

Massachusetts Chapter Newsletter

The Alzheimer's Association serves the entire state from Cape Cod to the Berkshires.

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www.alzmass.org

24-Hour Helpline: 1.800.548.2111

PHOTO COURTESY AUTHOR



A little girl and her grandmother share the joy of being together at a birthday party for family and friends.

Alzheimer's in the Family: How Parents Can Help Children Cope

By Kristin L. Haring, LICSW

"I keep telling her my name is NOT Travis!"
—7-year-old Sam

"She takes things from my room and hides them."
—11-year-old Alicia

Alicia's expression softens with a look of uncertainty and sadness. "I wonder if she got Alzheimer's disease because Grampy died?"

Alzheimer's disease can be a troubling experience for children. They may feel frightened, angry, or resentful toward a grandparent who is behaving in a confusing and disturbing manner.

Parents of young children, who are also caregivers for a family member with AD, are typically emotionally and physically drained. They are coping with caregiving on several fronts, managing household tasks, working outside the home, and coordinating social and after-school activities.

Hope. Yet, there are strategies parents can use to ease family stress without adding to their already-overflowing plates. Education, promoting empathy, and validating feelings provide children with tools that will allow them to be more in control of what often feels like an out-of-control situation.

How is Alzheimer's disease affecting your children?

As a support group leader for children coping with grandparents with Alzheimer's disease, I have had numerous opportunities to observe children and to discuss with them and their

continued on page 4

Mark Your Calendars Now!

Simons Symposium

Join us at the Charles Hotel in Cambridge to learn more about caregiver support and education. Dr. Mary Mittleman of NYU Medical School will present the 2004 Simons Lecture. See *Calendar* section for details.

Tuesday, November 9



November is Alzheimer's Awareness Month

Check your local paper and www.alzmass.org for listings



See our next Newsletter for full coverage!

inside

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PHOTO BY ROGER APPELL



Debonair ISES member Don Ganz of the New Vaudeville & Circus Co., and *Night at the Pops* volunteer Stephanie Douglas greet guests outside Boston Symphony Hall. (See story, page 3)

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From the President: Preparing to Launch

Campaign for Our Future: Last June, at our 5th Annual *Night at the Pops* fundraising event, Board Chair **Roberta Rosenberg** inaugurated our first major gift campaign to invest in a future without Alzheimer's disease. Timed to conclude with a celebration of the Association's 25th Anniversary in 2005, we are aiming to raise up to \$1 million dollars to fund three critical initiatives:

- Expand public awareness about Alzheimer's disease and the need to galvanize support for our cause.
- Develop our capacity to provide personalized counseling and support to families throughout Massachusetts.
- Increase our investment in cutting-edge research to diagnose, prevent, and put an end to this disease.

Never before have we set such an ambitious goal—but with a demographic tidal wave at our heels, we need to invest in greater public awareness, a vibrant support system, and effective medical treatments.

If you are able to contribute to our annual campaign or can join us as an investor in our 25th Anniversary vision for the future – we thank you for your partnership. Every contribution is vital.

Alzheimer's Awareness Month: November is National Alzheimer's Awareness Month. Make sure to attend an educational program in your local community. Check our Education/Events Calendar in the center of the Newsletter for our many program listings, and watch your local

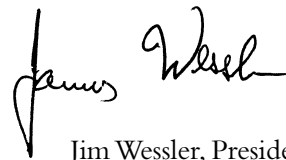
newspapers for others. Encourage other people to do the same.

Maintain Your Brain: Early next year, we plan to launch a new educational program, the Association's *Maintain Your Brain* initiative. A number of research studies have found a strong correlation between cardiovascular health and a reduction of risk factors associated with AD. Presenting evidence-based recommendations, we plan to provide practical advice to promote brain health; recommendations that we hope will become part of our state's public health message.

This message is most urgent in African American and Latino communities, which are impacted by higher rates of vascular disease. Vascular illness contributes to increased risk factors for Alzheimer's. Look to our website www.alz.org and future issues of this Newsletter for more information.

Staff: We are pleased to welcome two new staff members to the Alzheimer's Association.

Steve Rothman is our new MIS Coordinator and **Carolyn Whipple** is our Special Events Coordinator.



Jim Wessler, President and CEO
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alzheimer's  association™

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Pops "Evening of Magical Music" Grosses \$132,000!

By Sheila Watnick

"An Evening of Magical Music" came alive June 16 at Boston Symphony Hall, as members of the New England Chapter of the International Special Events Society (ISES) brought their talents to 450 guests at the Alzheimer's Association's 5th Annual *Night at the Pops*, elevating this event to an unparalleled level. The spectacularly imaginative reception preceded a performance of Classic Pops, led by principal Pops Guest Conductor Bruce Hangen and featuring Richard Hayman, harmonica legend and chief arranger for the late Arthur Fiedler, who rocked the audience.

"It truly was a magical evening," commented *Pops* Chair and Board Member Emeritus **Stanley Solomont**. Outside Symphony Hall, a tuxedoed stilt-walker greeted guests. A magician roamed about, and a performer whimsically clad in an elaborate *I Dream of Jeannie* costume (complete with lamp!) served appetizers in the reception area, while guests enjoyed a sumptuous buffet and dessert display, complete with a chocolate fountain.

Guests tried their chances on more than 80 silent auction and prize drawing items, thanks to generous donations from many businesses and individuals. A nearby room was turned into a Musical Memories Cabaret, where a singer and court jester performed.

Honorary Chair and emcee for the second year in a row, NewsCenter 5's **Gail Huff** kept the program moving as she welcomed Association family members and guests.

Gail also expressed appreciation to Board Member Emeritus **Marcia Simons** for bringing 50 guests to enjoy the evening. The reception ended with a surprise original tribute to the tunes of *This Magic Moment* and *Do You Believe in Magic?* in honor of Roberta Rosenberg, who was celebrating her birthday.

Leading this year's list of sponsors was Presenting Sponsor Regan Communications. Company President George Regan introduced and spoke passionately about former Boston Mayor **Kevin White** and his wife, **Kathryn**, also *Pops* Honorary Chairs. Mr. Regan served as public relations counsel under Mayor White.



Other sponsors included New Balance Foundation, reception sponsor; Praecis Pharmaceuticals, benefactor; Shirley Spero, beverage sponsor; Heritage at Framingham and Mary Ann Morse Nursing and Rehabilitation Center, silent auction sponsors; Cambridge Trust Company and Beverly Healthcare, supporters; Bingham McCutchen, Hearthstone Alzheimer Care, Life Care Center of Nashoba Valley, Kindred Healthcare, Sodexo, and Stanley Solomont, friends; and WCVB-TV NewsCenter 5, media sponsor.

Congratulations to **Fran Correia** of Whitney Place who walked away with the evening's grand prize, a trunk jam-packed with items and certificates from Wrentham Village Premium Outlets.

The 5th Annual *Night at the Pops* grossed a record \$132,000 for Association programs and services, an increase of \$35,000 from last year's total.

In addition to the *Pops* Honorary Chairs, NewsCenter 5's Gail Huff and Mayor Kevin and Kathryn White; and Chair Stanley Solomont, many *Pops* committee members contributed significantly to the evening's success. They included Ronald Agel, Amy Beck, Danielle Breault, Debbie Fermil, Judy Green, Patti Grossman, Mimi Herington, Harriet Smookler Hyman, Ellen Kallman, Irene Kaplan, Jill Kushner, Joan Linsky, Nancy Fernandez Mills, Debbie Mozes, David O'Hearne, Pat O'Hearne, Mary Pacella, Marc Romvos, Barbara Shapiro, Bernard Shapiro, Kathy Simon, Marcia Simons, Barbara Sinclair, Shirley Spero, and Lyn Trojanowski.

Stanley Solomont concluded, "I had the best committee this year! Members had wonderful spirit and great ideas. And, with ISES choosing this event as its 2004 public service project, what more could I want?"

The 6th Annual *Night at the Pops* will take place in June 2005.

development

Among the 450 attendees enjoying a vibrant evening at the Chapter's 5th Annual *Night at the Pops* gala (L to R): former Boston Mayor Ray Flynn; outgoing ISES President Jill Moran; NewsCenter 5's Gail Huff, Honorary Chair; former Boston Mayor Kevin White, Honorary Chair; and Association Board Member Emeritus Stanley Solomont, *Pops* Chair.



PHOTOS BY JOEY LIBBY



A magical top-hat theme commemorative cake provided the perfect photo backdrop for national Alzheimer's Association President and CEO Sheldon Goldberg (L), visiting from Chicago; and Chapter President Jim Wessler (R).

education

Kristin L. Haring, LICSW is a clinical social worker at the Geriatric Care Center of the Hunt Center in Danvers, Massachusetts. For more information on her children's group, please call Kristin at 978.774.4400 x4007.

