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Massachusetts Chapter

People with Dementia:
 The Bright New Face of Global Advocacy

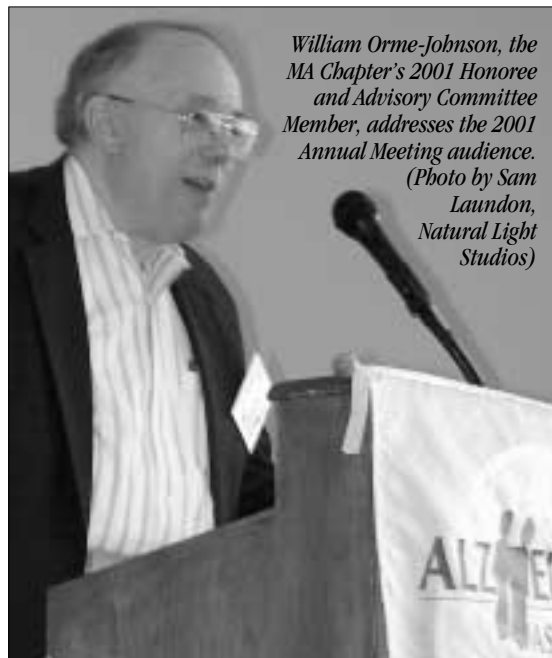
By Elaine Silverio and Gerald Flaberty

Better treatments, more accurate diagnostic testing for a wider range of cognitive disorders, greater physician education, and broader public knowledge of the signs of Alzheimer's disease and other dementias will almost certainly lead to the identification of more people in earlier stages of their illness.

"More sophisticated diagnostic techniques allow us to identify people with Alzheimer's disease earlier in the disease process, as well as those with mild cognitive impairment," says Stephen McConnell, Ph.D., Interim President and CEO of the national Alzheimer's Association. These techniques will also lead to greater recognition of related dementias.

But none of that may be happening fast enough. Today, for example, it takes an average of three years from the appearance of symptoms to the time someone with Alzheimer's disease or other dementia is actually diagnosed, with an attendant delay in treatment.

Lost time. "Treatment delayed is treatment denied," as Christine Bryden of Australia emphasized in remarks last October at the Alzheimer's Disease International (ADI) Annual Conference in Christchurch, New Zealand. Bryden was representing the Dementia Advocacy and Support Network International (DASNI), a web-based non-profit organization of people diagnosed with dementia.



William Orme-Johnson, the MA Chapter's 2001 Honoree and Advisory Committee Member, addresses the 2001 Annual Meeting audience. (Photo by Sam Laundon, Natural Light Studios)

Treatment delayed has compound implications. According to Marilyn Albert, Ph.D., national Chair of the Alzheimer's Association's Medical and Scientific Advisory Council and Director of the Geriatric Neurobehavioral Clinic at Massachusetts General Hospital, "We need to better understand how to evaluate competency in all patients with Alzheimer's disease, but particularly with patients who are very mildly impaired. Competency considerations affect their ability to sign wills,"

continued on page 4

Mark Your Calendars Now!

**Professionals Conference
 WEDNESDAY, MAY 8**

Professional caregivers won't want to miss *A Map Through the Maze* for the best information and speakers in our field! See Calendar (page 8) for details.

**Night at the Pops
 WEDNESDAY, MAY 29**

This year's musical soiree promises to be fabulous, with Maestro John Williams at the baton! See page 13 for details.

**Make the Link
 Golf Tournament
 MONDAY, JULY 22**

Join us for a relaxing afternoon of golf, followed by dinner and a spectacular auction! See Calendar (page 9) for details.

"The Why and How of Studying Alternative Medications in Alzheimer's Disease," **page 3.**



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From the Executive Director: Pointing the Compass Timeless Strength in Changing Times

During recent months, we have all lived with a constellation of extra challenges. Yet despite busy schedules and formidable responsibilities, the members and friends of the Alzheimer's Association have consistently stepped up to the plate to support this fine organization.

It is truly an honor for the staff and voluntary leadership to work for an organization with such a dedicated body of family members and supporters. Thanks to you, through December 31st, we were right on budget in terms of revenue and a little under-budget for expenses. Thank you for your end-of-year gifts, for all your tireless work around Memory Walk, and for inspiring and motivating us to aspire to new heights.

Strategic plan. Members of our Board of Directors joined some of our staff Saturday, January 26 for a day of strategic planning. Facilitated by former Board Chair **Susan McDonough**, we focused on evaluating the strengths and challenges facing your Alzheimer's Association, and developed goals and objectives for the next three fiscal years. We hope to complete this process by April, and will be able to make this plan available to all who are interested.

On Monday, January 7th, we welcomed **Kate Doyle** as our new Director of Public Policy. We are very excited about this new addition to our staff!

Before coming to the Alzheimer's Association, Kate was the national Director of Government Affairs for RESOLVE, The National Infertility Association. Prior to that position, Kate spent a number of years working in the Massachusetts State Legislature. Please join us in welcoming Kate to the Alzheimer's Association.

Transitions. In addition, we say goodbye and hello to **Richard Blinn**. Dick has been a dedicated Board member and supporter of the Alzheimer's Association for a number of years. As the President, New England Region for Genesis ElderCare, Dick Blinn has mobilized his company's resources to support the work of the Alzheimer's Association.

Due to the demands of his job, however, Dick has stepped down from our Board of Directors, but has also agreed to join the new Advisory Committee of the Alzheimer's Association. We thank Dick for his many years of service and are very pleased that he will remain affiliated with the Alzheimer's Association.

Speaking of the **Advisory Committee**, our Chapter has created a new committee composed of supporters of the Alzheimer's Association. These 25 individuals are committed to helping promote the Association's goals, but do not have the time to devote to a standing Committee or Board of the Alzheimer's Association.

The Advisory Committee meets once or twice per year. For more information, please feel free to contact the Association. We thank all of you for your valuable time, your unswerving dedication, and for caring so much!

—Jim Wessler



Susan McDonough, Vice President for Strategy and System Development for Covenant Health Systems, Chairperson of the Chapter's Statewide Advisory Committee, and former Chapter Board Chair.

Tribute to Harriet Udoff

Among other ways in which we will honor the late **Harriet Udoff**, we at the Association are putting together a Memory Book that we will give to her family. If you knew Harriet and have something you would like to contribute—maybe a note or photo (with caption), an anecdote, or a thought—please send it to Rachel Hawk, Alzheimer's Association, 36 Cameron Ave., Cambridge, MA 02140. Thanks for your help!

Simons Symposium

See story, page 3.
(Photos by Sam
Laundon, Natural
Light Studios)



Noted Neurologist Details Ginkgo Biloba Trial Alternative Medicines Explored at Simons Symposium

By Ann C. Hurley, R.N., D.N.Sc., F.A.A.N.

The 2001 Simons Symposium Lecturer, Steven T. DeKosky, M.D., held the full attention of his audience of 200 at the Colonnade Hotel in Boston November 7 with a cutting-edge perspective on the use of complementary and alternative medicines to treat Alzheimer's disease. As part of the Eleventh Annual Matthew and Marcia Simons Research Symposium, **"The Why and How of Studying Alternative Medications in Alzheimer's Disease,"** Dr. DeKosky demystified the world of pharmaceutical clinical research and skillfully described how potential medicines are identified and developed.

Dr. DeKosky, Professor and Interim Chair of the Department of Neurology at the University of Pittsburgh and Director of the University of Pittsburgh Alzheimer's Disease Research Center, delivered the Symposium at the invitation of the Chapter's Medical & Scientific Advisory Committee. He is former Chair of the national Association's Medical and Scientific Advisory Council and current Board member of the national Association, and is internationally renowned as a clinical neurologist and basic science researcher.

In the Symposium, Dr. DeKosky discussed the unique issues inherent in complementary and alternative medicine and related these issues specifically to Alzheimer's disease. Throughout recorded history, herbs and other "natural" treatments have been used with the intent of preventing and treating diseases. Currently the American public spends millions of dollars annually on herbal remedies and oral health products, such as over-the-counter vitamins and "nutritional supplements" classified as neither drug nor food.

Gray zone. While the American public is used to knowing that drugs requiring a prescription have undergone rigorous testing, are considered safe, and have a proven degree of efficacy before the U.S. Food and Drug Administration (FDA) approves them for sale, this is not the case for "non-food, non-drug" products. Once tests have shown that a potential new drug is not generally harmful, the next step is to compare the drug with a placebo (sugar pill that looks and tastes like the drug) in a randomized controlled clinical trial.



Simons Lecturer Steven DeKosky, M.D. with Chapter Board Chair Sanford Auerbach, M.D. and Chapter Executive Director Jim Wessler.

Over-the-counter products such as the dietary supplements, Dr. DeKosky observed, do not undergo this rigorous scrutiny. Dietary supplements must be labeled accurately and must be removed from the market if safety problems occur, but varying levels of scientific verification are used for making the claim that any such product is effective.

