

Volume 19, Number 1
 Winter 2001
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ALZHEIMER'S[®] ASSOCIATION

Massachusetts Chapter

End-of-Life Care Provides Comfort

By Ann C. Hurley, R.N., D.N.Sc., FAAN.

Family and professional caregivers working within the American health care delivery system will need to brace themselves for an even greater workload in years to come, in light of increasing numbers of older Americans who will require care for Alzheimer's disease or related disorders (ADRD). According to U.S. census data from 1900 through 2050, people over age 85—the category at highest risk for developing dementia—constitute the most rapidly growing segment of the population. Furthermore, evidence suggests that about 47% of people age 85 and older may develop Alzheimer's disease, and that currently 2.5 to 4 million Americans are already afflicted with it. Sadly, these numbers will continue to rise as our population ages.

These statistics underscore the need for focused public attention to the sensitivities as well as the difficulties involved in providing high quality end-of-life care for people with Alzheimer's disease, and the role of hospice in orchestrating care for the dying. The relentlessly progressive character of this disease process results in the patient's death from the natural course of progressive dementia. The course of life as experienced by the person with Alzheimer's disease is heavily influenced by decisions on the part of family members and professional caregiving staff to provide comfort and manage challenging symptoms of dementia.

Since technology exists that can prolong life in many cases, families need to consider the issue of withholding such technology in terms of striving for maximal comfort, rather than seeking survival at all costs. Despite the fact that no cure currently exists for Alzheimer's disease, receiving attention to quality of life issues and

continued on page 3



Arriving by Charles River Boat to kick off the Cambridge Walk are (L to R): Congressman Ed Markey, State Honorary Chair; Jim Wessler, Alzheimer's Association, MA Chapter Executive Director; Sandy Auerbach, MD., Alzheimer's Association, MA Chapter Board Chair; Bill Kubasek, Praecis Pharmaceuticals Inc.; and Deborah Blacker, MD., Sc.D., State Medical Chair. Greeting the dignitaries were emcee Nancy Quill of WMIX-FM radio and Cambridge Vice Mayor David Maher. See Memory Walk story, page 6. (Photo by Ellen Shub)

MARK YOUR CALENDARS NOW!

Western MA Conference: WEDNESDAY, MARCH 14

Don't miss Dr. Rudolph Tanzi's keynote address at the 10th Annual Western MA Professional Caregivers Conference. See page 18 for details, plus news of Open House April 28 in Springfield.

Greenman Art Exhibit, Reception: THURSDAY, MARCH 15

Treat yourself to a vignette of a talented artist's distinctive works at the Berenberg Gallery in Boston. See page 13 for details.

Al Dente Road Race: SATURDAY, MAY 5

Join us for the 5th Annual 4-mile Al Dente Road Race in Medford – complete with food, fun, and prizes! See page 17 for details.

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*Emeritus

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 Printed by Fidelity Press

From the Executive Director: Finding a Clear Voice Together!**Progress in Research, Funding, Patient Care Offers Hope**

Dr. Sandy Auerbach, Chairman of our Board of Directors and I recently returned from the Leadership Conference of the national Alzheimer's Association. It was an inspiring weekend, as our national organization celebrated its 20th Anniversary, just a few months after our Massachusetts Chapter celebrated its first 20 years. As many of you know, ours is one of the founding chapters of the national Association.

Although we have completed our merger between the former Western and Eastern Massachusetts Chapters, the rest of the nation is presently very involved in merger discussions. Our Chapter is still regarded as a flagship for advice and consultation by other Chapters, and as a model for the national realignment effort being pursued by our Association.

We had the privilege of listening to Dr. Steven DeKosky, Chairman of the National Medical and Scientific Advisory Council of our national Association. According to Dr. DeKosky, 20 years ago you couldn't find 20 scientists who were engaged and/or knowledgeable about Alzheimer's-related research. Today, the Alzheimer's Association has a panel of 2000 international scientists and physicians who review research applications for the Association.

Clear commitments. Over the 20-year history of the Association we have bestowed \$100 million in research grants. Furthermore, our Association, supported by thousands of advocates around the nation, has successfully advocated for \$3.8 billion in National Institutes of Health (NIH) funding for dementia-related research.