Children are grieving the loss of the grandparent they once knew.

Alzheimer's in the Family... *cont. from page 1*

parents how the disease impacts their lives. Children are grieving the loss of the grandparent they once knew: the person who had tea parties with them, took them out for pizza, babysat them, walked them to the park, and helped them with homework.

One child describes remembering when his grandmother had her license revoked; she used to drive him to school. The same child recalls when his grandmother, who used to read stories to him, could no longer read the words.

Changes. Children express anger and frustration about their grandparent's behavior: "She keeps repeating"... "I want to yell"... "She gets in my face." They worry about how their mothers can take care of them and their grandparents.



They express confusion, not always understanding what their grandparent is saying or what is making her angry. They often feel guilty or responsible for her behavior. Children may feel embarrassed in front of their friends; their grandparent's disease becomes a shameful family secret.

One parent reports that her children feel afraid when the grandmother yells at them and doesn't let up.

Once, that elder was never critical, but is now always

"Alzheimer's disease is a disease to the brain that isn't good or cheerful."

"on" them. She worries that they disregard their grandmother, and talk to her as though she were a child.

Another describes her children as resentful of the time she spends away from them caring for the elder parent. One mother shares that her daughter always believed her grandmother was yelling only at her, until she witnessed this behavior in a different setting and said, "Oh Mom, it's not just me, is it?"

All these are normal reactions. What can parents do?

Encourage your children to verbalize their feelings, even though they may be difficult for you to hear. Let them say they are angry or unhappy or afraid. Acknowledge your own feelings of sadness and loss. Allow children to grieve the loss of the grandparent they once knew, and help them remember their grandparent before the disease. Look through photo albums and recall special times they shared.

Some children never knew their grandparent without Alzheimer's disease. Those children will not grieve in the same ways, but need opportunities to learn what their grandparents were like before becoming ill.

Educate your children about the disease. As with other difficult subjects, your child's information will need to be shaped by some age-appropriate facts about what is happening. The Alzheimer's Association has wonderful books and a video for children whose grandparents have AD. Knowledge is empowering.

Emphasize that this is a disease of the brain; the behaviors are neither purposeful nor malicious, and not the child's fault. Talk calmly about what to expect and about your plans. Reassure your child regularly about your confidence in handling the changes; stay alert for gaps in understanding and unspoken worries.

Promote empathy. Encourage your children to imagine how their grandparent feels (i.e., sad,

"I love you. I miss you Nana. 'I fel yor hart.' I hope you feel better some day."

education

frightened, lonely, embarrassed) when he/she is asking to “go home,” is wandering aimlessly around the house, or when the child tells her repeatedly that she is calling him by the wrong name. Remind children how they have felt when lost in a store, when ill, or when they didn’t understand what they were being told.

Create a list of quiet activities for the child to do with the grandparent. These might include folding laundry, watching a video, looking through photo albums, singing, sharing a healthy snack, or just sitting quietly together. Encourage gentle, playful interactions. Grandma or Grandpa may be surprisingly willing to join in play with toys.

Practice. Create a list of responses to frustrating behavior, and practice them. When a child has rehearsed a desirable response, he/she is more likely to use it automatically when the need arises. Focus on the importance



Hugs, smiles, and a soft touch go a long way.

Encourage your children to imagine how their grandparent feels when he/she is asking to “go home.”

of not arguing with their grandparent: “the person with Alzheimer’s disease is always right.”

Encourage the child to have a calm demeanor; to make eye contact; and to speak slowly, gently, and clearly. Hugs, smiles, and a soft touch go a long way. Ensure that your child knows to get help from an adult in a situation that feels unsafe, rather than try to manage difficult behavior independently.

Remind your child what is the “adult’s job.”

Be sure to praise the efforts your child makes, and give yourself credit for easing the way.

If available, a support group provides a safe setting in which children can talk about their feelings, share experiences with other children, learn more about the disease, develop positive coping skills, and remember who their grandparent was before the disease. Recognizing and responding to children’s feelings is paramount in helping them cope with the devastating losses connected with Alzheimer’s disease, and can ultimately reduce overall family stress.



“Alzheimer’s disease is a disease that makes the person who has it, not be able to speak as much as they used to, and sometimes makes them stand in front of the door all day hopelessly for hours on end.”



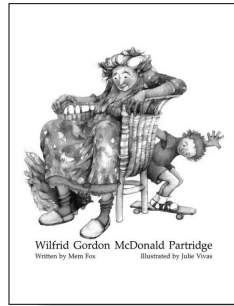
education

Book Reviews: A Collage of Children's Stories

Reviewed by Erin Whalen, Helpline Supervisor

Wilfrid Gordon McDonald Partridge

Story by Mem Fox;
illustrations by
Julie Vivas



Wilfrid Gordon McDonald Partridge is a story of a

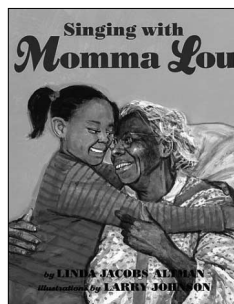
boy who lives next to “an old people’s home.” His best friend, Nancy Alison Delacourt Cooper, shares more in common with the boy than just having four names. This book looks at friendships and gifts that two people, regardless of age or ability, can give to one another.

Hunting. When Wilfrid learns that Miss Nancy has lost her memory, he asks, “What’s a memory?” for which he receives a myriad of responses. With a child’s sense of curiosity and care, Wilfrid searches for “memories” to help Miss Nancy remember.

Illustrator Julie Vivas gives special consideration to the sense of movement and motion in the characters, both young and old. Reinforcing the power of friendship, Vivas shows the older characters in poses filled with joy and fun in the company of Wilfrid Gordon.

Singing with Momma Lou

Story by Linda James
Altman; illustrations by
Larry Johnson



Granddaughter Tamika challenges her preconceived notions about her grandmother, Momma Lou, living with Alzheimer’s disease. Tamika wishes she could do anything other than visit her grandmother at the nursing home each week.

Clues. After her father shows her a scrapbook of her grandmother’s life and reminds her of their love and friendship, Tamika decides to use her grandmother’s scrapbooks to reconnect with

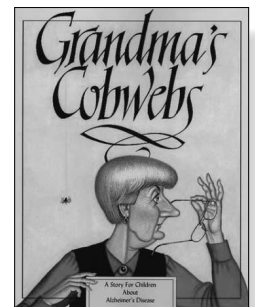
her—and maybe give Momma Lou back her memories. Week after week, she brings in photographs and mementos of her grandmother’s life. In doing so, she recaptures her grandmother’s legacy and the twinkle in her eye.

An excellent story about the power of love and reminiscence, exemplifying ideas for visiting and staying connected to someone who has AD throughout the course of the illness.

Larry Johnson provides elegant illustrations that highlight heartwarming scenes of family life.

Grandma’s Cobwebs

Story by Ann Frantti;
illustrations by
Sergey Sachkov



Claire’s grandmother is changing. She is growing more and more confused and sometimes gets angry quickly. Claire’s mother tells her it is because Grandma has Alzheimer’s disease, and Grandma says it’s because of the cobwebs in her mind.

Because of her disease, Grandma has to move in with Claire and her family. Claire has a difficult time understanding and adjusting to the changes in her grandmother.

Shift. Eventually, with her mother’s help, Claire realizes that her Grandma is still the same wonderful person at heart, even with her memory problems. Claire begins to think she is lucky to have a chance to take care of her grandmother.

An excellent book for children just learning about Alzheimer’s disease or those who have a relative living with them, this story encourages children to talk about their feelings, just as Claire did. An educational supplement for children, parents, and teachers accompanies this bold and colorfully illustrated book.

These books are available for sale through the Massachusetts Chapter, and may be available at your local library. Contact the Cambridge Office for more information at 1.800.548.2111.

A Window of Time

Story by Audrey O. Leighton; illustrations by Rhonda Kyrias



The beautiful, fluid illustrations of this book mirror the journeys of Shawn and his Grandpa. Shawn's grandfather is often confused and disoriented, reliving events that occurred over 65 years ago. Shawn believes his grandfather has a time machine that carries him back to when he was young.

Bond. Shawn enjoys hearing about his grandfather's life and imagines himself along on his grandfather's adventures. Together, they visit the farm Grandpa lived on when he was young boy, visiting the milking cows and galloping on horses. Their special bond transcends time and Alzheimer's disease.