Question of efficacy. He explained that pharmaceutical companies fund the stages of trials that determine efficacy; and that these trials require large numbers of participants, take a long time, and are very expensive. Once a drug goes off-label or becomes generic and the developer no longer holds a patent, the industry lacks a financial incentive to fund trials. Such is the case with the dietary supplements and vitamins that some persons use in hope of preventing Alzheimer's disease.

Dr. DeKosky underscored these kinds of concerns with use of non-drug, non-food products—the possibility of unknown or unintended interaction or toxicity, untested efficacy, delays in seeking conventional treatment, and wasted money. He explained that The National Institutes of Health (NIH) established The National Center for Complementary and Alternative Medicine (NCCAM) to fund research and education to respond to those concerns.

To attempt to prevent Alzheimer's disease, Americans spend \$200 million each year on **Ginkgo biloba**, a non-drug, non-food substance that has not undergone the standard scrutiny of a double-blind, placebo-controlled randomized drug trial. Dr. DeKosky directs the national multicenter trial to assess whether Ginkgo biloba can delay the onset of dementia in healthy adults.

This multicenter trial requires 3,500 participants, will take several years, and will cost \$24 million, an expensive outlay for the private sector to investigate a product it cannot patent. Yet only with these study results will the American public truly know whether Ginkgo biloba is effective in preventing Alzheimer's disease.

Many participants were also interested in **Vitamin E**, another over-the counter supplement used to attempt to prevent Alzheimer's disease. When asked about taking Vitamin E, Dr. DeKosky told participants that the dose is usually 1,000 mg/day, and cautioned that if they did use Vitamin E, to take additional Vitamin C (500 mg) to help Vitamin E get to the brain.

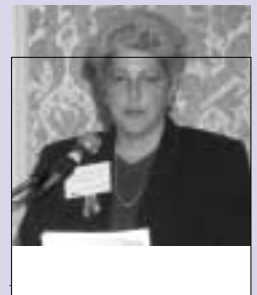
As with use of any of the substances mentioned in the lecture, it is usually advisable to consult with your physician.

In conclusion, Dr. DeKosky thanked those who volunteer for research studies, without whom research of this kind could not be undertaken. These volunteers are our heroes!

The Simons Symposium, which brings the most current scientific research to the public each year, is endowed by Chapter Board Member Emeritus Marcia Simons in memory of her late husband, Matthew Simons, who died of Alzheimer's disease. **W**

Medicine and Science

While the American public is used to knowing that prescription drugs have undergone rigorous testing, this is not the case for "non-food, non-drug" products.



Vice Chair and Chair of the Chapter's Medical & Scientific Advisory Committee. (Photos by Sam Laundon, Natural Light Studios)



Ginkgo biloba

Ann C. Hurley, R.N., D.N.Sc., F.A.A.N. is Executive Director of the Center for Excellence in Nursing Practice, Brigham and Women's Hospital, Brookline, MA.

Advocacy



(L) Elaine Silverio, R.N., B.S. is an Alzheimer consultant and facilitator of a support group for people with early onset, early stage dementia. (R) Gerald Flaherty is Director of Special Projects for the MA Chapter of the Alzheimer's Association.

"The net result of earlier diagnostics will change the face of the Alzheimer population, making the person with the disease, not just the family caregiver, a principal focus for the Association's services and support."

—Stephen McConnell



DASNI members Jan Phillips and Lynn Jackson at Christchurch.

Global Advocacy *continued from page 1*

make financial plans and the like—issues we tended to discount when patients were diagnosed at later disease stages."

Most Remain Undiagnosed

What's even worse than treatment delayed is no treatment at all. Almost a century after Dr. Alois Alzheimer gave his name to the most common type of dementia by diagnosing "Auguste D.," most people with dementing illnesses remain undiagnosed, and thus largely untreated. In a 1999 article in *The Gerontologist*, Linda Boise, Ph.D. and colleagues cite studies suggesting that dementia is identified by general practice physicians "in 50% or fewer cases."

And even that low estimate may be optimistic. According to Zaven Khachaturian, Ph.D., Senior Science Advisor to the Alzheimer's Association, "We need to know what the denominator is before we can tell how many people go undiagnosed. When you add to this problem the enormous economic, social, and cultural disparities in access to health services or information, the problem and the numbers of undiagnosed people become larger."

Fear and denial by caregivers and people with dementia, misdiagnosis and missed early symptoms by primary care physicians, lack of information about early signs by families and professionals alike, lack of access to appropriate medical evaluation—all of these factors would seem to contribute to Khachaturian's assessment that Alzheimer's disease "is underestimated, underdiagnosed, and the magnitude of the public health problem not fully appreciated."

One Clue to Under-Diagnosis

There is another clue, however, to problems of under-diagnosis and delay in diagnosis. Recent surveys suggest that the public sees a dementia diagnosis as nothing short of a death sentence. For more than 20 years, it has been common practice, within and outside the Alzheimer network, to describe the disease as a "tragedy," and family caregiving as a "burden." Frightening language may equal frighteningly high rates of denial by families and even physicians, and frighteningly low rates of self-identification by people in the earliest stages of their dementia.

Encouraging denial. As former family caregivers ourselves, we do not mean to infer that having a dementing illness or helping to care for someone who does is just another walk in the park. But we do mean to say that characterizations of dementia such as those that appeared in ADI's 1999-2000 Annual Report (e.g., "all the ordinary pleasures of life . . . are no longer possible," and "The mind is absent and the body is left as an empty shell . . .") indirectly encourage denial.

ADI is an umbrella organization of Alzheimer's associations throughout the world. If these statements represent the opinions of a highly reputable advocacy organization, what then can we expect from a less invested or educated public? ADI is

hardly the only offender, but it heard loud and clear from people with dementia about these characterizations. Its thoughtful response was to invite Bryden and other DASNI representatives to the Christchurch conference.

In fact, we may all have done *too* good a job over the years emphasizing the cognitive endpoints of dementing illnesses in our efforts to drive home in the most dramatic way the need for funding for research and services. As a result, negative words and phrases abound: irreversible, fatal, incurable, victim, burnout, burden, incompetence, loss of dignity, loss of self.

Double negative. The end result of such language is a double negative—it creates an atmosphere of fear and fatality among the public at the same time that it erodes the potential for people with dementia to be treated in a dignified way. Asked for their thoughts on the public's perception of them, members of the early-stage dementia support group that meets at the Alzheimer's Association's Massachusetts Chapter used phrases like "outlived our usefulness," "not worth involving in discussions," and "non-exciting medical nuisance." "People are afraid of us," said group member

Cathleen McBride. "They see our disability as huge, our abilities as insignificant."

Among others, national Alzheimer's Association Education Services Director Sam Fazio, in *Rethinking Alzheimer's Care*, and lecturer Joanne Koenig-Coste, in *Learning To Speak Alzheimer's* (forthcoming from Houghton Mifflin), have gently suggested how and why we might all bite our tongues.

That would help. But for early diagnosis to lead to a meaningful increase in public awareness, it must first lead to a significant increase in the number of people with dementia who choose to speak for themselves in an ever-more-public way. What they have to say may represent the most powerful tool available to the Alzheimer's Association to change public misperceptions by talking about what else it means to have a diagnosis of dementia.

The Emerging Advocate

Former President Ronald Reagan wrote to the American people on receiving his diagnosis of Alzheimer's in 1994, "I intend to live the remainder of the years God gives me on this earth doing the things I have always done." Others, like Bill Orme-Johnson, a former MIT professor diagnosed with Alzheimer's at age 58, have taken that determination to another level.



DASNI member Carole Mulliken

"People are afraid of us. They see our disability as huge, our abilities as insignificant."

—Cathleen McBride

Orme-Johnson's story was prominently featured April 8, 2001 in *The Boston Sunday Globe*, where he wrote, "I know how important it is to retain and use what I have." Five years after his diagnosis, he is still in a support group, still using what he has, speaking out to groups of people with memory loss, caregivers, college students, physicians, legislators—and anyone else who'll listen—in his efforts to ensure that others with dementing illnesses have the opportunity, like former President Reagan, to do the things they "have always done." "It has been very gratifying for me," he wrote, "to know that I can still be a 'professor' of sorts."

Learning process. That Orme-Johnson could remain so active doesn't surprise the Alzheimer's Association's Albert. "Patients are getting diagnosed much earlier than they did years ago, and we are now realizing how slowly the disease progresses in its early phase," she says.

DASNI member Lynn Jackson of Canada agrees. "Because we are taking the anti-dementia drugs, keeping active mentally and physically and staying better for longer, researchers and people involved with us are learning along with us as the years pass by." Jackson often repeats what another person with dementia once wrote to her, that "Knowledge is power. It is a balance of hope, leveler of anger, controller of denial."

That people with dementia have something to say and the ability to say it is clear. That so many of them might have been Orme-Johnson-like "professors of sorts" but never got the chance because they were never diagnosed, diagnosed late in their disease, or never had their diagnoses shared with them, is an ongoing tragedy in the truest sense of that loaded word.