This research is yielding exciting progress spanning the fields of genetics, diagnostics, and pharmacological therapy, with the goal of discovering drug interventions that some day may dramatically reduce amyloid deposits. In addition, the research is helping to refine caregiving techniques that are significantly impacting the emotional and behavioral well being of patients.

A recent meeting hosted by our Massachusetts Chapter confirmed the sense of invigoration from the research community. In honor of the 2000 Simons lecturer, Dr. Jeffrey Cummings, our Chapter hosted an informal dinner for many of Boston's top dementia researchers. It was the consensus from the research community that the pace of scientific advancement is truly breathtaking – encouraging news for patients and caregivers. It was also rewarding to hear scientist after scientist state their appreciation for the Alzheimer's Association and the work we do on behalf of patients and caregivers.

I also recently had a wonderful opportunity to attend an early stage patient and caregiver support group in Natick. Fortunately, I was able to meet with caregivers and patients, both of whom had powerful experiences and suggestions to share. I was particularly moved by my meeting with the patient group.

I was particularly moved by my meeting with the patient group.

Working with their able facilitators Joanne Koenig-Coste and Lois Pecora, individuals in the group had prepared questions. I listened, agreed with their points, and pledged that the Alzheimer's Association was doing what we could to address their concerns. I thought I would share these concerns and questions from people with early stage Alzheimer's disease:

- Why don't doctors talk more openly to us, the patients, about what will happen to us? Why do they speak to our family members and act as if we are not there?
- How can we help doctors know about the medications for Alzheimer's and about the benefits that we can get?
- How do we get the word out so that more patients can come to early stage patient groups like this?
- What can we do to let people know about all the available resources?



Moderator Nancy Fernandez Mills facilitates an exchange of ideas, memories, and voices at the Annual Meeting. Photo by Sam Laundon, Natural Light Studios

- Will the Alzheimer's Association extend hours to be open weekends and later at night? (Note: within the next year, we are hoping to have our Helpline available to the public 24 hours per day, seven days per week.)
- How can we get more money for our families so that all our savings are not used for care and nothing is left over?

As I said good-bye to these wonderful people I was once again reminded that people with Alzheimer's and related dementias have so much to offer, and we have so much to learn.

—Jim Wessler, Executive Director

End-of-Life Care Provides Comfort *continued from page 1*

being comfortable should be reasonable expectations of care.

Comfort goals. Hospice care represents an important option for families to explore in their quest to provide their loved ones with as much comfort and quality of life as is realistically possible in the advanced stages of illness. The goal of hospice care is to provide high quality end-of-life care that avoids unwanted attempts to sustain life, and focuses on the physical, emotional, and spiritual care of people with terminal illnesses. In addition, hospice care provides practical and emotional support for caregivers, including bereavement services.

The concept of hospice transcends the notion of site. Hospice care can be provided in a hospital, a nursing home, a community setting, or as a freestanding program, but most hospice care is provided in homes. The word **hospice** has multiple meanings: a philosophy of palliative care; a comprehensive, interdisciplinary patient/family systematic approach to coordinated end-of-life care and services; a Medicare benefit (requiring a physician's certification that the patient's estimated survival time is six months or less); and an industry within the health care system.

Quality indicators of a hospice program include an individualized comfort care plan, prevention of physical problems caused by medical treatment, provision of sensory stimulating and calming activities, preservation of human dignity, and psychosocial/educational support for families and staff.

Family members will want to consider several important concepts when thinking about hospice care as an option for loved ones in end-stage illness:

- **Advance Care Planning is necessary.** Everyone should have an established health care proxy. If the person has not already completed the health care proxy process before diagnosis, he or she should select a proxy and complete required legal forms as soon as possible. If no proxy exists and the person is unable to select one, the surrogate decision-maker should work with the health care team to establish an Advance Proxy Plan so that end-of-life decisions can be made in advance of crises. Discussions about advance planning should be initiated as early as possible after diagnosis so the person can make his/her wishes known.
- **The disease progresses.** No matter how exceptional the family and professional caregiving has been, Alzheimer's disease is a terminal neurological process that lasts from 2-20 years and will cause fatal complications unless the person dies from another cause. For example, some medications may delay the clinical symptoms of disease progression, but still

Despite the fact that no cure currently exists for Alzheimer's disease, receiving attention to quality of life issues and being comfortable should be reasonable expectations of care.

cannot halt the pathological changes of the disease process or their clinical consequences. Ultimately, the person may need round-the-clock care, which even the best of family caregivers may not be able to provide. Direct care may need to be transferred to professionals with an environment and staff capable of meeting the person's needs. Families need to be prepared for the late-stage complications of immobility, loss of speech, eating difficulties, and infections. Pneumonia is often the direct cause of death for a person with late stage Alzheimer's disease.