This is a wonderful story displaying the special, enduring relationship between a boy and his grandfather. Shawn's acceptance of his grandfather's reality can help other children better understand the confusion and disorientation caused by AD.

Someone I Love Has Alzheimer's Disease

Video produced by the Alzheimer's Association, MA Chapter



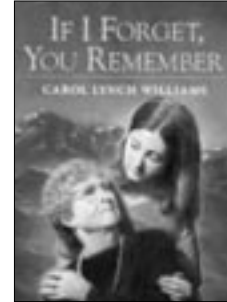
Young, understanding, courageous, and loving, the extraordinary caregivers in this video are children. In this program, they discuss the many emotions they experience in their new role. The children learn that Alzheimer's disease is not their fault, and that it is very important to address and speak about their feelings to parents, family, and friends.

Supplements. An excellent source of information and support showing real kids taking care of their family members, the video is accompanied by a curriculum guide with information and activities for children.

Children who have a relative living with them would benefit greatly from seeing this program. The important lessons of cherishing the moment and holding onto the good times resonate in the actions and words of these wise children.

If I Forget, You Remember

by Carol Lynch Williams



An Early Winter

by Marion Dane Bauer



These are chapter books more appropriate for older children.

Elyse, the young character in *If I Forget, You Remember* is excited about the summer she plans on being her best yet, until a call late in the night from her confused grandmother changes everything. Her grandmother's Alzheimer's disease is progressing; she is going to move in with Elyse's family.

Though Elyse had other plans, she learns that her friendship with her grandmother can continue and strengthen despite her grandmother's disease, as the two spend summer days together. Read this wonderful book and find out what adventures Elyse and her Granny encounter as they face Alzheimer's disease together.

In *An Early Winter*, Tim knows that his grandfather is sad and not sick, as his mother and grandmother insist, and he won't let them place his grandfather in a nursing home. He decides the two of them will run away together.

Growth. When the pair set out on their expedition and get into some difficult situations, Tim realizes that his grandfather is having some real problems. Read *An Early Winter* and find out how Tim learns that he can help to take care of his grandfather, and yet still learn from him and love him, even as he becomes more and more confused.

The book *Wilfrid Gordon McDonald Partridge* looks at friendships and gifts that two people, regardless of age or ability, can give to one another.

advocacy


Association Website Named in Top Ten List for Seniors

The Mature Market Resource Center has named the Alzheimer's Association's public website, www.alz.org, as one of the best senior-related sites for consumers and professionals.

According to editor, producer, and author **Robert Powell** of CBS MarketWatch.com, the Association's website was cited because it "...helps visitors better understand the disease that currently affects 4.5 million Americans. It describes risk factors, warning signs, diagnosis, treatments, and stages.

He continues: "The site also addresses the myths commonly associated with Alzheimer's, including the suggestions that memory loss is a normal part of aging, that Alzheimer's is not fatal, and that there are therapies available to stop the progression of the disease."

Public Policy News: Fall Update

By *Kate Doyle*

On the Federal Front: Ronald Reagan Legislation

U.S. Senators Barbara Mikulski (D-MD) and Kit Bond (R-MO), and U.S. Representatives Edward Markey (D-MA), and Chris Smith (R-NJ) have proposed "The Ronald Reagan Alzheimer's Breakthrough Act of 2004." This important piece of national legislation would double the funding for Alzheimer's research at the National Institutes of Health, the National Caregiver Support Program, and the Alzheimer's Demonstration Grant Program: a total of \$1.675 billion.

Tax break. The bill would help family caregivers pay for the costs of caring for loved ones with Alzheimer's by providing a \$5,000 tax credit to reimburse them for expenses such as home health care services, prescription drugs, and specialized day health. The legislation would also launch "News You Can Use," an education campaign to provide information on techniques that may help promote brain health.

Please join with the Alzheimer's Association, and contact your legislators to ask for their help in making Alzheimer's disease a national priority.

On the State Front: Massachusetts Selected As Site for Medicare Homebound Demonstration

U.S. Health and Human Services (HHS) Secretary Tommy Thompson and Centers of Medicare and Medicaid Services (CMS) Administrator Mark McClellan announced that Massachusetts is one of the three states chosen to participate in the demonstration mandated by the Medicare Modernization Act, to test relief from the Medicare Homebound requirement.

The demonstration will evaluate a more liberalized definition of "homebound" for certain Medicare beneficiaries with chronically disabling conditions. Under this demonstration provision, up to 15,000 patients in three states will be allowed to receive Medicare home health benefits regardless of their absences from the home, if they meet strict criteria related to the severity and permanence of their disabling

condition. Congressman Ed Markey sponsored the demonstration legislation in the U.S. House of Representatives; the Association had joined him in lobbying CMS for Massachusetts' participation.

Heroes. At the press conference in June, Rep. Markey stated: "Medicare home health beneficiaries who have late stage Alzheimer's disease, ALS, Parkinson's disease, and other severe, chronic, and disabling conditions should not have to fear that their next trip outside the home could cause their benefits to be terminated..."

He continued: "Medicare beneficiaries and their families who battle these devastating diseases are everyday heroes—but even heroes need help. I am hopeful that the demonstration project...will provide a measure of help to Massachusetts home health patients and their families who are coping with these severe medical conditions."

Fiscal Year 05 Budget

The state legislative process takes nearly six months to produce a budget. The ultimate result of all the budget hearings and testimony emerges in the final Joint Conference Committee, in which both sides of the General Court come to terms. The FY 05 Budget includes the following highlights:

- Allocates \$75,000 for dementia-specific adult day health programs.
- Creates a special commission to analyze the regulation of assisted living facilities, with a final report due not later than January 31, 2005. The Alzheimer's Association is named to this commission.
- Requires nursing homes to make Family Councils more independent of management.
- Increases funding for the Prescription Advantage Program to \$110 million.
- Re-authorizes the Governor's Advisory Council on Alzheimer's Disease and Related Disorders until July 2005.
- Allocates \$4 million in funding for the Home Health Workforce Initiative, setting aside \$4

million to provide an adjustment to the Medicaid class rates paid to home health aides, home health nurses, and physical and occupational therapists.

- Allocates \$20 million for a wage increase for human service and home care providers.
- Repeals the expanded Medicaid estate recovery law. This provision will protect a range of

assets from the probate process, including homes held jointly.

We are fortunate to have many friends in government, as well as many dedicated and committed family members, patients, and health care professionals working to help us achieve our goals. To all of you, we extend our gratitude and our hope that the burden of dementia on families and patients will be lightened by our work.

early stage programs

The Long Arm of Advocacy

By Elaine Silverio

One of the aims of the Early Stage Program in Massachusetts is to support and encourage early stage persons and their families in their efforts to advocate for themselves and others. Their raised voices draw attention to the disease, encourage early detection, and drive the creation of services to support them. Their voices are compelling. People listen.

When **Henry Adleman** and his wife, **Annette**, of Needham, deserted the cold of New England last fall, succumbing to the warmth of Florida, they left behind close connections to other supportive families also dealing with Alzheimer's disease. After Annette was diagnosed with AD two years ago, Henry started on his passionate mission to seek education and support for the two of them, and to enhance Annette's ability to cope with her diagnosis.

Initiative. The couple participated in the Association's early stage education sessions, joined an early stage support group in Natick, and attended our first early stage social and dance last November. Henry's frequent Internet searches uncovered useful information he often shared with professionals and other families.

So it is understandable that when Henry arrived in Florida, he contacted the Southeast Florida Chapter of the Alzheimer's Association, ready to participate in their early stage activities to continue valuable support for Annette and himself. Initially disappointed that this Florida Chapter did not have an early stage program, he found a willing and enthusiastic staff member in **Donna True**.

Creation. Donna had been contemplating the start of an early stage group. In her words: "Henry inspired us to *action* by sharing his thoughts on the Massachusetts program with us, helping us plan, generating a flyer, and making phone calls."

Henry and Annette Adleman, formerly of Needham, get ready to step onto the dance floor at the Westborough Marriott at last year's Early Stage Dance.



PHOTO BY ELAINE SILVERIO

We enthusiastically shared our own training manual; and with a spirit of collaboration and passionate energy shared by Henry, Donna, and **Laura Zel** of one of Florida's Area Agencies on Aging, their early stage group was born in January 2004. Henry extended his involvement to making meeting reminder calls and organizing group social activities. He made a significant positive impact on several families' lives in a very short time.

Continuity. Annette was again able to share her feelings and experiences in a similar kind of open, empathetic, and safe environment to what she had experienced up North. The message is clear: even when we are tempted to accept a situation without hope and without question, we *can* mobilize forces, we *can* fight, we *can* create what is needed for people with dementia.