Raising their Voices

Can we really raise awareness and address this issue by empowering people with dementia to raise their voices? If the people at Dementia Advocacy and Support Network International are any barometer, yes. DASNI evolved from an e-mail correspondents' group that formally opened its website in August 2000 with the help of member Laura Smith of Montana. It now includes more than 150 people with dementia from the U.S., Canada, Mexico, Brazil, Australia, New Zealand, the U.K., France, and Japan.

DASNI members' advocacy on their own behalf began to assume a larger international dimension after they responded to language cited earlier in the ADI annual report. DASNI proposed changes to the ADI Charter of Principles.

Care-partners. The group applauded ADI's principle that "a person with dementia continues to be a person of worth and human dignity, and deserves the same respect as any other human being," but also sug-

DASNI members Christine Bryden and Morris Friedell at last October's ADI meeting in Christchurch, New Zealand.

All photos of DASNI members taken, with permission, from the DASNI web site at www.dasninternational.org.

gested that "people with dementia are a constituency equal in dignity to donors, care-partners, and researchers." The word "care-partner" alone, substituted for "caregiver," is illustrative.

And while DASNI also applauded the ADI principle that "people with dementia should as far as possible participate in decisions affecting their daily lives and care," it also sought a more direct role in ADI's "management and leadership." The DASNI proposals will be taken up in October of this year at the ADI Annual Meeting in Barcelona, Spain.

Changing the Face of Dementia

Like ADI, the national Alzheimer's Association has recognized the emerging role of people with dementia. As Alzheimer's Association Interim President McConnell emphasizes, "The net result of earlier diagnostics will change the face of the Alzheimer population, making the person with the disease, not just the family caregiver, a principal focus for the Association's services and support."

National forum. DASNI members Morris Friedell of Montana and Jan Phillips of California have been invited to speak about that organization and Internet advocacy at the Association's Annual Public Policy Forum in Washington, DC. They will join others with dementia April 27-30 to exchange ideas about the Association's advocacy agenda and tactics, something other DASNI members discussed in February at a meeting with Association Vice President Kathleen O'Brien in Los Angeles.

That many DASNI members are younger than the typical person with dementia in no way indicates that older people with Alzheimer's disease or other dementing illnesses are not involved in advocacy efforts. They not only participate in the advocacy activities of the national Alzheimer's Association and its chapter network, but their participation stands to increase exponentially with the aging of baby boomers, who represent the largest generation in American history.

Vocal generation. Moreover, the Alzheimer's Association projects that in less than 50 years, the current estimate of 4 million U.S. residents with Alzheimer's disease or other dementia—at least 90% of whom are age 65 or older—will triple. Baby boomers identified with early stage dementia will have significant cognitive and physical capabilities.

"They will become increasingly vocal and active in encouraging the medical, scientific, and public policy communities to listen to their needs and to welcome them as participants in their care," says Sanford Auerbach, MD, Board Chair of the Association's Massachusetts Chapter. "They will accept neither a practice of medicine seen as paternalistic, nor an image of themselves as a 'burden' on society with regard to the cost or care necessitated by their illness."

Too many people with dementia have already missed the opportunity to participate in decisions regarding their daily routines, long-term care options, or, perhaps most cruelly, to understand what was happening to them. Something so simple



Chapter early-stage group member Caitleen McBride and her husband Owen.

"I hope we can all have an impact locally, because we can have a global impact on a global organization whose name represents people like us."

—Carole Mulliken

"If people with memory loss look at us as examples of the possibility of fighting back, they will be more likely to get early diagnosis."

—Morris Friedell

continued on page 14

Public Policy

Kathleen Doyle is the MA Chapter's Director of Public Policy.



*Kate Doyle,
Director of
Public
Policy.
(Photo by
Kathryn
Hedgepeth)*

We identified nursing home quality of care as the number-one issue of concern to families dealing with Alzheimer's disease.

Advocacy Agenda 2002: Forward March!

By Kathleen Doyle

The Alzheimer's Association, Massachusetts Chapter has embarked on an ambitious advocacy agenda for the year 2002, and Chapter advocates are keeping us on pace to meet it. Each year the Alzheimer's Association selects legislative priorities consistent with the policies adopted by the Alzheimer's Advocacy Committee.

These priorities are based on our members' needs and developed through feedback from member surveys, general member communications, and Alzheimer's sponsored events.

Throughout the year, the Alzheimer's Association may work on other legislative and regulatory proposals as they arise.

We identified nursing home quality of care as the number-one issue of concern to families dealing with Alzheimer's disease. Other issues flagged by the survey include expanded access to care and services for patients living at home; guardianship issues; and prescription drug coverage. A brief report on the public policy initiatives follows:

Nursing Home Quality of Care

The quality of care in nursing homes continues to be a major concern for patients and families. The Association has helped to form CORE Coalition (Coalition to Reform Elder Care), an aggregate of advocates, nursing home providers, family members, and labor representatives working on improving access to quality of care in nursing homes.

The Chapter has and will continue to work with the Governor's Advisory Council on Alzheimer's Disease to address the practice of discharging agitated dementia patients to acute care hospitals. The Fiscal Year 2002 Conference Committee Budget established an Advisory Council on Nursing Home Quality. In addition to working with various administrative agencies on these issues, we may also advocate for standards of care as outlined in the Association's Special Care Unit Guidelines.

Nursing Home Workforce Issues

The CORE Coalition successfully advocated for a package of certified nurse aide wage increases and workforce development provisions in the FY 2001 and FY 2002 budget cycles. In the coming year, the Alzheimer's Association will continue to work with the CORE Coalition to ensure that these provisions are implemented promptly and correctly. We will also work with the Direct Care Workers' Initiative to secure additional funding for wage increases in the FY 2003 Budget.

Prescription Drug Coverage

Working in concert with other advocacy groups, we succeeded in establishing an expanding Pharmacy Program for seniors and low-income persons with disabilities. A host of issues remain to be worked out in implementing the program,

administered by Elder Affairs. This program would increase access to prescription drugs for enrollees with income-scaled premiums, co-pays and deductibles, and would offer unlimited drug coverage after the deductible is met.

Alzheimer's Advisory Council Reauthorization

The Council was established by legislation to review and recommend ways to streamline the provision of services for Alzheimer patients and families, and to increase public education and knowledge of the disease.

Additional advocacy priorities for the coming year include the following:

Expanded Access to Community Care and Services

As indicated in your survey returns, an overriding concern for dementia patients and their families is access to community-based care. Over the past year the Association has worked on a number of approaches to expanded community-based services.

Guardianship and Competency Issues

Guardianship and competency issues are perennial problems for people with dementia and their families. During recent years, the Chapter has supported bills to make guardianship proceedings more simple and affordable, and to create a

Public Guardianship Commission for dementia patients who do not have families, or resources to assist them.

Medicare Issues


The Medicare Program continues to suffer fallout from the cutbacks included in the Balanced Budget Act of 1997, and families continue to experience difficulties in assessing Medicare-covered services. We have supported the advocacy efforts of home health agencies and nursing homes to restore some of their lost funding.

Respite Care

The national Alzheimer's Association continues to support funding for a \$3,000 caregiver tax credit and increased funding for the Family Caregiver Support Program.

Research Funding

The first public policy priority of our national Alzheimer's Association is an increase in research funding for dementia illnesses.

Join Us! These are just a few of the exciting initiatives in which the Alzheimer's Association has successfully participated. If you would like to play a more active role in our advocacy efforts, contact Susan Kelley-Grasso at (617) 868-6718. Susan can sign you up for our Public Policy mailing list, which will entitle you to frequent updates on legislative and other advocacy developments. 



Advocates Bruce Steiner and Jim Anthony at the Family Conference. (Photo by Sam Laundon, Natural Light Studios)

Chapter Hosts Discussion of Newly-Funded Research

Part I: Blueberries and Light Therapy

By Gerald Flaherty

No private organization provides more money than the national Alzheimer's Association for research into the causes, treatments, prevention, and cure of Alzheimer's disease. Of the 82 research grants awarded to U.S. scientists in 2001 by the Association, Massachusetts ranked with California and New York as the site reflecting the greatest number of funded studies.

Spotlight on science. Six researchers from Massachusetts who received Association funding in 2001 joined us at our Cambridge Offices Thursday evening, December 6 to talk about their important work in a panel discussion moderated by Dr. Marilyn Albert, national Chair of the Association's Medical and Scientific Advisory Council.

The work of two of these scientists, Drs. Barbara Shukitt-Hale and David Harper, encapsulated below, is drawn from their abstracts and comments. The work of the other four, Drs. Robert Moir of Massachusetts General Hospital; Thomas Perls of Beth Israel Deaconess Hospital in Boston; and Carlos Saura and Michael Wolfe, both of Brigham and Women's Hospital in Boston, will be presented in a future edition of this Newsletter.

"We want to be able to keep our volunteers and members up-to-date about the types of scientific investigations our Association supports," said Roberta Rosenberg, Chair of the Chapter's Medical & Scientific Advisory Committee, which coordinated the event. "These kinds of events also strengthen our relationships with leaders in the scientific community."

Reception. The 2001 grantees mingled with about 50 guests, including members of the Chapter's newly formed Advisory Committee of scientists and community leaders, during the wine and cheese reception preceding the discussion. Two additional grantees, Drs. Ashley Bush of MGH and William Esler of Brigham and Women's, could not attend due to scheduling conflicts, but we also hope to present their research at a later date.