- **Family support matters.** Even though family members may see the patient progressively decline, the notion of death can still be abstract or at least an event that trails indefinitely into the future. Families should seek assistance in helping to prepare themselves for the inevitable. Hopefully, the family can establish a trusting relationship with a professional caregiver to help in making end-of-life decisions and in providing support to the family.
- **Informed choices lead to higher quality care and comfort.** Families need to learn all they can about relevant nursing issues in managing their loved one's end-of-life care. For example, palliative and aggressive care philosophies are not mutually exclusive. A person's care plan may call for no artificial feeding, but to work up and treat infections aggressively. Caregivers can manage symptoms and improve the quality of life for the person suffering from the disease. □

For further information, please refer to these three books:

- Mahoney, E.K., Volicer, L. & Hurley, A.C. (2000). *Management of challenging behaviors in dementia.* (Baltimore, MD: Health Professions Press)
- Volicer, L. & Bloom-Charette, L. (1999). *Enhancing the quality of life in advanced dementia.* (Ann Arbor, MI: Edward Brothers)
- Volicer, L. & Hurley, A.C. (1998). *Hospice care for patients with advanced progressive dementia.* (New York: Springer)

Ann C. Hurley, R.N., D.N.Sc., F.A.A.N. is Associate Director for Education and Program Evaluation, Geriatric Research Education and Clinical Center, E.N. Rogers Memorial Veterans Hospital, Bedford, MA; and Education Core Leader, Boston University Alzheimer's Disease Center.

Patient Care and Family Support



The lovely Memorial Garden outside the dementia units at the Bedford V.A. Hospital provides a tribute to veterans, as well as a peaceful setting for respite for the hospital community of staff, families and residents. The Garden was designed and landscaped by Jim Richards, Nursing Assistant. Photo by Susan Hewitt, MSW

2000 Annual Meeting

Annual Meeting Celebrates Twenty Years of Caring

By Heidi Ganss

Almost 200 Association members and guests, including many former staff and Board members, celebrated the 20th Anniversary of the founding of the Massachusetts Chapter September 14 at the Heritage Museum in Lexington.

Outgoing Board Chair Dr. Nina Silverstein acknowledged the importance of the Board of Directors to the Chapter's success. She recognized and thanked eight retiring Board members – Joan Johnson, Maria Maskaluk, Rev. Thomas Mayers, Dr.

Governor's Council on Alzheimer's Disease. She also enabled the restructuring of the State Respite Care benefit, allowing family caregivers to access greater blocks of reimbursed respite services. (See photo, page 12.)

Influential leader. Phyllis O'Hara, member of the Western MA Advisory Council, was also recognized for her many contributions to the Chapter. She served as President of the Western MA Chapter from 1990-1994, and founded the Pioneer Valley Alzheimer Specialists group. In addition, Phyllis has

served on the statewide Public Policy committee, and since her retirement has continued as a workshop leader, public speaker, patient and family advocate, and in many other important roles.

Board Member Emeritus Marcia Simons was presented with the Third Annual Myer Saxe Memorial Award by Development Committee Chair and Board Vice Chair Kathleen Salmon-Robinson. The Myer Saxe Memorial Award, named in memory of one of our Chapter's founders and Board members, was established to recognize outstanding volunteer leaders for exemplary fundraising efforts on behalf of the Association. Mrs. Simons' generous sup-

port enabled the Chapter to establish the endowed Matthew and Marcia Simons Annual Research Symposium in 1990.

