today*, July 23, also featured the “vaccine” story. Giving additional coverage to the news was *BBC News*, *The Wall Street Journal*, *National Post*, and local newspapers nationwide.

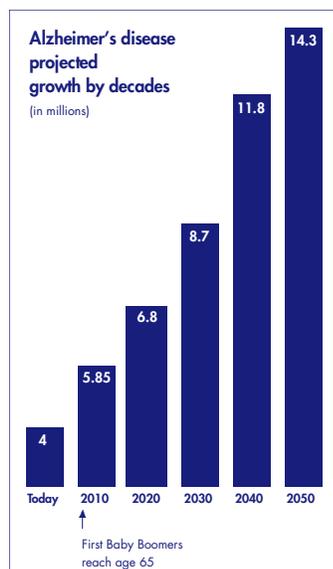
New Survey Reveals Communication Gap Between Doctors and Caregivers

Discussing the Alzheimer’s Association’s doctors/caregivers communication gap survey, Orien Reid, chair of the Association’s board of directors, Stephen McConnell, PhD, vice president of public policy, Danny Chun, director of media relations, Judith Riggs, now retired deputy vice president of public policy and programs, and several Association chapter executive directors were recently quoted in national and local media news

Alzheimer Chart Projects Steady Rise in Disease

The chart below was provided by the Association’s Media Relations Department to dozens of newspapers and magazines nationwide, including *Contemporary Long Term Care* magazine, which published the chart in its July 2001 issue.

The chart is a clear representation of the impact of Alzheimer’s disease on society if nothing is done to halt its progression.



Graph published in *Contemporary Long Term Care* magazine, July 2001.

outlets. These included CBS, CNN, MSNBC, Heath Scout News, WebMD Medical News, *Newsday*, *Reuters*, *Los Angeles Times*, and *USA Today*. The survey was released in June at the American Medical Association’s media briefing in New York City. (See *Caregiving article, page 6.*)

For more information, visit <http://www.alz.org/media/news/current/060601alzsurvey.htm>.



Hayworth’s daughter, Princess Yasmin Aga Khan, chats with Charlie Nix and Association board chair Orien Reid.

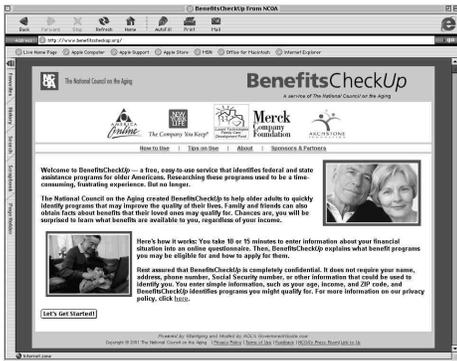
Rita Hayworth Gala Raises \$700,000 for Alzheimer Research

More than 700 guests enjoyed a fabulous dinner from Wolfgang Puck Catering and dancing to the smooth sounds of the Woody Herman Orchestra at the 14th Annual Rita Hayworth Gala on May 12. Several Chicago newspapers featured articles about the gala, which raised nearly \$700,000 for research funded by the Alzheimer’s Association. The gala’s theme, “Music in My Heart,” was the title of one of Hayworth’s films. Photos of Hayworth’s daughter, Princess Yasmin Aga Khan, and board chair Orien Reid accompanied the May 17 *Chicago Tribune* gala article.

The Rita Hayworth Galas, held in New York and Chicago, honor legendary film star Rita Hayworth, who had Alzheimer’s and died in 1987 at 69. The 2001 Chicago gala was co-chaired by JoAnn Shaw and Roger Quick, and Princess Yasmin, honorary vice chair of the national board of directors, served as General Chair.

Princess Yasmin also was guest of honor at a garden party hosted by Jennifer Nasser, national board member, in Bloomfield Hills, Michigan, on June 10, to raise money for the Alzheimer’s Association.

New Web Site Links Seniors and Caregivers to Assistance Programs
 In early June, the National Council on the Aging (NCOA) launched a Web site—<http://www.benefitscheckup.org>—that connects older adults or their caregivers to all the federal, state, and local assistance programs for which they qualify. According to NCOA, an estimated 5 million seniors over age 55 are not accessing some of the benefits available to them. Visitors to the



<http://www.benefitscheckup.org>

Web site spend about 10 to 15 minutes filling out an anonymous questionnaire that does not require any identifying details such as name, address, telephone, or Social Security number. The system generates a list of potential benefits, with each result linked to further details about eligibility and how to apply.

Programs covered include Social Security, Medicaid, Medicare, Meals on Wheels, transportation, property tax exemptions, state drug benefits, utility bill assistance, and many others.

People lacking Internet access at home can find the closest library with public computers or other public access facility by calling the Digital Divide Network toll-free at (866) 583-1234. Operators at the service provide facility names, addresses, and telephone numbers in English or Spanish.

Letters to the Editor

Dear Advances:

I received the summer issue of Advances (vol. 21, no. 2), and was impressed and excited about the information it contained. It is helping many people understand Alzheimer's disease better. The article on frontotemporal dementia was interesting since I, too, have this disease. Your cover article, "Early Onset Alzheimer's, Fighting Back and Speaking Out," was also most informative.

I commend Mr. Nichols and Mr. Wagenaar for their courage in advancing the awareness of early-onset Alzheimer's and its effect on the person with the disease, their partner, family, and society. My name is Linda Raymer and I'm 60. I was diagnosed with early-onset Alzheimer's in November 1994 at the age of 53.

Like other women of my generation, for many years I was a housewife and mother. I waited until my youngest child went to college before I worked full time and had to quit in 1994 because of my diagnosis. I did not accumulate enough credits to collect Social Security benefits.