In an Association Newsletter article we wrote (see Spring 2002 issue), Gerald Flaherty and I raised the question as to whether early stage persons and families could be empowered to raise awareness and emerge as advocates. Thank you, Henry, for reminding us of the power of your voice and your love, Annette's voice, and the voices of many others living with memory disorders. You have both made a difference in the North; and now, again, in the South.

For more information about early stage groups and other programs, contact Elaine Silverio at 617.868.6718 x205.

alzheimer's education/event

Cambridge Somerville Partnership Program

Is It or Isn't It? Diagnosing Alzheimer's Disease. The Cambridge Somerville Alzheimer's Partnership is sponsoring its annual program in recognition of Alzheimer's Awareness Month. The event is free and open to the community. The featured speaker will be **Dr. Alan Abrams**, Medical Director of Cambridge Health Alliance's Center of Excellence in Senior Care. Dr. Abrams will discuss normal aging, and the differences between normal memory loss and Alzheimer's disease.

The conference will take place at the VNA Assisted Living in Somerville, 259 Lowell St. Lunch will be provided by Healthcare Services Group, Inc. Parking is available and carpooling is encouraged. Please register by October 22. For more information and to register, contact Shauna Peet at 617.628.2601 x3089.

Thu., Nov. 4: 12-2:00 p.m.

3rd Annual Steger Concert

The Liberty Alzheimer's Partnership will hold their 3rd annual benefit concert, "An Evening with Elliot Steger and Trio," featuring Dr. Elliot Steger, accomplished jazz pianist and composer. The evening's events benefit the Chapter. The concert and dessert reception will be held at the National Heritage Museum in Lexington. Tickets are \$20. For more information, contact Hilary Viola at 781.221.7079 or 978.263.8720.

Fri., Nov. 5

North Shore Partnership Conference

The North Shore Alzheimer's Partnership is proud to present its 5th Annual Conference for Family and Professional Caregivers at North Shore Community College, Ferncroft Rd. Danvers. Our keynote speaker will be **Dr. Paul Raia**. This free conference will include workshops, free on-site respite, lunch, resource exhibits, and raffles.

The Partnership has developed an Alzheimer's resource directory, which will be given out that day. For more information, call Gwen Kopka at 978.750.4540.

Sat., Nov. 6: 9:00 a.m.-3:00 p.m.

Simons Symposium

The 14th Annual Matthew and Marcia Simons Research Symposium will be held at the Charles Hotel in Harvard Square, Cambridge. **Mary S. Mittelman, Dr.P.H.**, will deliver the 2004 Simons Lecture: *Drugs May Help People with Dementia. What Helps Caregivers?*

Dr. Mittelman is Research Associate Professor at New York University School of Medicine, and Director of the Psychosocial Research and Support Program at the William and Sylvia Silberstein Institute for Aging and Dementia.

In a landmark study at the NYU School of Medicine that began in 1987 and is still ongoing, Dr. Mittelman proved that counseling and support, individually tailored to the needs of each family, improve the well-being of caregivers, and help them keep their relatives with AD at home.

The lecture and dessert reception are open to the public, and free of charge. Please call 800.548.2111 or visit our website at www.alzmass.org for registration information.

Tues., Nov. 9: 7-8:30 p.m.

Partnering with Your Doctor

Do you or someone you love have memory problems? This workshop will help patients and care-partners communicate with their doctors, get prepared and organized for physician visits, reduce stress, and ensure the best health care possible for the patient. This workshop is free of charge. Attleboro Council on Aging, 25 South Main St. Contact Michelle Jussaume, 508.675.2105 x380 to register.

Wed., Nov. 17: 4:30-6:00 p.m.

November is National Alzheimer's Awareness Month!

Throughout the month of November, there will be increased national and local media attention to AD and the problems it causes in peoples' lives. In addition to those offered by the Chapter, many facilities and agencies will offer educational programs to the public—often free of charge.

Check your local paper and take the time to attend programs that interest you. **Talk to your neighbors about what you know, and become a part of this educational process yourself.**



PHOTO BY MARK LUINENBURG



calendar: nov, dec 04; jan 05

Legal & Financial Issues and Answers

For people in any financial situation, this 1½-hour program offers information by an elder law attorney about topics such as protecting yourself against future incapacity (using durable powers of attorney, health care proxies, and medical directives); and making the best use of Medicare and MassHealth (Medicaid) to help finance care at home or in a nursing home, while protecting other family members. Too many people wait until it's too late before learning about these issues.

While this program is not intended to substitute for a personal appointment with an elder law attorney, you will have the opportunity to hear about typical issues and problems that can be avoided or reduced by adequate planning.

Pre-registration is necessary. Please call 800.548.2111 to register. Space con-

straints may limit group size. This program is offered at various sites and times throughout the year.

Sites and Schedules:

- **Brookline:** Brookline Council on Aging, 93 Winchester St. Presenter: Atty. Harry Margolis. **Fri., Nov. 19: 12:30-2:00 p.m.**
- **Cape Cod/Wellfleet:** Council on Aging, 715 Old Kings Highway. Presenter: Atty. Paul Attea. **Thu., Dec. 2: 1:45-3:15 p.m.**
- **Hadley:** Hadley Council on Aging, 46 Middle Street. Presenter: Atty. Joan Golowich. **Tues., Nov. 16: 3:00-4:30 p.m.**
- **Lowell:** HealthSouth at St. Joseph's Hospital, 220 Pawtucket St. Presenters: James P. Cleary III & Joseph A. Cleary P.C. Attorneys at Law. **Wed., Nov. 17: 6:00-7:30 p.m.**
- **Ware:** Mary Lane Adult Day Health Center, 40 Chestnut St. Presenter: Atty. Patrick Murray. **Mon., Nov. 8: 4:30-6:00 p.m.**

save the dates

Basic Training for New Support Group Leaders

Free workshops for new and prospective support group leaders are offered at various times and locations throughout the state. Contact Debra Katt-Lloyd at 978.937.5576 for information about the program, and contact Melissa Arsenault for registration details at 617.868.6718. Upcoming training dates can also be found on our Calendar online at www.alzmass.org.

Early Stage Programs, Support Groups

Please see the Support Group section of this Newsletter (pp. 19-20) for listings of 15 Early Stage support groups in Massachusetts.

If you'd like to be on the mailing list for other Early Stage education, support, and social programs, as well as e-mail updates, please notify Elaine Silverio by e-mail at elaine.silverio@alz.org or call the Association.

Getting Started: What To Do When Your Family Member Has Memory Loss

Designed especially for family members, this program provides information about how to get a diagnosis, understanding and addressing difficult behaviors and communication problems, and how to find and what to expect from local resources. Presented by trained Alzheimer's Association staff and volunteers. Group size may be limited. Free of charge.

For all programs, call 800.548.2111 for more information or to register.

The Alzheimer's Association is grateful to Citizens Bank Foundation for their generous support of this program.

Sites and Schedules:

- **Beverly:** The Hunt Center at Beverly Hospital, 75 Lindall St. Presenter: Kristine Taylor. **Wed., Nov. 3: 2:00-4:30 p.m.**
- **Cambridge:** Alzheimer's Association Office, 36 Cameron Ave. Presenter: Dr. Paul Raia. **Tues., Nov. 30: 3:00-5:30 p.m.**
- **Cape Cod/Wellfleet:** Council on Aging, Long Pond Rd. Presenter: Diane McCafferty. **Thu., Nov. 4: 1:45-4:15 p.m.**
- **Franklin:** Franklin Senior Center, 80 West Central St. Presenter: Jan Chiampa. **Thu., Nov. 18: 9:00-11:30 a.m.**
- **Newton:** Newton Senior Center, 345 Walnut St. Presenter: Pam Kunkemueller. **Wed., Nov. 10: 6:00-8:30 p.m.**
- **Pittsfield:** The Berkshire Athenaeum, One Wendell Ave. Presenter: Stephen Smith. **Wed., Dec. 1: 3:00-5:30 p.m.**
- **Raynham:** Raynham Council on Aging, 2215 King Phillip St. Presenter: Maureen Bradley. **Mon., Jan. 31: 10:00 a.m.-12:30 p.m.**
- **Springfield:** Baystate Visiting Nurses & Hospice, 50 Maple St. Presenter: Ellen Nepomuceno. **Wed., Jan. 12: 10:00 a.m.-12:30 p.m.**
- **Sturbridge:** Sturbridge/Fiskdale Senior Center, 480 Main St. (Route 20 at Arnold Rd.) Presenter: Debbie Boucher. **Thu., Nov. 4: 4:00-6:30 p.m.**
- **West Roxbury:** West Roxbury Public Library, 1961 Centre St. Presenter: Michael Kincade. **Wed., Nov. 3: 1:00-3:30 p.m.**
- **Wilmington:** Buzzell Senior Center, 15 School St. Presenter: Joanne Chaulk. **Thu., Nov. 4: 4:00-6:30 p.m.**

calendar

save the date!