Pioneer honored. Dr. Marilyn Albert, former Board Chair, current Professor of Psychiatry and Neurology at Harvard Medical School and Director of the Gerontology Research Unit at Massachusetts General Hospital, introduced the Chapter's 2000 Honoree, Dr. F. Marott Sinex. Dr. Sinex, a pioneer in the truest sense of the word, was a professor of biochemistry at Boston University School of Medicine when in 1978 he founded the Massachusetts Society Against Dementia. The society was the precursor organization to our current Alzheimer's Association, Massachusetts Chapter. Dr. Sinex was also instrumental in founding the national Alzheimer's Association in 1978. He is an Emeritus Member of our Board of Directors.

The program then turned to Association business, including the election of new officers. Three new candidates for the Board of Directors were approved: Barbara Milensky from Berkshire County and Joanne Chaulk from Chelmsford were nominated to the Board, and Marcia Simons was nominated Board Member Emeritus.



Dr. Pam Sheridan, Tanya Crews, and Board Member Ruth Moy enjoy the post-meeting dessert reception at the National Heritage Museum. (All Annual Meeting photos by Sam Laundon, Natural Light Studios)

Pamela Sheridan, Jean Tyler, Nancy Hindlian, David Hayes, and Linda Nassar Judge.

Dr. Lillian Glickman, Secretary of the State's Office of Elder Affairs, received the Chapter's 2000 Advocacy Award. She was recognized for her exceptional public commitment to advocacy issues on behalf of people with dementia and their families in Massachusetts. Dr. Glickman's many contributions to the field include serving as a founder and current chair of the



Board Member Emeritus Marcia Simons (front, center), who received the Myer Saxe Memorial Award, poses with family members and friends.



Panelists Mike Splaine, Dr. Marilyn Albert and Joanne Koenig-Coste share reflections on the past 20 years, as well as predictions for the future.

The slate of candidates for re-election to a second three-year term was presented and accepted: Dr. Sanford Auerbach, Richard Blinn, Patricia Clark, Sue Levkoff, Robert Margil, Paulette Masse, Ruth Moy, Harold Schiff, Stanley Solomont, Ann Turner, Sumer Verma and Rosalie Wolf. The slate of Officers for the 2000-2001 Board of Directors was accepted: Dr. Sanford Auerbach, Chair; Kathleen Salmon-Robinson, Vice Chair; Donald Davidoff, Treasurer; and Roberta Rosenberg, Clerk.

Keynote Panel. Nancy Fernandez Mills, a family member, active Chapter volunteer and Emmy-award winning media professional facilitated the keynote panel. (See photo, page 2.) The lively, informative presentation featured remarks by Michael Splaine, Director of the Advocacy Program at the national Alzheimer's Association; Dr. Marilyn Albert; and for-

mer Board Chair Joanne Koenig-Coste, Alzheimer's disease consultant and trainer.

Incoming Board Chair Dr. Sanford Auerbach commented on the effectiveness of Dr. Nina Silverstein's tenure as Board Chair and presented her with a floral bouquet. He described the Alzheimer's Association's role as the primary resource for patients, families and professionals; as well as the need to continue advocacy efforts and expand our outreach to the thousands of isolated patients and caregivers not currently receiving assistance.

The meeting concluded with the presentation of a special commemorative 20th Anniversary video, donated and produced by Brian Johnson of BKJ Productions. □

Heidi Ganss is the Massachusetts Chapter's Director of Development.



Western MA Advisory Council Member Phyllis O'Hara receives award from Jeff Graham of Berkshire Healthcare System (L) and Executive Director Jim Wessler (Center).



June Carter with Dr. F. Marott Sinex, Board Member Emeritus and Massachusetts Chapter's 2000 Honoree.

2000 Annual Meeting

Dr. Sanford Auerbach described the Association's role as a primary resource and emphasized the need to continue advocacy efforts and expand our outreach to the thousands of isolated patients and caregivers not currently receiving assistance.