In addition to Dr. Albert's national research role with the Alzheimer's Association, she is Professor of Psychiatry and Neurology at Harvard Medical School and Director of the Harvard-Mahoney Neuroscience Institute. Following her introduction by Chapter Board Chair Dr. Sanford Auerbach, Dr. Albert led the grantees through a discussion of their promising research.

Drs. Albert and Auerbach then facilitated a lively exchange with the audience on the fascinating range of work represented by the panelists. Their specific Association-funded studies appear below in italics.

Barbara Shukitt-Hale, Ph.D., of Tufts University in Boston, has drawn attention for her work on nutritional issues in Alzheimer's, most recently for *Age-Related Alterations to Inflammatory Insult: Reductions by Dietary Supplementation with Fruit Polyphenolics*.

Dr. Shukitt-Hale explained that **oxidative stress and inflammation** are thought to be major factors in brain aging and in age-related neurodegenerative disease. Changes resulting from aging may set the environmental conditions in the brain for further inflammatory and oxidative insult in Alzheimer's disease, and increased vulnerability to such insults may set the stage for the development of the disease in predisposed individuals.

If this is the case, she believes, then it might be important to try to desensitize this theoretically fertile ground and perhaps forestall or reduce the likelihood of developing the disease. To this end, some of the effects of inflammation could be retarded or even reversed by increasing anti-inflammatory protection in the brain and/or reducing brain susceptibility to inflammation. Previous findings in Dr. Shukitt-Hale's laboratory suggested that this goal might be accomplished by increasing dietary intake of fruits and vegetables.

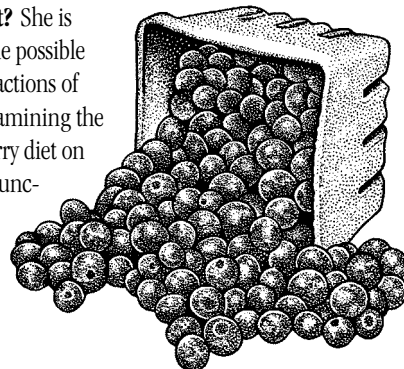
Her recent results have shown that polyphenolics, a class of compounds in fruits, were able to reverse several parameters of brain aging (e.g., deficits in cell communication), as well as age-related motor and cognitive deficits (in working memory,



for example), when fed to aged rats from 19-21 months, possibly by attenuating oxidative stress-induced damage. Blueberries are a polyphenolic focal point in Dr. Shukitt-Hale's investigations.

At first, Dr. Shukitt-Hale believed that blueberries were showing their protective effects through their antioxidant properties. However, her findings also suggest that in addition to antioxidant properties, the blueberry polyphenolics may elicit other actions that impact behavioral impairments.

Blueberry diet? She is now investigating the possible anti-inflammatory actions of polyphenolics by examining the effects of the blueberry diet on inflammation as a function of age. Her team will induce inflammation in rat brains by administering



continued on page 14



Medicine and Science

Gerald Flaherty is the MA Chapter's Director of Special Projects. Drs. Harper and Shukitt-Hale will participate in a panel discussion moderated by Dr. Marilyn Albert at the Association's annual *Map Through the Maze* interdisciplinary conference for professionals May 8 in Marlboro. Part II of this series, featuring the research of the four other scientists who received research grants, will be presented in the Summer edition of this Newsletter.

Chapter Board Chair Dr. Sanford Auerbach (L) and Panel Moderator Dr. Marilyn Albert (R) congratulate research grantees (L to R) Dr. David Harper and Dr. Barbara Shukitt-Hale. (Photo by Heidi Ganss)



ALZHEIMER'S EDUCATION CALENDAR

Care for People with Alzheimer's Disease

A professional education program designed to teach participants to become trainers within their long-term care facilities. Topics include understanding Alzheimer's disease, activities of daily living, communication techniques, behavioral management, working with families, and taking care of ourselves.   Pre-registration is required for this full day of training and the cost is \$500 for two representatives from an agency. Alzheimer's Association, Cambridge Office, 36 Cameron Ave., Cambridge. Call Donna Smart-Gorham at (617) 868-6718.



May 7, June 4

Community Care Training



A professional education program designed to teach participants to become trainers within their community agencies or facilities. One or two representatives attend in order to learn about Alzheimer's disease and dementia, Habilitation therapy, behavior issues, activities, and more. After the program, the representatives return to their facilities to teach other staff members.   Pre-registration is required for this full day of training and the cost is \$500 for two representatives from an agency. Alzheimer's Association, Cambridge Office, 36 Cameron Ave., Cambridge. Call Donna Smart-Gorham at (617) 868-6718. • **June 12**



A Map Through the Maze: a Multidisciplinary Conference for Professionals, is our annual forum especially designed for all health care professionals whose work brings them into contact with people with dementing illnesses or their families. The conference is intended for health care practitioners working in assisted living facilities, nursing homes, community agencies, hospitals, or any other setting. This year's conference will be held at the Royal Plaza Hotel in Marlboro.

Since our field is demanding and rapidly developing, *A Map Through the Maze* is intended to offer the best, most current and interesting workshops and presenters for the benefit of our attendees. Featured speakers at this year's program will be researchers Dr. Barbara Shukitt-Hale and Dr. David Harper, whose work is summarized in our Newly-Funded Research article (see page 7). Call (617) 868-6718 or refer to our web site at www.alzmass.org for a brochure.   **May 8**

Support Group Leaders Forum

Presented by the Support Group Committee of the Alzheimer's Association. Designed for new as well as experienced support group leaders.   A \$25 fee includes continental breakfast and lunch. The Forum will be held at Whitney Place in Natick. Call (617) 868-6718 for a brochure.

June 13 (9 a.m.-1 p.m.)

Family Orientation

An education meeting for family members. Topics include diagnosis, treatment, medications, planning, home management, and more. Each Family Orientation session is repeated on a monthly basis.

The program is free of charge. Locations, times, and dates are listed below:

Cambridge: Held at Cambridge Office of Alzheimer's Association, 36 Cameron Ave., Cambridge. Presented by Dr. Paul Raia. Pre-registration is not necessary and the program is free of charge.


May 16, June 20, July 18 (10:00 a.m.-12 p.m.)

Lowell: Held at Alzheimer's Association, Lowell Area Office, HealthSouth at St. Joseph's, 220 Pawtucket St., Lowell. Pre-registration is not necessary and the program is free of charge.


June 12, July 10 (10:00 a.m.-12 p.m.)

Newton: Sponsored by the West Suburban Alzheimer's Partnership. Held at Newton Senior Center, 345 Walnut St., Newton. Presented by Pamela Kunkemueller. Pre-registration is not necessary and the program is free of charge.


May 8, June 12, July 10 (6:45-8:45 p.m.)

Northampton: Held at VNA and Hospice Alliance, 168 Industrial Ave., Northampton.  Pre-registration is recommended; call (413) 787-1113. Free of charge.


May 8, June 12, July 10 (3:30-5:00 p.m.)

Roxbury: Held at Community of Color Outreach, 116 Roxbury St., Roxbury. Presented by Michael Kincade.  Pre-registration is recommended and the program is free of charge. Please call (617) 868-6718, ext. 202.

May 23, June 27, July 25 (6:00-8:00 p.m.)

Springfield: Held at Good Life Center, 1600 E. Columbus Ave., Springfield.  Pre-registration is recommended. Please call (413) 787-1113 for details.

May 8, June 12, July 10 (3:30-5:00 p.m.)

Watertown: Sponsored by the West Suburban Alzheimer's Partnership. Held at West Suburban Elder Services, 124 Watertown St., Watertown. Presented by Susan Garland.  Pre-registration is required; please call (617) 972-5692. Free of charge. **May 6, June 3, July 1 (2:00-4:00 p.m.)**

Wellesley: Sponsored by the West Suburban Alzheimer's Partnership. Held at Wellesley Council on Aging, 219 Washington St., Wellesley. Presented by Peggy Mullen. Pre-registration is not necessary and the program is free of charge.

May 28, June 25, July 23 (1:30-3:30 p.m.)

Westwood: Sponsored by the West Suburban Alzheimer's Partnership. Held at Westwood Council on Aging, 210 Nahatan St., Westwood. Presented by Peter Byron. Pre-registration is not necessary and the program is free of charge.

May 16, June 20, July 18 (1:30-3:30 p.m.)

All meetings
free of charge
marked

Times may be subject to change.

call the number listed.

 indicates pre-registered.

If in doubt, call

617/868-6718

Visit www.alzmass.org

for up-to-date information.



All Education Calendar photos by Janet Taylor.



Save the Dates!!! Watch for Upcoming Events:

3rd Annual Night at the Pops

Ron Della Chiesa, Honorary Chair • Stanley Solomont, Chair
Wednesday, May 29 • Contact: Sheila Watnick,
(617) 868-6718 ext. 208 or sheila.watnick@alz.org

5th Annual Make the Link Golf Tournament, Auction

Monday, July 22 at the Andover Country Club, chaired once again by Bob Cipriani of Fidelity Press, Inc. Sponsorship opportunities are available. Please contact Dick Fleiss if you're interested in serving on the Committee or for more information at (617) 868-6718 or richard.fleiss@alz.org.