17th Annual Public Policy Forum

Make your voice heard by joining hundreds of Alzheimer's advocates nationwide at the 17th Annual Alzheimer's Association Public Policy Forum. For more details, please call Kate Doyle, Director of Public Policy at 617.868.6718.

April 30-May 3, 2005

Taking Control of Alzheimer's Disease: Techniques for Early Stage Patients and their Care-Partners

Developed for early stage people with memory disorders, this four-part series explores ways in which symptoms can be managed and abilities maintained longer. These sessions will combine education and support to enhance understanding of dementia, and to show how early stage persons can participate in decisions affecting their lives.

The course will run for two hours per session, for four consecutive weeks. It is free of charge and has limited enrollment. Early stage people, care-partners, and other family members should plan to attend together.

For information about this and other upcoming programs, contact Elaine Silverio at 617.868.6718 x205.

- **African American series in Boston:** location and dates to be determined.
- **Mild Cognitive Impairment (MCI) Support:** a bi-monthly group will be started after January for people diagnosed with mild memory loss.

Please call Elaine with your questions, or to express an interest in either of these programs.

Save the Date: A Map through the Maze

An Interdisciplinary Conference for Alzheimer Care Professionals: *A Map through the Maze* will be held at the Royal Plaza Hotel in Marlborough. Professionals should plan to attend this full day of interesting workshops with an Exhibitor Fair and Poster Session.

More information will be available on our website and in the next Newsletter. Call after February 15th for a brochure. Presented by the Alzheimer's Association, MA Chapter.

Thursday, May 5, 2005

development

**Memory Ride a Free-Wheeling Success**

Many thanks to the Noonan family and the entire Memory Ride organizing committee, who executed yet another successful, well-planned event! On July 16, close to 100 riders (see group shot, below) embarked on the 150-mile, 3-day journey through the hills of southern Vermont and New Hampshire, concluding in Boston.

Rider **Dick Fleiss** was all smiles as he got off his bike in Boston and described the experience as "both grueling and exhilarating." At the closing ceremonies, Alzheimer's researcher **Dr. Ken Kosik** of Harvard Medical School thanked the

riders and event organizers, offering words of encouragement and a sense of optimism for the progress being made on the research front.

More than \$150,000 was raised by the riders, all of which will be directed to the Alzheimer's Association's research program. Chapter President **Jim Wessler** added his thanks to the Memory Ride committee, volunteers, and the riders, and committed to riding himself next year. If you'd like to join him, mark your calendar for July 15-17, 2005 and visit www.memoryride.org for more information.



Spirit of Remembrance

On May 11, more than 60 Association supporters gathered at our Cambridge Office to pay tribute to our 2003 *Spirit of Remembrance* display honorees. The Spirit of Remembrance is a permanent display in our Cambridge Office lobby. It was an emotionally moving and meaningful event as attendees remembered and celebrated the following individuals:

Millennium Society

Eileen Dickinson
Ann Kulin
Robert Margil
Emory J. Sullivan
Joan H. Walsh

Founder's Club

Anna Annese
Hyman & Dora Auerbach
Anna E. Boyd
Thomas E. Cavanaugh, MD
Catherine Kokinacis
Georgia Livadas
Elizabeth Osborne
Frank L. Shulman
Charlotte Tarlow
Marie J. Tuscano
Zelma Turner

Ambassador

Olivia Braverman
Albert E. Gibbons
Frank S. Colagiovanni
Ann S. Connelly
Julie & Albert Crossen
Ann Hayden
Harvey W. Hebert
Catherine S. (Lia) Holland
Dorothy N. Lieson
Esther Malandrino
F. Warren Nugent, MD
Isabel F. Olney
Catherine Pallis
Della Estelle Roth
Florence Rubin
Myer Saxe
Irene Steger
Sarah J. Votaw
Beulah Wykoff

Benefactor

Philip & Domenica Amara
David Bachrach
Eugene F. Ball
Mae M. Bass
Joan C. Bedrosian
Charlotte G. Brady
Arnold A. Brandt
Pauline Brolin
Robert Couturier
Mabel Daly
Josephine A. DiCarlo
Arlene V. Dooley
Shirley Dorfman
Vivian Dunn
Mary E. Frederick
Ernest Gauthier
Mary R. Gendron
Sylvia Goldstein
Morris Granas
Annie M. Johnstone
Yolanda P. Laquidara
Leonard G. Leader
Arvo I. Lehto
Ralph L. Leo
William Looney
Alice Rockwell Lynch
Aldo Magnani
Mary T. Mahoney
Raymond J. Marshall
F. Garrett McSweeney
Henri A. Montigny
Roger Newburger
Elma R. Nichols

Ida O'Clair
William O'Grady
Helen M. Osterhout
Paul Raia, PhD
Nancy F. Randall
Roy T. Raymond
Chickie Riordan
Lee Roberts
Thomas A. Scalley
Erna Schaetzlein
Mary Siefert
Marion B. Snyderman
George T. Squires
Catherine Stella
Frank L. Uman
William Widerman

For more information on including your loved one's name on the 2004 *Spirit of Remembrance* display, please contact our Development Office at 617.868.6718 (memorial gifts of \$250 and higher provide the opportunity to include someone's name).

The devoted family of Joan Walsh, who lost her battle with AD last December, paid loving tribute to her at our Spirit of Remembrance dedication ceremony in May. Shown in photo (L-R) are Bob Huntley, Joe Walsh, Sheila Walsh, John Walsh, Marie Walsh, and Marjorie Morse.

development



PHOTOS BY ROGER APPELL

Arleen Kulin of Cambridge, who attended the 2003 *Spirit of Remembrance* dedication ceremony, read a heartfelt poem she wrote in honor of her mother, Ann Kulin, who lost her battle with AD in 2003. The following is an excerpt; please call our Cambridge Office at 617.868.6718 for a copy of the full poem.

***"...I miss your words
I miss your spirit
I love your face
And I love you
You are my mother."***



development

7th Annual *Make the Link* Golf Tournament

With meteorologist **Dick Albert** offering his support in kicking off the 7th Annual *Make the Link* Golf Tournament, all at the Alzheimer's Association were hoping for good weather. And though the forecast was gloomy, the mood at the tournament certainly was not!

On May 24, 144 golfers joined the Chapter at the Ipswich Country Club for an exciting day on the course. We're thrilled to report that the event raised over \$140,000, a significant growth over last year's event, and a true testament to the hard work and commitment of everyone involved.

This commitment began with **David Thomson**, who served as Golf Committee Chair for the second year in a row. This year, David was particularly passionate about the cause as he lost his father, Bob Thomson, to Alzheimer's last fall. Involved in all aspects of the tournament, David tirelessly promoted the event and helped to secure over \$60,000 in event sponsorship.

Former Boston Bruin **Steve Leach** worked alongside David as Honorary Chair. Other participants in the day included hockey legend **Ray**

Boston Red Sox pitcher **Derek Lowe** and former Red Sox catcher **Bob Montgomery**, special guests at *Make the Link*, enjoyed reminiscing at the reception. Our sincere thanks to them both for sharing their time and extraordinary talents—we hope to see them both again next June 6 for our 8th Annual *Make the Link*!



Former Boston Bruin Steve Leach (L) served once again as Honorary Chair of our *Make the Link* Golf Tournament, which raised more than \$140,000 for Association programs and services. Our thanks to Steve, whose commitment stems from his personal experiences with Alzheimer's, and to other special guests, including NewsCenter 5 meteorologist Dick Albert (C), and Steve's former teammate and good friend Ray Bourque (R).

Bourque, Boston Red Sox pitcher **Derek Lowe**, and WEEI's **John Dennis** who co-hosted the evening program with WMJX radio personality **Nancy Quill**, a member of the Alzheimer's Association's Statewide Advisory Committee.

Winners. Nancy and John presented the winning foursome of Billy Lane, Mike Larosa, Dave Loffredi, and Sean Fleming with watches donated by DeScenza Diamonds, fleece-lined jackets donated by Verizon Wireless, and sneakers donated by Reebok. The two also hosted the live auction

consisting of 11 terrific items; a silent auction helped raise even more funds for Chapter programs and services.

With such an exciting lineup of activities and guests, it came as no surprise that the tournament sold out quickly. So quickly, in fact, that the Association added an early morning golf option for other loyal supporters.