Development

Memory Walk 2000 reaps \$410,000 to help Massachusetts patients and families

by Sheila Watnick

They came from all across Massachusetts, ranging in age from eight months to eightysomething. Their footprints, quietly soft but sure, identified them as patients, family members, professional caregivers, and friends. Bolstered by the support of sponsors from California to Ireland, they wore round decals bearing the names of the people being honored. They were the 3,000 walkers, many who braved formidable weather, to take part Sunday, September 24 in our eighth

Morganelli, a popular meteorologist from WWLP-TV, Channel 22 (Springfield) promoted the event on his web site and arrived that day to emcee and walk among the 38 teams. One of the teams included a group from Sigma Kappa at the University of Massachusetts, Amherst (the sorority's national cause is Alzheimer's care/research).

The autumn snapshots continued to abound at other Memory Walks. In Lenox, the 2-mile walkers sauntered among the many crafts and food booths at the annual Apple Squeeze

Festival. In Worcester, Harriette Chandler, newly elected State Senator and Chair of the State Health Care Committee addressed participants, 160 of which were from the Worcester County Church of Christ. Eighteen holes of golf at the Chelmsford Country Club was just one of the exciting raffle prizes awarded at the Lowell walk along the Merrimack River. And in Haverhill, canine participants were an important part of the mix, as several walkers took their pets for a 3-mile stroll.

At the main site at Canal Park in Cambridge behind the

CambridgeSide Galleria, State Honorary Chair Congressman Ed Markey led walkers in the 6.2-mile (10K) "Spirit" Walk along the Charles River. State Medical Chair Deborah Blacker, M.D., Sc.D. followed with walkers participating in the newly formed 2-mile "Hope" Walk. Later in the day family members Sheila Walsh, Ed Wade, and Dave Currier told their personal stories about how the Alzheimer's Association had impacted their lives. Dave then introduced co-songwriter Linda Chase, who delivered an impassioned debut of *At the Journey's End*, a song written especially for Memory Walk. (CDs are available for \$10 apiece with a portion benefiting the Alzheimer's Association. Call Paws Music at 781.935.4116.)

Amidst the hubbub of activity and excitement, there was no doubt that Memory Walk served as a day of healing, a day of sharing, and a day of hope for an end to this dreaded disease.

Sheila Watnick is the Massachusetts Chapter's Associate Director of Development/Special Events Manager.



Against the backdrop of the campus of Shakespeare & Co. in Lenox, the Berkshire Health System team poses for a photo. The group raised approximately \$2500. (Photo by Jim Wessler)

annual Memory Walk, which raised an unprecedented \$410,000 to help the 130,000 Massachusetts patients and 400,000 family members affected by Alzheimer's disease and related disorders. This total represents a \$90,000 gross increase over funds generated in last year's Walk!

Congratulations to **Maria Santaren** of Jamaica Plain, our top individual statewide fundraiser, who will receive two round-trip tickets on Southwest Airlines. Maria raised \$8400 for the Massachusetts Chapter! (More category winners will be announced in the next issue of this Newsletter.)

Across the state, each community's Memory Walk was individualized by the colors, textures, and creative spirit of the citizens whose dedication made it possible. At the newly formed Athol site, for example, State Senator Stephen Brewer cut the ribbon and WJDF-FM radio's Fred Deane reported live all along the rainy 4-mile route. At Battleship Cove in Fall River, a group of Parrotheads (Alzheimer's care/research is the official charity of singer/songwriter Jimmy Buffett's fans and followers) kept things colorful and lively. In Walpole, participants tied purple ribbons on a recently planted Memory Tree as they walked through Bird Park. At Stanley Park in Westfield, Nick

THANKS TO OUR SPONSORS!

STATEWIDE

Title sponsor: Praecis Pharmaceuticals, Inc.

Benefactor: Genesis ElderCare

EASTERN MASSACHUSETTS

Patrons: Blaire House Healthcare Centers, Sunrise Assisted Living.

Friends: Beverly Healthcare, Boston Alzheimer's Center, The Boston Globe, Cambridge Trust Co., Community Newspaper Co., EPOCH Senior Living, Southwest Airlines, Welch Healthcare and Retirement Group, WMIX-FM radio.

Gold: Life Care Centers of America, McLean Hospital Geriatric Psychiatry Service, Stanley Solomont.

Silver: The Alzheimer Center at Quabbin Valley Healthcare; Athena Diagnostics, Inc., a division of

WESTERN MASSACHUSETTS

Gold: Berkshire Healthcare Systems, Inc.; Sweet Brook Care Centers, Inc.