Alzheimer's at Tanglewood: an Encore Sunday, August 11

A dessert reception and performance to benefit the Alzheimer's Association, MA Chapter. For more information, call (413) 787-1113 or kathryn.hedgepeth@alz.org.

10th Anniversary/Annual Memory Walk September 21-22, 28-29

- Saturday, September 21 (Berkshire Walk)
 - Saturday, September 21 (Northern Quabbin Valley Walk)
 - Sunday, September 22 (Central MA Memory Walk)
 - Sunday, September 22 (Greater Boston/Main Walk)
 - Sunday, September 22 (Northern Middlesex Walk)
 - Sunday, September 22 (Southeastern MA Walk)
 - Sunday, September 29 (Pioneer Valley Walk)
- (As of press time, the dates above were confirmed—others to follow.) Contact Sheila Watnick, (617) 868-6718 or sheila.watnick@alz.org

are unless change; please each program. on is required. elpline at 8. s.org ting.

Spring Reading: Books from our 2002 Publications List

Alzheimer's Disease: The Answers You Need by Helen Davies and Michael Jensen; 1998, soft-cover, 138 pages. Written for people who have Alzheimer's disease, this book helps patients make adjustments and overcome frustrations, while never denying the problems. Using a question-and-answer format, the information is delivered in a clear, useful style. Prices: members \$9.95, non-members \$10.95.

Alzheimer's Early Stages: First Steps in Caregiving by Daniel Kuhn; 1999, soft-cover, 266 pages. This book focuses on the specific concerns of families of people newly diagnosed with Alzheimer's disease: medical aspects of the disease, guidance in long-term planning, giving care and receiving support. **Prices:** Chapter members \$13.95, non-members \$14.95.

Speaking Our Minds: Personal Reflections from Individuals with Alzheimer's by Lisa Snyder, 1999, soft-cover, 161 pages. Seven people of varying ages and backgrounds vividly describe their experiences of Alzheimer's disease. The narratives are interspersed with the author's thoughts and observations. These people are defined not by what is lost but by what endures. **Prices:** Chapter members \$10.95, non-members \$12.95.



Newly updated and completely redesigned, our *Family Care Guide* is soft-cover and spiral-bound, 134 pages. This popular guide offers practical advice for dealing with many of the everyday problems that confront people with Alzheimer's and caregivers. The easy-to-read format includes topics such as planning ahead, communication techniques, managing common problems such as wandering and driving, and strategies for coping with issues of daily living. **Prices:** Chapter members \$14.50, non-members \$15.50.

For all book orders, add \$3.00 for shipping and handling (\$0.25 for additional books to the same address). Call (617) 868-6718 for a complete publications list and order form, or visit our web site at www.alzmass.org.



Readership Poll

PLEASE LET US KNOW! Just clip this section and mail to Newsletter Poll, Alzheimer's Association, 36 Cameron Avenue, Cambridge, MA 02140

It would be very helpful to us in planning each Newsletter to have your feedback and suggestions.

1. Do you usually read most or all of each issue? ___
2. How would you rate the overall quality of our Newsletter?
Excellent ___ Good ___ Fair ___ Poor ___
3. What topics would you like to see covered?
a. _____
b. _____
c. _____

Education

Comments from attendees:

"Shirley helped put a face on the illness—a face of hope."

"It helped to meet other people, and see how much support is in place for us."

"The conference was a good catalyst for siblings and step-siblings."

"The whole day was so helpful and informative."

"Superior program—a true experience of learning and sharing."




Family Conference Celebrates Relationships

Our annual conference for people with Alzheimer's disease and their families, Living with Alzheimer's, was a huge success! Held at the Holiday Inn in Worcester December 8th, our good-weather lucky charms worked this time around, drawing 200 participants.

From the free respite program provided by **Friendship Place Adult Day Health Center** of South Lancaster, to the inspiring opening and closing remarks by a person with dementia and a spouse, the conference offered an important opportunity for attendees to share knowledge, support, and fellowship.

Excellent presentations and workshops supplemented the day's activities.

Both presenters and worker-bees were drawn from the Association's Board and staff, as well as people from the Worcester area and beyond. Our Development staff had secured support from three organizations—Fallon Community Health Plan, Beverly Healthcare, and The Tapestry Program at Whitney Place Assisted Living Residences—that underwrote virtually all costs. It would be difficult to imagine a more successful conference, or a better example of how our Association team works together harmoniously to provide education, support, and outreach across Massachusetts. 

—Rachel Hawk



(Conference Photos by Sam Laundon, Natural Light Studios)

Shirley Geller addressed the morning session of the Family Conference with the following personal statement:

What It's Like To Have Alzheimer's Disease

As a person who was diagnosed with Alzheimer's disease about a year ago, I have been asked to talk about what it feels like to have this disease. I use the word disease because while many people associate memory loss with normal aging, Alzheimer's is more than that. It is a biological disease. There should be no stigma associated with a biological disease, but sometimes there is.

Starting with the negative side of this disease, I would say that the worst part is when I think about the future. This disease is progressive, and I am fully aware of it, even on a daily basis. This is both scary and depressing. I know also that there will be a time when a nursing home will enter the picture.

I am no longer driving, which means a loss of independence, but I am getting used to that. I always had trouble remembering faces, but I now have difficulty with names, as well. Since we spend summers on the Cape and part of the winter in Sarasota, moving has become an adjustment. I am also told that I keep repeating the same question, not remembering that I have already asked and received a reply.

If I start relating a story or incident, I get halfway through and forget the point that I was trying to make. When I read something it doesn't stay with me, and my bridge skills are diminishing. What bothers me a great deal is that I've always dealt with financial matters and I am now having difficulty in this area.




I have always kept important papers and things of that nature in certain places, and I now find I can't remember where they are. Where did I put a particular item? What did I make for lunch or dinner? When did I wash my hair? Did I brush my teeth yet? Where is the leftover food I'm sure I put in the refrigerator? Or when I'm about to say something, oops! It is suddenly gone. When I go to get something, I ask myself, what is it that I came into this room to get? Not all these symptoms are chronic, and I do have many good days.

I am blessed to have a wonderful husband, daughter, son-in-law, and two delightful grandsons. Dr. Schiff, my neurologist, is a very kind and caring person and is never too busy to answer my questions over the phone. The support group I attend is also extremely helpful.

It's important to be able to share problems and concerns with others in the same situation, and to have leaders who are able to help with good suggestions. Frankly, I sincerely feel things could be worse.

People are amazed that with this problem, I still have a positive attitude.

Sometimes it's even helpful to forget certain things from the past. For example, when I commented that my daughter has always been wonderful, a friend reminded me of the problems I had with her when she was a young adult. I couldn't believe it! I asked my husband if this was true and he said it was.


Finally, I will just say that I am very determined to get the most out of life each and every day. 

Open House Marks 21 Years of Caring

The new Western Regional Office of the Alzheimer's Association, MA Chapter was officially opened at the Good Life Center in Springfield Thursday, December 13. About 125 guests were welcomed into the new office headquarters to meet the staff and enjoy a delicious luncheon buffet.

Proclamations. Springfield Mayor Michael Albano welcomed the Alzheimer's Association to the city during a brief program prior to the lunch. State Senator Brian Lees and Mary Jenewin-Caplin, Director of the Governor's Western MA Office, presented proclamations recognizing the Association's 21 years of service to the Commonwealth.

In addition, Massachusetts Executive Office of Elder Affairs Secretary Lillian Glickman updated guests on the impact the recession and current budget cuts are having on various programs for seniors. Heartfelt remarks by family caregiver Herb Abair relating the support he received from the Regional Office staff also highlighted the brief program.

Special thanks to Landmark at Monastery Heights in West Springfield for providing the scrumptious lunch! And extra kudos to the volunteers who organized the event: Denise Beaulieu, Shirley Burke, Bill Caplin, Cheryl Dunn, Art Ford, Bill Gaw, Gary Grumoli, Sheri Iodice, Denise Perlaky, and Marilyn Simpson. We also appreciate the generous assistance and warm welcome from the Good Life Center staff, especially Antonietta Carrano, Marje Vallone, Charlotte Lee, and Jorge Castellano. 



Deborah Hollingworth of Greater Springfield Senior Services, Community Advocate Yoko Kato, and Western MA Education Coordinator Jeannie Banas (L to R) visit with Roxanne Mosber (back to camera) of Western MA Hospital, Westfield.



Ginny Sinkoski (L), Helpline Coordinator, shares a happy moment with Regional Director Kathbryn Hedgepeth (C) and guest Karen Charbonneau (R).



MA Executive Office of Elder Affairs Secretary Lillian Glickman (2nd from R) discusses State support for Alzheimer's services with Chapter Executive Director Jim Wessler (C), Bill Gaw (R), and Denise Beaulieu (L) of the Governor's Center. (All Open House photos by Denise Perlaky)



Bud Delphin (C) introduces fellow Regional Leadership Council member Art Ford (R) to Dagmar Nowak (L) of The Atrium at Cardinal Drive.