Sponsors. The Association is grateful to all the event sponsors, particularly Title Sponsor Verizon Wireless and C.P. Berry Construction, Presenting Sponsor. We also extend our gratitude to our other sponsors, including Motorola, Tufts Health Plan SecureHorizons, Boston Red Sox, Cushman & Wakefield, Benchmark Assisted Living, William A. Berry Construction Company, *The Boston Globe*, Fleet Center, Greater Media/Boston, Kindred Healthcare, Lucent Technologies, LF InfoComm U.S.A., Inc, Praecis Pharmaceuticals, Thomson Companies, Voyager Pharmaceuticals, and Weiss Capital Management.

Next year's tournament, scheduled for June 6, 2005, will be held once again at the Ipswich Country Club. This year's event sold out quickly, so if you're interested in sponsoring or playing in next year's tournament, please contact the Association's Development Office at 617.868.6718.

We are thankful for the hundreds of volunteers who assist us each year, including (L-R): *Make the Link* volunteers Christine Kostigen, Donna Swanson, and Sarah Mansfield, who helped coordinate the very successful silent auction.

PHOTOS BY KEN CEGELSKI, BEST VALUE PHOTOGRAPHY



More Newlyweds Make Pledge from the Heart

We are grateful for the generosity of the following couples, who made gifts to the Alzheimer's Association in lieu of wedding favors:

- **Kate Higgins & Chris Shea**, married May 29 in Belchertown, who made a gift in memory of Dr. Francis Higgins, Kate's grandfather.
- **Shanna Strait & Tim Connor**, married June 19 in Worcester, who made a gift in memory of Tim's two grandmothers.
- **Leeann Geoffroy & Joseph Dillon**, married August 21 in Windham, NH, who made a gift in memory of Simone Geoffroy.

Congratulations and best wishes to all three couples. We wish them a lifetime of love and happiness together!

Special Events/Special People

- The annual **McCourt Gala** was held May 14 at the elegant Boston Harbor Hotel. Organized by **Brian and Paul McCourt** and their hard-working committee in honor of their parents, the McCourt Gala provided a memorable evening of live music, dancing, and lively conversation—more than 400 people attended!

A portion of the proceeds from the very successful silent auction, representing over \$10,000, was donated to the Alzheimer's Association to provide programs and services for people with AD and their families.

- All attendees agreed that July 23 certainly was **A Night to Remember!** Organized by **John Spencer**, in honor of his mother, who has AD, the second annual evening of dinner and dancing at Smuggler's Den on the New Bedford waterfront was back by popular demand.

- **Amanda Pastymak**, senior at St. Mark's High School in Southboro, stands with one of the recycling bins she has designed and distributed throughout Massachusetts, with proceeds going to support the Chapter. Having lost her grandmother five years ago, Amanda says she is "determined to do what I can to spare the heartache and suffering Alzheimer's causes."



- Once again, the loud rumbling of motors could be heard from Framingham to Oxford, MA as the 5th Annual **Motorcycle Memory Run** was held on July 11. The event attracted more than 100 bike enthusiasts. Many cars and trucks followed the 90-minute route to enjoy lunch, music, and raffle prizes at the end.

Proceeds for the event, totaling over \$2,100, benefited the Alzheimer's Association. Many thanks to event organizer **JoAnn Waring Tupper!**

Rounder Records Helps Keep Music in Mind

Keeping Music in Mind is a 13-song CD to benefit the Alzheimer's Association, Massachusetts Chapter. The compilation was produced entirely in-kind by Rounder Records, and features nationally-renowned artists such as Lisa Loeb, Alison Krauss, Bruce Cockburn, and Jimmie Dale Gilmore; as well as local favorites Ellis Paul, Vance Gilbert, and Merrie Amsterberg, who became interested in Alzheimer's when her father lost his roommate to the disease last spring.

"I'm grateful for the opportunity to contribute a song," Merrie said. "I hope it raises a ton of money." The featured musical selections are upbeat and eclectic, with genres including gospel, folk, bluegrass, and pop.

Shaleen Tethal, Licensing Manager at Rounder, whose father has AD, organized the compilation. She currently serves on the Greater Boston Memory Walk Committee.

The CD is given out to all participants of Memory Walk who raise \$500 or more, and is available for \$10 at all Massachusetts Chapter events or through our website (www.alzmass.org). All proceeds will go to the Alzheimer's Association, Massachusetts Chapter.

development



PHOTO BY THELMA DIAZ-YOUNG

Heritage at Framingham

Diane Morais looks on as her daughter **Danielle** has her face painted at Heritage at Framingham's *2nd Annual Walk to Remember* on May 16. More than 100 walkers raised \$3,500 as they enjoyed a fun-filled day with clowns, caricaturists, music, raffles, and a barbecue, while bringing greater public awareness of Alzheimer's disease.



regional
news

Western Regional Office

Tanglewood Party Raises over \$40,000

By Kathryn Hedgepeth



Berkshire musician Mike Schiffer filled the Hawthorne Tent with music.

Not even the threat of summer thunderstorms could dampen the festivities at the 4th Annual *Alzheimer's at Tanglewood on Parade* event, held August 3 on the beautiful Tanglewood grounds in Lenox, Mass.

Many guests arrived early and enjoyed an afternoon concert before Co-Chairs **Pam Burger** and **Karen Gold** welcomed them to a pre-concert reception in the Hawthorne Tent. During the brief program, NBC personality, critic, author and Honorary Chairman for *Alzheimer's at Tanglewood* **Gene Shalit** spoke from his heart and funny bone about his brother Nathan's Alzheimer journey.

Guests enjoyed a sumptuous assortment of hors d'oeuvres and desserts while bidding for items in the Travel, Art, and Entertainment auction. High bidders included Andrew Bass for a week's stay on St. Croix in the U.S. Virgin Islands; Patrice DeSanty for a long weekend on Lake Champlain; Suellen Solomon for an Annie Clarke-Gerrity original artwork: *The Mask of Alzheimer's*; Rick and Julie Lafley for a Florida vacation; and Diane Weinstein for a getaway at the Mount Washington Hotel and Resort in NH. Peter Bodnar was the lucky bidder on a copy of the last episode of *Frasier*, signed by the entire cast and donated by actor and advocate **David Hyde Pierce**. All items were generously donated, and the spirited bidding raised over \$7,500 for the Association.

High notes. Following the Alzheimer's reception, guests adjourned to the Koussevitzky Music Shed for a gala concert with the Boston Symphony Orchestra, the Boston Pops, and Tanglewood Music Center Orchestra. The evening ended with a spectacular fireworks display over the Tanglewood grounds.

The event raised over \$40,000 in total, thanks to the generous support of its sponsors and all attendees: the Harold Grinspoon Charitable



Event Co-Chair Karen Gold (R) and Regional Director Kathryn Hedgepeth (L) welcome Gene Shalit to Tanglewood.

Foundation, Berkshire Healthcare Systems, EPOCH Assisted Living at Melbourne, the Gold and Gallagher Family, Hearthstone Alzheimer Care, Kindred Healthcare, Charles Magriel, Northern Berkshire Health System, and *The Berkshire Eagle*. Special thanks to Berkshire radio station WBRK, which assisted with extensive on-air promotion; and AmeriCare Associates and Hadley Printing Co. for production of the program book.

Additional appreciation is extended to all of the contributors to the auction: Stephanie Abrams; the *Alzheimer's at Tanglewood* Committee; Berkshire Healthcare Systems; Boston Celtics; Boston Red Sox; Boston Symphony Orchestra; Pamela Burger; Chesterwood Museum; Chocolate Springs; Clark Art Institute; Annie Clarke-Gerrity; Barbara and Burnard Crawford; Valerie Falk; Filene's; David Fox, Photographer; Foxwoods Resort and Casino; Isabella Stewart Gardner Museum; Hank and Karen Gold; Hancock Shaker Village; Royster Hedgepeth; Deborah Hollingworth; David Hyde Pierce; Inn on Cove Hill, Rockport; Jalapeno's Mexican Restaurant; Kripalu Center for Yoga & Health; McCormick & Schmick's Seafood Restaurant; Mount Washington Hotel & Resort; Movement Resource Studio; The Porches; Norman Rockwell Museum; Gene Shalit; Sheraton Hotel, Boston; Fredrica Sloan; Southwest Airlines; The Store at Five Corners; and WGBY, Boston.