Silver: The Arbors at Amherst; The Atrium; Berkshire Healthcare Systems; Charlene Manor; East Longmeadow Skilled Nursing Center; Fairview Manor; Kimball Farm; Linda Manor; Mount Greylock; Skilled Nursing Unit at Berkshire Medical Center; Willowood of Great Barrington; Willowood of North Adams; Willowood of Pittsfield; Willowood of Williamstown; Little's Pharmacy & Surgimed; Loomis House Nursing Center; Melbourne Place Assisted Living Community; Northern Berkshire Healthcare Systems; Quabbin Valley Health Care; Renaissance Hotels of Holyoke and Westfield; Sisters of Providence Health System, Extended Care Network; SunBridge Healthcare Corporation.



Fall River walkers view the historic USS Massachusetts (affectionately known as The Big Mamie) at Battleship Cove in picturesque Heritage Park while strolling along the river. (Photo by Moe Masse)

Bronze: Berkshire Bank; Easthampton Savings Bank; Eisai, Inc. and Pfizer, Inc.; Jewish Geriatric Services; The Memory Clinic; WestMass ElderCare; Williamstown Savings Bank.

Walkers Awareness Friends: Bacon & Wilson, Balise Motor Sales, Bank of Western Massachusetts, Berkshire Life Insurance, Country Curtains, Craneville Place of Dalton, Franklin County Home Care Corporation, Attorney Michael Hooker, Hoosac Bank, Memory Disorders Program at Baystate Medical Center, Northampton Cooperative Bank, Pittsfield Cooperative Bank, Qualified Plan Consultants, W.J. Quinn Construction Co.

Donors: Canyon Ranch in the Berkshires; Coakley, Pierpan, Dolan & Collins Insurance; H.L. Dempsey Co.; Devanny Condron Funeral Home; Hart's Pharmacists; Kavanagh Furniture; Oliver Auto Body Co.; Mount Snow, VT; Reeds Landing; The Student Prince; Umlauf & Dunn Realty.



Elan Pharmaceuticals; Belmont Manor Nursing Home; Boston University Alzheimer's Research Center Staff; Hearthstone Alzheimer Care; HomeRuns.com; SunBridge Healthcare Corporation.

Donors: The Clarks Companies, Saint Vincent Hospital.

Exhibitors: AHCP/At Home Care; Briarwood Healthcare; Elihu White Alzheimer Center for Living; Independent Living, Inc.; Pelham Heath Care Services; Pfizer, Inc.; Whitney Place.

African drummers Cliff Ginandes, Dave Currier, and Dan Sirois joined Congressman Ed Markey (also pictured above) in leading the Cambridge Walk and then entertained en route. (Photo by Ellen Shub)



We gratefully acknowledge participating individuals and organizations at many of our nine Memory Walk sites on the following pages.

CAMBRIDGE

Committee: Roger Appell, Dave Currier, Lisa Diamandis, Barbara Gold, Valerie Gramolini, Judy Green, Nancy Holcomb, Alan Jacobson, Millie Laby, Elizabeth MacAskill, Judy Rauchwarger, Stanley Solomont, Lucia Vaughn, Ed Wade, Sheila Walsh, Gail Wolfe.

Volunteers: Karen Bibo, Missy Bibo, Paul Bibo, Sheila Branock, Stephanie Bronson, Susan Catterall, Jill Connor, Florence Cooperstein, Julie Del Prado, Elizabeth Diamandis, Victoria Diamandis, Jean DiPrima, Jim DiPrima, Jackie Donaher, Kevin Donaher, Louise Dussault, Arnie Ehrlich, Sarah Fallas, Marilyn Fenter, Carolyn Fleiss, Joan Fogel, Barbara Gloss, Harry Gloss, Susan Goodman, Donna Kaminski, Jay Kaminski, Mary Jane Karloupek, Jamie Katz, Liz Kelly-Kislowksi, Laura Kittery, Rob Kluin, Douglas Knight, Louis Laider, Chris Lorant, Patty MacDonald, Bonnie Mann, Tom Mayers, Bob Morrison, Brendan Morrison, Marena Morrison, Sandy Morrison (Brookline), Sandy Morrison (Lynnfield), Tim Morrison, Jean Murray, Tegan Murray, Jasmine Pedroze, Lauren Pfair, MaryAnn Sessions, Steve Shapiro, Sue Sharrow, Dorothy Shrank, Lillian Simons, Matt Sisson, Carol Steiner, Ann Strand, Nelia Tavares, Ned Van Winkle, Karen Vaughn, Melissa Venti, Michelle Ventresca, Brendan Walsh, Brian Walsh, Kathy Walsh, Steven Walsh, Irving Watnick, Andrew West, James West.