Leadership Council member Bill Caplin (R) greets honored guests (L to R) Gary Grumoli of Landmark Assisted Living, Springfield Mayor Michael Albano, Springfield Department of Elder Affairs Director Jorge Castellano, and State Senator Brian Lees.

Professionals Conference

More than 143 health care providers convened November 6 for the 11th Annual Western MA Professional Caregivers Conference at the Springfield Sheraton Hotel. Keynote speaker Ladislav Volicer, M.D., Ph.D. presented "Nonpharmacological Management of Alzheimer's Disease."

Dr. Volicer is Clinical Director of the Geriatric Research Education and Clinical Center, E.N. Rogers Memorial Veterans Hospital, Bedford, MA. He is also the co-author of *Management of Challenging Behaviors in Dementia* (reviewed in the Summer 2001 issue of this Newsletter), along with Ellen K. Mahoney and Ann C. Hurley.

Three workshops focusing on alternative treatments were also incorporated into the program. Dr. Volicer presented Pain Management; The Boston Alzheimer's Center and Elaine Silverio presented Environmental Management and Social Management. At end of day, participants reviewed the conference with an interactive mock Care Plan Meeting. 




Marcia McKenzie, Western MA Community Services Coordinator, with Elaine Silverio, Conference Speaker and Consultant.

Clergy Conference Extends Support

Consultant and author Joanne Koenig-Coste was the keynote speaker at a groundbreaking conference for clergy members held January 23, "Alzheimer's Disease: A Spiritual Journey." Forty-six clergy and lay participants gathered from central and western MA and southern NH to talk about the links between the emotional and spiritual needs of people with dementia and their caregivers.

Sharing anecdotes from her personal and professional life as a caregiver, Joanne skillfully drew the audience into the world of people with Alzheimer's disease and their families. Her comments sparked a lively discussion about the impact of Alzheimer's on the humanity of people with the disease, and how to incorporate their religious practices and spiritual needs into innovative care plans.

Road map. To acquaint participants with some of the organizations available to help them through the maze of decisions they need to make in assisting others, the half-day program also featured a panel discussion. Speakers addressed care options, hospice, and area resources available through the Alzheimer's Association and the State network of Aging Services Access Point (ASAP) agencies. 



Save the Date!

Alzheimer's at Tanglewood: an Encore Sunday, August 11

Join us for a dessert reception and performance to benefit the Alzheimer's Association, MA Chapter. For more information, call (413) 787-1113 or e-mail kathryn.hedgepeth@alz.org

Joanne Koenig-Coste shares ideas with family members at the Clergy Conference.

Development

Thanks to Winterfest

Raffle Door Prize

Donors:

Anderson's Jewelers,
Wellesley
Appetito Restaurant,
Newton
Best Cellars, Brookline
Billerica Country Club,
Westford
Boston Beer Company
Blue Ribbon BBQ, Newton
Boston Bruins
Bretton Woods Ski Area
The Briar Group, Brighton
Buff's Pub, Newton
Capital Grille
Clear Channel
Entertainment
Corners Framing
Dick's Last Resort, Boston
EB's Bark and
Elizabeth Deist
Erawan of Siam, Waltham
The Fairway, N. Eastham
Giacomo's Restaurant,
Boston
Hair West, Wellesley
H.D. Chasen Co., Inc.,
Somerville
House of Blues, Cambridge
John Harvard's Brew
House, Cambridge
Michael Salon, Brookline
Minuteman Car Wash,
Medford
Moby Dick's, Wellfleet
Museum of Fine Arts
New England Mobile Book
Fair, Newton
O'Hara's Restaurant,
Newton
Redbones BBQ, Somerville
Santa's Village, Jefferson,
NH
Sugarbush Resort, Warren,
VT
The Bookstore Restaurant,
Wellfleet
Total Skin Care, Boston
Town Crier Motel,
Eastham
Union Street Restaurant,
Newton
Verizon Wireless
Wayland Golf Shops
Wireless Zone

Winterfest Raises over \$13,000 for Chapter Programs, Services

More than 400 people turned out for a festive evening of dancing and lively conversation at the 11th Annual James "Vic" Jordan (1918-1994) Winterfest Benefit, held January 26 at The International in Boston. This year's Winterfest Benefit raised over \$13,000 for Association programs and services.

"Winterfest is a loving tribute to our wonderful grandfather, Vic Jordan, and we know he'd be pleased that the funds raised are used to help other people with Alzheimer's disease and their families in Massachusetts. The continued extraordinary generosity of our family and friends and outpouring of support we've received is heartwarming," commented **Betsy Nordman**, one of the event's founding chairs.

"We're grateful that The International once again donated the use of their facility, plus a delicious buffet," added longtime Committee member **Polly Carpenter**. Polly's beloved grandmother and namesake, Pauline Carpenter (1898-1990) had Alzheimer's disease.

Many thanks to the Winterfest Committee: Jen Anthony, Christine Bourassa, Pauline Carpenter, Allan Chasen, Sebastien Dubois, Andrea Evans, Heidi Ganss, Tim Ganss, Scott Kerry, Kristin Klayner, Betsy and Mike Nordman, Melanie Manning, Kostas Splagounias, Lydia Tower, David and Julie Tremblay, Katha Washburn, Jennifer Weinstock, and Rich Whelpley.

Special prizes. A highlight of the evening was the raffle, in which the most popular item was a signed New England Patriots team football. Grand prize raffle winners Alison Reynolds of Newton and Maria Glavas of New York City were thrilled to receive a Fisher mountain bike and a trip to Aruba, respectively. Many thanks, as well, to the generosity of the other businesses that donated door prizes for the Winterfest raffle. **fi**



Winterfest Committee members (L to R) Kostas Splagounias, Polly Carpenter and David Tremblay worked tirelessly for months to help raise over \$13,000 for Association programs and services. (Photo by Betsy Nordman)

Charity News Note

Worth Magazine cited the Alzheimer's Association as one of the top twelve charities in the United States in the December, 2001 issue. **fi**



The 2002 Winterfest Committee took time out to pose for a group photo. Since the first Winterfest Benefit in 1992, the Committee has grown from 3 to more than 20 active, committed members. (Photo by Lisa Mulville)



Winterfest Committee members (L to R) Christine Bourassa, Scott Kerry, and Jen Anthony share a festive moment. A talented graphic designer, Jen created a professionally-printed Faces of Alzheimer's display to increase event attendees' awareness of Alzheimer's disease. Christine and Jen's devoted grandmother Dorothy Baker (1907 - 2000) was featured on the display. (Photo by Betsy Nordman)

Massachusetts Elks Reach out to People with Alzheimer's

The Alzheimer's Association is grateful to the Elks! Louis Connelly, President of the Massachusetts Elks Association, was pleased to present a check for \$1,000 to the Alzheimer's Association January 16th. Lou, whose brother-in-law has Alzheimer's disease, graciously designated the Association as a recipient of the Massachusetts State Elks charitable funds.

Forget-Me-Not. Thanks, also, to the Braintree Elks and Kathy Ross Graves who donated \$1,500 from their Forget-Me-Not Road Race, held in September, 2001. Kathy and her committee members Keith McHugh, Melissa Ross, and Angela Geso Ferriss worked tirelessly for months, and it paid off handsomely.

In addition, the Peabody Elks presented the Alzheimer's Association with \$1,000 from the Theresa A. & Maurice L. Sullivan Humanitarian Trust. The Benevolent and Protective Order of Elks of the United States of America is one of the oldest, largest fraternal organizations in the country. Since its inception in 1868, the Order of Elks has grown to include nearly 1.2 million men and women in almost 2,200 communities. **fi**

Ron Della Chiesa Named Honorary Chair of May 29 *Night at the Pops*

On Wednesday, May 29, Ron Della Chiesa, 30-year veteran of WGBH and host of the station's Classics in the Morning, The Boston Symphony Orchestra Live Broadcasts and The Jazz Songbook, will join us as Honorary Chair when Maestro John Williams takes the baton at the Alzheimer's Association's Third Annual *Night at the Pops*.

An hors d'oeuvres reception beginning at 6 p.m. will serve as prelude to the 8 p.m. program at Symphony Hall in Boston. Ironically, Della Chiesa was the first person to interview Williams when he started with the Boston Symphony.

For the third year in a row, Board Member and Pops Chair Stanley Solomont and presenting sponsor Praecis Pharmaceuticals, Inc. promise a festive evening for a wonderful cause. A new twist this year will be a raffle with very special items!

Thank you, Marcia Simons! The Alzheimer's Association is deeply appreciative of the many generous gifts received in honor of dedicated Board Member Emeritus Marcia Simons, shown with

Chapter Executive Director Jim Wessler at the recent opening of the Matthew Simons IMAX Theater at the New England Aquarium. (Photo by Joey Libby)



Dr. Selkoe's Work Featured in *Boston Magazine*

The scientific work of Alzheimer's Association Board Member Dennis J. Selkoe, M.D., Co-Director of the Center for Neurologic Diseases at Brigham and Women's Hospital, was prominently featured in the February, 2002 issue of *Boston Magazine*. Dr. Selkoe's research focuses on what exactly causes Alzheimer's disease; he theorizes that beta-amyloid, a sticky protein secreted by cells, eats away at the brain over time.