Plans are already underway for Tanglewood 2005, so mark your calendars for August 2, 2005 and plan to join the fun at *Tanglewood on Parade!*

See more photos, next page ►

Clergy Conference Inspires, Educates

The clergy are in a pivotal position to encourage, guide, and support people with dementia and their families. With this in mind, our 3rd Annual Clergy Conference was held at Elms College in Chicopee on June 23.

Approximately 65 participants from across the state, representing a wide range of Christian, Jewish, and other faith communities, joined to spend the day learning how to work with patients and families during their journey through Alzheimer's disease. The speakers emphasized the ongoing spiritual needs of both patients and families as they discussed effects of the disease and possible strategies for intervention.

Rev. Kathleen Rusnak, Ph.D., who is known for her work with hospice patients and their caregivers, delivered the insightful, enlightening, and often humorous keynote presentation. The day continued with excellent lectures by **Janice Ford, R.N., M.S.** and **Joanne Koenig Coste, M.Ed.**; as well as two inspiring panel discussions with family members, caregivers, and professionals. Participants had time to browse through displays by local agencies, and to explore resources available within the group of attendees.

Many declared it an "Excellent conference!" and encouraged anyone interested in the spiritual aspects of caregiving to attend the 2005 conference.

Cape Cod and the Islands Part of the Family

By Diane McCafferty

If people who have a common history and a common purpose form a family, then those of us who have cared for someone with Alzheimer's disease are a family. I had volunteered to help the Noonan family with their annual fundraising event, Memory Ride, on what turned out to be a hot and humid July day on Cape Cod.

Memory Ride is a 150-mile bicycle ride from Brattleboro, Vermont to Boston (see story, p. 12). Proceeds go directly to fund Alzheimer's research. Eight years ago, the ride was started with only 5 riders, 4 of whom were Noonan family members. This year, 88 riders completed the two-day event. Noonan family members came from far and wide to help out, one from as far away as Oregon.

Branches. When a Noonan family member asked me why I had volunteered to help, another Noonan answered for me, "Obviously, because she has someone with Alzheimer's disease in her family." That was all that needed to be said. Understanding was immediate—and for that day, I was a member of their special family.

For those of you struggling with the disease: remember, you are not alone. There is family all around you who are doing what they can to help.

regional news



USGA Tournament

Education Coordinator **Jeannie Banas** recruited and coordinated 75 volunteers to sell hot dogs, snacks, and beverages at the 4th hole concession stand during the 59th U.S. Golf Association Women's Open Championship, held in South Hadley June 28 to July 4. Volunteers, who ranged in age from 14–80, included high school students, caregivers, nurses, and Regional Leadership Committee members, earned \$1,700 for the Chapter's family respite program. We had an exciting four days, especially when pro golfer **Annika Sorenstam** (above) stopped by the booth to say "thank you" for her snack during a rain delay!

Tanglewood Photo Gallery

PHOTOS BY BARBARA CRAWFORD



Richard Lafley and Julie Dialessi-Lafley celebrate their successful bid for a Florida vacation.



Co-Chair Pam Burger welcomes guests.



(L-R) Faith Bandama, Diana Chirandu, Cynthia Lohnes, and Sharon Vargo take a break from their silent auction bidding.

patient care & family support

ALL CONFERENCE PHOTOS BY BRENDA VITALE



Joanne Koenig Coste, M.Ed., served as keynote speaker.



Curt Rudge, Chief Park Ranger for the MA Dept. of Conservation and Recreation, demonstrated how dogs are used in search and rescue for lost Alzheimer patients—the subject of his poster display.

Mary V. Hanley, M.A., R.N. is Nursing Instructor, Medical Center Employee Education at the Veterans Administration Boston Healthcare System, Boston, Mass.

Professionals Conference Breaks Records

By Mary V. Hanley, M.A., R.N.

A Map through the Maze, our annual interdisciplinary conference for professionals, was held at the Royal Plaza Hotel in Marlborough, Massachusetts on May 5, 2004. For the first time, the day-long conference sold out, with over 700 people attending.

This year's conference offered a myriad of topics demonstrating the complexity of Alzheimer's disease (AD) for novices and seasoned professionals who care for patients and families with AD. The well-informed speakers were enthusiastic about sharing their knowledge and experience, whether it was bench research, dealing with difficult behaviors, or preparing patients and families for end-of-life care.

Along with the 39 workshops, the poster session and exhibitor fair offered many opportunities for participants to explore cutting-edge research and resources in the community. Special thanks are in order to Praecis Pharmaceuticals and Beverly Healthcare for their generous financial support.

Joanne Koenig Coste delivered the keynote address, *Speaking Alzheimer's*. She was introduced by Massachusetts Chapter President **Jim Wessler**, who provided a vivid snapshot of Joanne's rich background and personal story of caring for her husband, who suffered with dementia in the years before the advent of "how-to" books or Habilitation Therapy.

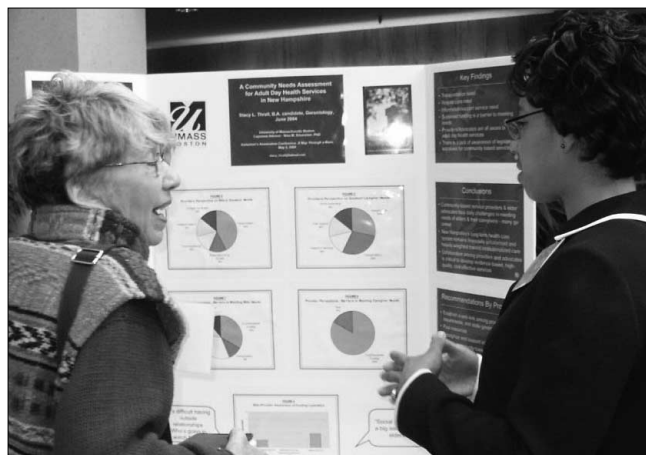
Virtuoso. He noted that Joanne's years of providing care for her husband and raising her young family instilled in her the insights, skills, and passion to co-author the Massachusetts Chapter's Train-the-Trainer manual on Habilitation Therapy with **Paul Raia, Ph.D.**; and to actively participate in the leadership of the Alzheimer's Association. Joanne is currently serving as an editorial board member of the **American Journal of Alzheimer's Disease** and recently published the book, *Learning to Speak Alzheimer's*, already in its second printing.

More than 700 people attended our annual conference, the largest of its type in New England. The busy exhibitor fair highlighted the state's programs and services.



Joanne presented a passionate, poignant, and humorous talk about her experiences living with a loved one who suffered from AD. She spoke of her need to share the knowledge and skills she has gained as a facilitator of support groups, director of the first dementia special care unit (SCU) in the state, and as a family therapist, to mention a few of her accomplishments.

Essences. The audience burst into laughter at her self-deprecation and wonderments, and held back tears at Joanne's tales of her family's challenges. Her inspirational talk set the tone for the day: hope through education, research, and social support. Joanne left us with the very important message that we need to accept the patient's reality, use humor, and most importantly, show love always in both verbal and non-verbal ways—the essence of *Learning to Speak Alzheimer's*.



Attendees had the opportunity to discuss projects with researchers during the poster session. Stacy Thrall, a gerontology student from U-Mass Boston (R), explains her project, "Community Needs Assessment for Adult Day Health Centers."