Entertainment: Brother Blue; Linda Chase; Dave Currier, Cliff Ginandes and Dan Sirois, African drummers; Mike Myers, the World's Oldest Five-Year-Old; Nancy Quill, WMJX-FM, emcee; Soul City; Anna Huckabee Tull, acoustic guitarist and songwriter.

Raffle prize donors: Au Bon Pain, Bakers Best Café and Catering, Barnet Distributors, Boston Duck Tours, Bread & Circus Whole Foods Market, Carberry Bakery & Coffee House, Charles River Boat Co., Christopher's, Corners Framing, Coyote Impressions, Crafty Yankee, Elizabeth Renee



Promoting the Alzheimer's Association and Memory Walk, Audrey Cogswell (L) and Natalie Pasco (R), volunteers from GE's Long Term Care Division, national sponsors of Memory Walk, join staff and other volunteers answering phones on the air during the WGBH-TV Channel 2 pledge drive. (Photo by Sheila Watnick)

Esthetics, Friday's American Bar and Grill, Grafton Street Pub & Grille, Healthworks, House of Blues, Image Creators, Jacoppi's Colonial Tyng Manor, Jade Garden Chinese Restaurant, Janet Feld, La Scala Restaurant, Lexington Toyota, Lilac Moon Gifts, LisaJames Salon, Marino's Ristorante, The Mount Washington Hotel and Resort, O'Hara's Food and Spirits, Outback Steakhouse, Salon Monte Carlo, Sedona Sun, Mr. and Mr. David Solomont, Sprint, Zani Muscular Therapy.

Special thanks: Arcadia Farms; Balloon Designs with a Unique Twist (Peabody); Barry Aston, D.M.D.; Amy Beck, R.N.; Belmont Springs; Debbie Bennett, R.N.; Cambridge Vice Mayor David Maher; Boston Italian Ice; Brigham's; Cambridge Glass & Mirror; Barbara Catalano-Trinque; Cataldo Ambulance; Charles River Boat Co.; Elaine Cohen; Coyote Impressions; Peter DeVito, Penny Papadopolous and Bob St. John; CambridgeSide Galleria; Denise Dussault; Eisai, Inc. and Pfizer, Inc.; Fred Fantini; Garelick Farms; Herman Goelitz Candy Co., Inc.; The Grand Lodge of the Masons of Massachusetts; Johnny's Foodmaster; Lexington Ace Hardware; Ed MacAskill; Ksenia Mack; Kate Marshall; Mount Auburn Hospital Food Service; Museum of Science; New England Confectioners; Candy O'Terry, WMJX-FM; Polaroid Corporation; Jim Pullano; Shaw's/Star Market; Elaine Silverio; Penelope Soufan; Sudbury Farms; Michael and Janet Venti; Veryfine; Heidi Wallner; Watermark Donut Company; Wild Oats; Wilson Farms.

ATHOL

Wanda Landry, Site Coordinator

FALL RIVER

Co-chairs: Tadd Clelland and Paulette Masse

Photographer: Maurice (Moe) Masse

Committee: Judy Elste, Terrie Arruda, Patty Ricketts

Volunteers: Debra Abel, Terrie Arruda, Ryana Barbosa, Tina Barbosa, Margaret Crawford, Judy Elste, Lucille Hargraves, Sharon Jansen, Fall River Mayor Edward Lambert, Carol Mahon, Patty Ricketts, Irene Wright.