For more information on Dr. Selkoe and his cutting-edge research, visit www.alzmass.org/selkoe on the web.



Dr. Dennis Selkoe fields audience questions at an Alzheimer's Association Annual Meeting. (Photo by Ellen Shub)




Board Member Stanley Solomont will serve as Chair for our 3rd Annual Night at the Pops, to be held Wednesday, May 29th at Symphony Hall in Boston. Stanley (C) is shown with Board Chair Sanford Auerbach, M.D. (L) and Advisory Committee member Betty Avruch at last year's Night at the Pops. (Photo by Joey Libby)

Tickets are \$185 each or \$900 for a table of five. To order tickets or advertise in the program book, please contact Sheila Watnick at (617) 868-6718 x208 or e-mail sheila.watnick@alz.org. 

Development

Memory Run Scores Big

JoAnn Tupper did it again! The 2nd Annual Memory Run, a motorcycle race from Framingham to Hampton Beach, was held July 15, 2001 and raised over \$1,600 for Association programs and services. Rev-up your engines for the 3rd Annual Memory Run! 

Let Your Company Boost the Value of Your Gift!

The companies listed below are just a small sampling of the hundreds of organizations that offer corporate matching gifts programs. Help make an even bigger difference in the lives of people with Alzheimer's disease and their families by checking with your Human Resource department, and get a matching gift form from your employer. It's that easy!

Aetna	John Hancock Mutual Life Insurance Company
American International Group	Keyspan Energy
Analog Devices	Lucent Technologies
AT&T	Massachusetts Mutual Life Insurance Company
Avon Products, Inc.	Massachusetts Port Authority
C.R. Bard, Inc.	McGraw-Hill Companies
Boston Mutual Life Insurance Company	Mellon Financial Corp.
Bristol-Myers Squibb Co.	Merrill Lynch & Co. Inc.
CambridgeSoft	Morgan Stanley Dean Witter
Cisco Systems, Inc.	New England Financial
Computer Associates International, Inc.	Novartis Corp.
Deloitte & Touche	Reebok International, Ltd.
Delta Air Lines	Stride Rite Corporation
Diebold, Inc.	Sun Microsystems, Inc.
Eastern Mountain Sports	3Com Corporation
Federated Department Stores, Inc.	Thomson Financial Services
Fidelity Investments	United Parcel Service
Fleet Financial Group	WordsWorth Books
GTE Corporation	Xerox Corporation
Harcourt General, Inc.	
Hasbro, Inc.	
International Business Machines	

Advocacy

“(Alzheimer’s disease) is underestimated, under-diagnosed, and the magnitude of the public health problem not fully appreciated.”

—Zaven Khachaturian

“Treatment delayed is treatment denied.”

—Christine Bryden

Medicine and Science



The work of the remaining scientists (L to R), Dr. Carlos Saura, Dr. Robert Moir, Dr. Thomas Perls, and Dr. Michael Wolfe, will be presented in our next Newsletter. (Photo by Heidi Ganss)

Global Advocacy *continued from page 5*

as that knowledge may have given them the chance to redefine what quality of life can mean.

In the 12 years that the early-stage support group for people with dementia has been meeting at the Association’s Massachusetts Chapter, fewer than 5% of those participating have expressed regret at knowing their diagnosis. Asked recently why they think early diagnosis is important, current group members’ answers showed insight and a keen understanding of both their disease and their limitations. Their collective point was that knowledge carries with it a sense of power and control that they, along with their care-partners, can transfer into action.

Surely they can convey that insight and understanding to others. Given the many remaining barriers to diagnosis and treatment, it would seem they must.

A Global Impact

When professionals in the Alzheimer network hear, “If there’s no treatment, why get a diagnosis?” we will continue to explain that there are indeed effective pharmacological and rehabilitative treatments for people with Alzheimer’s and other dementias. But our experience tells us that this message will not be heard in the same way as it would if delivered by someone like DASNI’s Friedell. “If people with memory loss look at us as examples of the possibility of fighting back,” he insists, “they will be more likely to get early diagnosis.”

People with dementia, as evidenced by groups like DASNI, can also “help the Association do some consciousness-raising



DASNI can be reached at
www.dasninternational.org

to improve its relationship with early-stage people,” says DASNI member Carole Mulliken of Missouri. “I hope we can all have an impact locally, because we can have a global impact on a global organization whose name represents people like us.”

Inclusive trend. DASNI is just one organization with a modest but growing membership. In order to make their point for inclusion, some members question what they see as

a caregiver-focused orthodoxy within the global Alzheimer network more vigorously than do others. Nevertheless, their activism signals a movement in step with the activities of many individuals with dementia and their care-partners in the U.S. and elsewhere.

By encouraging inclusion and supporting the mobilization of the Mullikens, Friedells, Phillips, Smiths, Jacksons, Orme-Johnsons, McBrides, Brydens, and the potential thousands of others like them, the Alzheimer’s Association advances its mission to remain a primary source for reliable information and support. Such a defining step in the Association’s evolution is consistent with what other health organizations have experienced in order to counter widespread lack of public awareness and enhance the important work they do.

Alzheimer’s disease and related dementias do indeed pose unique issues for the people who have them, and for all their care-partners. But whatever may set dementia apart from other major illnesses, it is increasingly clear that it is not a lack of will among people who have it to advocate for themselves or for people like themselves. **■**

Newly-Funded Research *continued from page 7*

lipopolysaccharide (LPS), a bacterial toxin and potent inflammatory agent. Previous studies have shown that chronic infusion of LPS into the brains of young rats can reproduce many of the inflammatory and neuropathological changes seen in the brains of Alzheimer patients in some similar regions, as well as produce changes in spatial learning and memory behavior.

Using young (6-month-old) and middle-aged (16-month-old) rats fed a control, blueberry, or piroxicam (a nonsteroidal anti-inflammatory) diet, Dr. Shukitt-Hale will test the effectiveness of blueberries in forestalling LPS’s initiation of an inflammatory insult and ensuing negative effects on cognitive behavior; and in activating inflammatory mediators in the brain. She will test these animals with a battery of cognitive and motor tests before analyzing their brains for markers of inflammation, which can then be correlated with behavioral changes.

David G. Harper, Ph.D., of McLean Hospital in Belmont, discussed his work on *Light Treatment of Circadian Rhythm Disturbances in Alzheimer’s Disease*. He emphasized that Alzheimer’s carries enormous personal and social costs.

Institutionalization of people with the disease, for example, is frequently initiated as a consequence of caregiver exhaustion. Insomnia and temporary specific agitation such as **sundowning** are among the leading reasons for this exhaustion.

These two non-cognitive symptoms of Alzheimer’s may also share an underlying etiology in circadian rhythm disturbances. Recent results from Dr. Harper’s lab have provided evidence for this possibility, particularly phase-delay of core-body temperature and activity rhythms, in the etiology of insomnia and temporary specific agitation.

Dr. Harper is testing this hypothesis by using light treatment to reverse the phase-delay of the circadian rhythm seen in Alzheimer’s. He hypothesizes that bright light, given to people with Alzheimer’s at a time of day that will cause the return of circadian rhythmicity to a pattern matching their environmental rhythms, will improve sleep and lower some agitation. Dim light given at the same time, he thinks, will neither shift the circadian rhythm nor address the functional difficulties that bright light treatment will ameliorate. **■**