Congress should address this concern. I thank Advances for their coverage of the Public Policy Forum and for bringing awareness and speaking for others who aren't able to have their voices heard and their story told.

Sincerely,

Linda Raymer
 Clinton Township, Michigan

We Want to Hear From You!

Please share with us your experiences related to issues covered in *Advances*, or suggest topics you'd like to read more about.

Rx CORNER

Bristol-Myers Squibb Company is currently conducting Phase I clinical trials to test an experimental compound, a gamma-secretase inhibitor, which may disrupt an important chain of events in Alzheimer's disease.

Gamma-secretase (γ -secretase) is an enzyme (or group of enzymes) that makes the second of two cuts in a protein, resulting in the protein fragment called beta-amyloid (A β). This fragment is the primary component of amyloid

plaques, abnormal structures that may be a key factor in brain cell degeneration in Alzheimer's.

The γ -secretase inhibitor is designed to block the enzyme's cutting activity and, thereby, prevent the formation of A β . If the compound is shown to be well tolerated in humans, the γ -secretase inhibitor will be tested further to answer two critical questions:

- Does this γ -secretase inhibitor block A β formation in humans?
- Are treatments to reduce levels of A β effective strategies for delaying the progression of the disease?

perfect example of growth and adaptation over time,” said Reid, gesturing to the packed audience. “This event was founded 10 years ago by a core group of committed visionaries who saw a need and were determined to fill it. They created the largest national event devoted specifically to Alzheimer research and care. And we’re all glad they did!”

Two of the conference founders and former education conference chairs Linda Wright and Liz Kendall, who are active on the national board, gave a historical perspective of the “old” days with a slide show capturing key moments from past events. There were also posters from the 10 previous conferences on display.

“This has far exceeded our wildest expectations. You (the audience) are why we started this conference,” said Wright. “It was an important opportunity to give knowledge but also to gain knowledge. You’ll all agree there are roads yet to be discovered and traveled, but the Association and an outstanding chapter network has remained steadfast in their mission—to meet the needs of people with Alzheimer’s and their caregivers.”

In her remarks, Kendall quoted Margaret Mead, “Don’t underestimate the power of a few people to change the world.” This quote, she

said, served as a catalyst for building the conference from a small cadre of volunteers and staff to the large network it is today, including education of nationwide participants, advocacy, public policy, and research experts. “I can’t identify any weakest link and that is my final answer,” concluded Kendall.

Conference Caps Off Decade of Progress in Care and Research

“It was a milestone conference that capped off an exciting decade of progress,” said Sam Fazio, the Association’s director of education and training. “We’ve been fortunate to draw such a high caliber of faculty and attendees to this event.” ♦

If you were unable to attend the 2001 education conference and would like a Proceedings Book at a cost of \$20, call (800) 223-4405 or e-mail alz@pbd.com. Use #ED585Z. The next education conference is scheduled for 2003.

The Association’s next research conference, the 8th International Conference on Alzheimer’s Disease and Related Disorders, will take place in Stockholm, Sweden, July 20-25, 2002.

For more information on the research conference, call (312) 335-5813 or log on to the conference Web site: www.alz.org/internationalconference.

Kudos to Conference Chairs

During the opening plenary session, former chairs of the education conference planning committee were recognized for their hard work, dedication, and commitment to excellence with applause and a gorgeous crystal plaque. Kudos to:

- Liz Kendall, 1992
- Liz Kendall and Linda Wright, 1993
- Maria Aranda and Linda Wright, 1994
- Liz Kendall, 1995
- Bill Keane and Barb Sand, 1996
- David Lindeman and Barb Sand, 1997
- Dorothy Seman and David Lindeman, 1998
- Dorothy Seman and Mark Laker, 1999
- Linda Wright, 2000
- Ladislav Volicer, 2001



Photos by Larry Dermady

Ido Nap, left, and Les Dennis, who were both diagnosed with early-onset Alzheimer’s, shared their story at a media briefing.



Conference chairs, from left, Bill Keane, Linda Wright, Liz Kendall, Dorothy Seman, and Ladislav Volicer.

Alzheimer's Association Loses Dear Friend, Advocate



Maureen Reagan

The Alzheimer's Association mourns the passing of Maureen Reagan, who was a member of the Association's national board of directors and one of its leading advocates in the fight against Alzheimer's disease. On Aug. 8, Ms. Reagan succumbed to skin cancer. She was 60.

"We offer our heartfelt sympathies and condolences to Maureen's husband, Dennis, their daughter, Rita, and to her entire family," said Alan J. Stone, president and CEO of the Alzheimer's Association.

"Millions of Americans have been helped by her dedication and compassion and by her tireless efforts to raise public awareness about Alzheimer's, support caregivers, and substantially increase our nation's commitment to Alzheimer research."

Ms. Reagan testified several times before Congress to advocate for increased funding for Alzheimer research and caregiver support. Most recently, she called on Congress to help find a prevention or cure for the disease by doubling Alzheimer research funding at the National Institutes of Health to \$1 billion a year.

To honor Ms. Reagan's commitment to fighting Alzheimer's disease, the Alzheimer's Association has established the Maureen Reagan Tribute Fund.

Donations to the fund can be sent to the Alzheimer's Association, 919 North Michigan Avenue, Suite 1100, Chicago, Illinois 60611-1676, or made on-line at the Association's Web site, www.alz.org, or by telephone at (800) 272-3900.

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Letters with questions or story ideas should be addressed to Barbara Hafmann, Advances Editor. Faxes can be sent to (312) 335-1110, or email to barbara.hafmann@alz.org. Advances does not publish unsolicited poems or short stories, nor do we accept advertisements.

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