Acton: Joanne Chaulk or Jean Fleming	866.447.0009 978.264.9643	Lexington: Sandra Simon	617.558.9086
Agawam: Judy Pothul	413.821.9911	Littleton: Gail Mallardo	978.486.3512
Amesbury/Newburyport: Patricia Lavoie	978.290.1797	Longmeadow: Greg Goodman	413.567.6211
Amherst: Judi Jackson	413.548.6800	Lowell: Margaret Swanson	978.459.0546
Andover: Kristine Arakelian	978.623.8321	Lynn: Mark Hurd or Wendy Kaplan Valerie Jacobs	781.592.5661 508.261.1333
Arlington: Laurie August	781.316.3400	Mansfield: Christine Filocco or Deborah Supernant	508.481.9898 508.485.4040
Athol: Wandra Landry	978.249.3717	Marlboro: Seth Dudley Joyce Henderson	781.324.5759 781.395.5542
Attleboro: Nicole McGurin Sharon Leary	508.222.4950 978.226.6150	Medford: Douglas Lloyd or Sheila Witkus	508.473.0862
Auburn: Michelle Edelstein or Brenda Rojas	508.832.2200	Mendon: Marlene Fregeau or MaryPat McDavitt	978.682.3582 508.946.2490
Belmont: Nava Niv-Vogel or Lauren Storck	617.484.5501 617.484.0949	Methuen: Terri Orsillo	508.588.2622 508.947.4774
Beverly: Trish Crean	978.927.4227	Middleboro: Robella Coates Carol Ann Landreville Maureen Bradley	508.473.0862 508.793.0088 617.898.1094
Boston: Barbara Hawley Maxam or Maureen Tardelli	617.724.0055 781.391.7878	Milford: Marlene Fregeau	781.581.1202
Braintree: Eileen Schongold Ailsa LaCoste	781.848.3678 781.843.1860	Millbury: Michelle Stevens	508.325.5360
Bridgewater: Kathy Hayes or Sue Daniels	508.697.0929 508.697.4368	Milton: Cathy Smyth	508.650.9003
Brockton: Nancy Bresciani John Scott	508.583.2517 508.587.6556	Nahant: Rev. David Dodge	508.655.5000 x3988
Brookline: Howard Block Ruthann Dobek	617.983.5409 617.730.2777	Nantucket: Pam Meriam	508.655.3344 x3999
Burlington: Stacey Kohler Ann Cooper	781.744.8114 781.270.9008 x202	Natick: Judy Sabol Lois Pecora or Jim Worthington	781.455.7555 888.836.8866 x417 508.997.9396
Cambridge: Alice McCarter or Mary Costello Trudy Bauer or Ruth Gordon	617.547.3543 x25 617.491.1815	Needham: Sherry Jackson Nancy Cohen	978.465.5361 x122 978.290.1797
Canton: Susan Sheehan	781.828.7450 x307	New Bedford: Jean Melia	617.928.0007
Chelmsford: Patty Keane Susan Antkowiak	978.251.8491 978.934.0000	Newburyport: Amy Faucon	617.630.2767
Chicopee: Judy Pothul Virginia Cebula	413.821.9911 413.593.0088	Newburyport/Amesbury: Patricia Lavoie	413.664.4536
Concord: Patricia Oliphant	978.318.0046	Newton: Mara Klein Collins Sheryl Clarke	508.393.2386 508.234.6481
Dalton: Sandy Epperly	413.238.5574	North Adams: Beth Hinkley	781.769.4495
Danvers: Gwen Kopka Darcey Adams or Pam Taylor Gayel Cote	978.750.4540 978.774.4400 x3064 978.762.7625 x14	Northborough: Sue Corbett Cecilia Boatman	781.769.2200 x209 978.531.2254 x137
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Duxbury: Sandi Wright	781.585.2397	Peabody: Linda Smith	413.499.1992
East Longmeadow: Ellen Nepomuceno Mary Anne Stout	413.781.5070 413.596.2665	Pittsfield: Louise Posnick Bea Cowlin Beth Hinkley	508.747.3332 508.947.4774 617.471.5712
Fairhaven: Sharon Jensen	508.991.8600	Plymouth: Sharon Mazzilli or Maureen Bradley	617.233.1145
Fall River: Judy Elste or Paulette Masse	508.675.2101 401.559.5668 (free call)	Quincy: Kathy Prince Beverly Moore	781.681.1075 617.361.7486
Fitchburg: Harriet Klayman Jodie Bourgeois	978.343.5216 978.342.9428	Rockland: Lauren Walsh	617.868.6718
Foxboro: Diane Caldwell	508.339.7183	Roxbury: Ilene Marsh or Michael Kincade	781.233.8123 781.784.6781
Framingham: Deborah Young	508.879.8000	Saugus: Debbie Bennett	508.679.2240
Gardner: Judy Wilson Kelly Lanza	978.632.1230 978.632.5477	Sharon: Mary Fegan or Christine Lewis Dushku	413.532.8098 508.765.9771
Gloucester: Claire Phillips	978.281.9765	South Hadley: Gerri Bennett	508.248.7344
Great Barrington: Karen Hutson Susan Peisner Joan Nimmo	413.528.2650 413.528.1881 413.528.4560	Southbridge: Roger LaMontagne Susan Klezcka	413.782.1800 413.781.5070
Hingham: Jo Ann Mitchell Eleanor Blair	781.749.5417 781.749.4774	Springfield: Kathryn Nowak-Crane Ellen Nepomuceno	781.344.7661 508.379.9700
Holden: Naomi Sohlman	508.829.0270	Stoughton: Denise Conley or Christine Galanis Karen Sprague	978.657.0800 978.851.3121
Holyoke: Dottie Blain-Hamel	413.322.5625	Swansea: Michael Spearin	413.773.5555 x262
Hopkinton: Patricia McKinney	508.435.0222	Tewksbury: Kathy Moriarity Paula Drelick	781.224.2800
Jamaica Plain: Susan Kelley-Grasso	617.868.6718 x220	Turners Falls: Molly Chambers	413.967.2225
Joneston: Sandra Fahrenholt	781.585.4100	Wakefield: Kristine Taylor	508.758.2173
Lancaster: Kristi Mendoza	978.365.4537	Ware: Stasia Wozniak	508.295.1040
Lee: Dolores Thimot	413.243.4747	Wareham: Carolyn Cardoza Dianne Connelly	
Leicester: Eva Dawson	508.987.8056		

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 lifesaving by their members.

Our website support group leader list, found at www.alzmass.org, is updated frequently. For more information about Massachusetts support groups, call our Helpline at 1.800.548.2111.

Please call the listed group leaders for details.

(continued on back page)

support groups

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 1.800.548.2111.

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.

Support Groups *continued from page 19*

Watertown: Ruth Gordon 617.491.1823
Webster/Dudley: Debra Boucher 508.791.8131
 or Gary Davis 617.653.7242
Wellesley: Peggy Mullen 508.533.7020
West Springfield: Val Moschilli 413.781.1282
Westboro: Aimee Rizzo 508.836.4354 x3706
 Susan Garvey 508.366.9131
Westfield: Ellen Nepomuceno 413.781.5070
Westford: Arlene Parillo 781.863.1166
 or Joanne Shaughnessy 978.264.4666
Weston: Shirley Earle 781.893.0154
Westport: Susan Oliveira 508.636.1026
Westwood: Peter Byron 781.326.5652
Weymouth: Lynne Wilkinson 781.337.3121
 Julie Barcelo 781.340.9100
Wilbraham: Beth Vettori 413.596.0006
Williamstown: Eleanor Derby-Kilfoyle 413.458.8127 x108
Woburn: Jennifer Jaroch 781.932.0350
Worcester: Faith Bandama 508.791.5543 x3319
 Marie Cote 508.753.4791
 Patrice Fanjoy 508.752.2546
 Debbie DeRossier 508.754.3800 x126
 Therese DeLongchamp 508.755.7277
 Cindy Lamica 508.852.5800 x203
 Katherine Ferreira 508.791.4200

Specialized Groups

Adult Child Caregivers
 West Roxbury: Susan O'Connell 617.325.1230
 or Margaret Wright
Children's Group (ages 8-12)
 Danvers: Kris Haring 978.774.4400 x4007
Families of VA Patients with AD
 Bedford: Chris Jagiello 781.687.2701

Interfaith Support Group
 Framingham: Malka Young 508.875.3100
 Springfield: Marcia McKenzie 413.787.1113
People under 65-Early Stage & Early Onset Alzheimer's and their Caregivers
 Cambridge: Nancy Cohen 781.788.0044
People with Early Stage Alzheimer's and Their Caregivers
 Amherst: Jeannie Banas 413.787.1113
 or Wanda Landry 978.249.3717
 Andover: Bernadette Graycar 978.623.8321
 Athol: Wanda Landry 978.249.3717
 Attleboro: Nicole McGurin 508.222.4950
 or Joyce Coletto 508.222.0118
 Brockton: John Scott 508.587.6556
 or Tadd Clelland 508.427.6099
 Concord: Arlene Parillo 781.863.1166
 or Mary Baum 978.369.4728
 Danvers: Carol Owen 978.774.4400
 Dartmouth: Peter Ham 508.997.0794
 or Maureen Hebert 508.679.0011
 Duxbury: Bonnie Haley 781.934.5774
 Milton: Cathy Smyth 617.898.1094
 or Susan Sheehan 781.828.7450 x307
 Natick: Joanne Koenig-Coste 508.879.5338
 or Lois Pecora 508.655.3344 x3988
 Springfield: Ginny Sinkoski 413.787.1113
 or Ellen Nepomuceno 413.781.5070
 Westboro: Aimee Rizzo 508.863.4354 x3706
 or Muriel Baum 508.435.0019
 Worcester: Gary Davis 617.653.7242
 or Deb Boucher 508.791.8131
Spanish-language Group/En Español
 Boston: Conchita Rodriguez 617.868.8599
Spouses' Group
 Brockton: Geralann DiDomenico 508.427.6099
 West Roxbury: Susan O'Connell 617.325.1230
 or Stephanie Walsh

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