Support Group listing continued from back cover

Mansfield: Christine Filocco or Deborah Supernant	508-261-1333	West Roxbury: Susan O'Connell or Stephanie Brinkhaus	617-325-1230
Marlboro: Bonnie Plankey or Jessica Sorgi Joyce Henderson	508-481-9898 508-485-4040	West Springfield: Lois Goralski	413-781-1282
Medford: Douglas Lloyd or Sheila Watkus	781-324-5759 781-395-5542	Westboro: Julie Palmieri	508-836-4354 x3706
Mendon: Marlene Fregeau or MaryPat McDavitt	508-473-0862	Westfield: Ellen Nepomuceno	413-781-5070
Merrimac: Patricia Lavoie	978-803-3296	Weston: Shirley Earle	781-893-0154
Methuen: Donna Koski	978-682-3582	Westport: Susan Oliveira	508-636-1026
Middleboro: Robella Coates Carol Ann Landreville	508-946-2490 508-947-4774	Westwood: Peter Byron	781-326-5652
Milford: Marlene Fregeau	508-473-0862	Weymouth: Barbara Orlandi Denise Moore or Julie Barcelo	781-337-3121 781-340-9100
Millbury: Michelle Stevens	508-793-0088	Wilbraham: Beth Vettori	413-596-0006
Nahant: Rev. David Dodge	781-581-1202	Williamstown: Fredrica Sloan	413-458-8127
Natick: Judy Sabol Lois Pecora	508-650-9003 508-655-5000 x3988	Winchester: Valerie Gramolini	978-897-7455
New Bedford: Jenny Nelia	508-998-7807	Woburn: Jennifer Jaroch	781-932-0350
Newburyport: Patricia Lavoie	978-777-2700	Worcester: Faith Bandama Laurie Googins or Ann Fitman	508-791-5543 508-753-4791
Newton: Mara Klein Emily Saffer or Carol Westheimer	617-928-0007 617-558-6443 781-455-8588	Allison Leger	508-752-2546
North Adams: Beth Hinkley	413-664-4536	Debbie DeRossier	508-754-3800 x126
Norwood: Mary Beth Whitefield	781-769-4495	Worthington/Cumington: Sandra Epperly or Lucille Temple	413-238-5584
Peabody: Linda Smith	978-531-2254 x137		
Pittsfield: Louise Posnick Robert Hamilton Beth Hinkley	413-445-2300 413-499-0524 413-499-1992		
Plymouth: Deborah Feurtado	508-746-7016		
Quincy: Kathy Prince Beverly Moore	617-471-5712 617-233-1145		
Reading: Anne Marie Bourque or Marie Ammer	781-944-1132 781-942-9059		
Rockland: Lauren Walsh	978-878-0099		
Roxbury: Ilene Marsh or Michael Kincade	617-361-7486 617-868-6718		
Saugus: Debbie Bennett	781-233-8123		
Scituate: Marla Kaplan	781-681-1065		
Somerset: John Rogers	508-679-2240		
South Hadley: Gerri Bennett	413-532-8098		
Southbridge: Roger LaMontagne Susan Klezcka	508-765-9771 508-248-7344		
Springfield: Ellen Nepomuceno	413-781-5070		
Stoughton: Denise Conley Karen Sprague or Marsha Phillips Young	781-344-7300 781-344-7661		
Taunton: Barbara Richards	508-823-4493		
Tewksbury: Elaine St. Cyr Sharon Hooper or Paula Drelick	978-657-0800 978-851-3121		
Turners Falls: Molly Chambers	413-773-5555		
Wakefield: Lynn Zaloga	781-224-2800		
Ware: Stasia Wozniak	413-967-2245		
Wareham: Carolyn Cardoza	508-758-2173 or 991-5015		
Watertown: Ruth Gordon	617-491-1823		
Wayland: Candace Steingisser	508-358-3000		
Webster: Carolyn Racicot	508-949-3598		
Wellesley: Amy Beck Peggy Mullen	781-237-6400 508-533-7020		

Specialized Groups**Caregivers of Mentally Retarded Adults with AD**

Kevin Leahy 781-324-4303

Families of VA Patients with AD

Bedford: Jennifer Hill 781-687-2701

Interfaith Support Group

Framingham: Malka Young 508-875-3100

Springfield: Marcia McKenzie 413-787-1113

People under 65 with Early Stage Alzheimer's and Their Caregivers

Cambridge: Elaine Silverio 508-429-1577

People with AD and their Caregivers

Wellesley: Peggy Mullen 508-533-7020

People with Early Stage Alzheimer's and Their Caregivers

Amherst: Jeannie Banas or Wanda Landry 413-787-1113

Chicopee: Beth Hewson 413-592-5199

Concord: Kate Marshall 978-369-4728

or Joanne Chaulk 978-486-0590

Danvers: Carol Owen or D'arcy Adams 978-774-4400 x3064

Natick: Joanne Koenig-Coste 508-879-5338

or Lois Pecora 508-655-5000

Springfield: Ginny Sinkoski 413-787-1111

Westboro: Rosalie Hentz 508-366-9933 x3797

or Muriel Baum 508-435-0019

Weymouth: Julie Barcelo 781-340-9100

Spanish-language Group/En Español

Boston: Conchita Rodriguez 617-868-8599

Springfield: Lydia Serrano 413-781-8800

Spouses' Group

Brockton: Geralann DiDomenico 508-427-6099

Chelmsford: Susan Antkowiak 978-934-0000


Younger Adult Caregivers

Cambridge: Erin Whalen 617-868-6718

Support Groups

Our web site support group leader list at www.alzmass.org is also updated more frequently. For information about support groups on Cape Cod or the Islands, call that Chapter at (508) 775-5656.

Please call the listed group leaders for details. We make every effort to keep this list up-to-date, but some listings may be incorrect because production of the Newsletter takes nearly three months, and because we are not always notified of a change. If you have any problem contacting a group leader, please call our Helpline at (617) 868-6718.

These support groups are free and open to the public. In addition, many day programs and long-term care facilities offer groups for families of their patients. Support groups are independently run and this listing should not be construed as a recommendation. 



We rely on private contributions to provide critical programs and services for Alzheimer's patients and their families. Please help. We urge you to use the enclosed envelope to make your tax-deductible gift and be as generous as you can.

Support Groups

Support groups provide a forum for family members and friends of people with Alzheimer's disease or another dementing illness. Groups also exist for people who have early-stage Alzheimer's disease—refer to **Specialized Groups** at the end of the alphabetized list of communities.

At these groups, people learn about the disease, share concerns and information, and support each other in coping with the effects of Alzheimer's disease or one of the related disorders. Groups may vary in size, frequency of meeting, and leadership style but are often termed *life-saving* by their members.

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Abington: Marie Bates	781-871-0200	Jeanne Parent	978-777-5717
Acton: Joanne Chaulk or Jean Fleming	978-486-0590 978-264-9643	Gayel Cote	978-762-7625 x14
Agawam: Judy Pothul	413-821-9911	Dorchester: Donna Allen	617-474-1194
Amherst: Melissa Rohde	413-548-6800	Duxbury: Sandi Wright	781-585-2397
Andover: Rachel Zalvan	978-623-8321	East Longmeadow: Ellen Nepomuceno	413-781-5070
Arlington: Laurie August	781-316-3400	Mary Anne Stout	413-525-8150
Athol: Wandra Landry	978-249-3717	Easthampton: Wendy Perrault	413-527-7737
Attleboro: Mary McCormick or Ginny McDermott	508-222-6655 508-222-0118 x2122	Fall River: Maureen Hebert	508-679-0011
Sharon Leary	978-226-6150	Paulette Masse	508-379-9700
Ayer: Jeannette Coutu or Gary Davis	978-772-1704	or Judy Elste	508-675-2101
Belmont: Lauren Storck	617-484-0949	Fitchburg: Alice Murphy or Joanne Harris	978-343-5368
Beverly: Lorraine Bettencourt	978-927-4227 x23	Judy Wilson	978-632-1230
Boston: Barbara Hawley or Maureen Tardelli	617-726-2639 617-391-7878	Foxboro: Diane Caldwell	508-337-8419
Bourne: Judy Anthony	508-759-0654	Framingham: Deborah Young	508-879-8000
Braintree: Denise Hughes or Chris Togneri	781-848-2714	Jayne Goldman	508-788-6050
Bridgewater: Kathy Hayes or Sue Daniels	508-697-0929 508-697-4368	Gardner: Judy Wilson	978-632-1230
Brockton: Nancy Bresciani Marie Albert, RN	508-583-2517 508-587-6556	Ray Cormier	978-632-5477
Brookline: Pattie Chase or Howard Block	617-232-8848 617-277-4289	Gloucester: Maureen Powers	978-281-1750
Burlington: Stacey Kohler or Sue Mike	781-744-8114	Great Barrington: Kelly Thorne	413-528-2650
Ann Cooper	781-270-9008 x202	Hadley: Linda Wallace or Jennifer Read	413-584-5057
or Nancy Kinton	781-721-0788	Haverhill: John Freeman	978-346-4743
Cambridge: Alice McCarter or Mary Costello	617-547-3543x22	or Nancy Savarese	978-683-2771
Trudy Bauer or Ruth Gordon	617-491-1815	Hingham: Jo Ann Mitchell	781-749-5417
Canton: Susan Brady	781-828-7450 x307	Eleanor Blair	781-749-4774
Chelmsford: Pat Keene	978-251-8491	Holden: Naomi Sohlman	508-829-0270
Susan Antkowiak	978-934-0000	Hyde Park: Wendy Marks	781-449-5368
Chicopee: Judy Pothul	413-821-9911	Jamaica Plain: Tara Fleming	617-983-2300
Concord: Arlene Parillo or Kate Marshall	978-897-2569 978-369-4728	or Susan Kelley-Grasso	617-868-6718
Danvers: Gwen Kopka	978-750-4540	Kingston: Holli Spooner	781-585-4100
D'arcy Adams	978-774-4400 x3064	Lee: Dolores Thimot	413-243-4747
		Leicester: Eva Dawson	508-987-8056
		Littleton: Gail Mallardo	978-486-3512
		Longmeadow: Sheila King	413-567-6212
		Lowell: Scott Souci or Margaret Swanson	978-459-0546
		Ludlow: Barbara Messler	413-589-7581
		Lynn: Lisa Mercurio	781-596-2992
		Malden: Jolyn Ek	781-324-4999

Support Group listing continues on inside cover



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