Donors of services and prizes: The Arbors of Taunton; Blaire House of New Bedford & Specialized Adult Day Health; Brandon Woods of Dartmouth; Bristol Elder Services, Inc.; Center for



Twelve-year-old Elizabeth Diamandis set up shop at Coyote Impressions in Arlington and raised more than \$200 for Memory Walk. (Photo by Lisa Diamandis)

Behavioral Medicine at St. Anne's Hospital; Country Gardens Skilled Nursing & Rehabilitation Center; Elder Behavioral Services at Morton Hospital and Medical Center; Fall River Adult Day Health; The Landmark of Fall River; Marriott MapleRidge of Dartmouth; Miriam Hospital Memory Loss Clinic; Nautical Whalers Parrothead Club; Nichols House Alzheimer's Center; Now & Then Band; Oak Hill Nursing Home.

Major donors/supporters - Fall River Heritage State Park (special thanks to Mark Lagasse); USS Massachusetts Memorial Committee, Inc. - Battleship Cove; The Marine Museum at Fall River; Dunkin' Donuts; Old Country Buffet.

HAVERHILL

John Stevens, Site Coordinator

LENOX

Committee: Stephen Cozzaglio, Eileen Gleason, Cara Holcomb, Barbara Milensky, Maryellen Ford Mouglin, Dana Nichols, Janice Paquette, Dick Rilla, Fredrica Sloan, Jennifer Summers, Kelly Thorne, Maureen Tuggey.

Special thanks: Emcee Dan Valenti, host of Open Mic on WBRK-AM radio and columnist for The Berkshire Eagle.



Aptly named Team Spirit 2000 are members of one team on the Walpole Walk (L to R): Derrick Janson, Sue Janson, Matt Morin and Chris Janson, all of Attleboro; and Sharon Curtis of Norwood. The three 10-year-olds commented on what a good time they had while helping people. (Photo by Kathy Vachon)

LOWELL

Volunteers: Susan Antkowiak; Paula Campbell; JoAnne Chaulk; Carol Cleven, State Representative; George Eliades, Esq.; Paul Goyett, Lowell Auxiliary Police; Joan Johnson; Don and Donna Koski; Dr. Stephen Moses; Scott Souci; Terry Toland.



Monica Phillips Young; Richard Young.

Refreshments: Brighton Garden of Dedham Assisted Living, Caritas Norwood Hospital, Roche Brothers, Sunrise Assisted Living.

Sponsors: Cataldo Nurseries, Littleton; Chelmsford Country Club; Chelmsford Gifts; City of Lowell; Representative Carol Cleven, Chelmsford; Joan Fontaine, Chelmsford; Beth Fried of Carlsen Fried, Wellesley; Mail Boxes Etc., Westford; Mann Orchards Farm Store & Bakery, Methuen; Mt. Washington Cruises; ProActive Eldercare, Littleton; Andrew St. Onge, Special Events Coordinator, City of Lowell; State Parks, Lowell; Trinity Emergency & Healthcare Services; The Wine Cellar, Westford.

WALPOLE

Volunteers: Kathy Vachon, R.N., Site Coordinator; Debbie Dolan; Carol Falcone; Nancy Ferrari; Marge Forsberg; Paul Forsberg; Jamie Brenner Gutner; Courtnie Graybill; Chad Graybill; Jennifer Giusti; Jerry Giusti; Joanne Giusti; Julia Manning; Sue McQuaid; Tom McQuaid; Joan McHallum; Bob Vachon; Patty Webster; Ed Wiseman;



Tamara Sfeir (1) and Melissa DesJardins, (second from left), Site Coordinators from the Worcester Walk, express thanks to State Senator Harriette Chandler, Chair of the Health Care Committee. Looking on is Outreach Coordinator Michael Kincade from the Alzheimer's Assn., MA Chapter. (Photo by Tim Maher)

Members of Sigma Kappa sorority from Boston University came in full force to walk in Cambridge. (Photo by Ellen Shub)

WESTFIELD

Committee: Art Ford, Chair; Denise Beaulieu; Meredith Brown; Pat Clark; Elaine DelGreco; Jeff Graham; Cindy Hutcheson; Janet Laroche; Roxanne Mosher; Jeanne Schmidt; Al Schubach; Theresa Verdile; Audrey Walbert.

Special thanks: Nick Morganelli, Chief Meteorologist, WWLP-TV Channel 22 News.

Friends: The Boston Globe, Southwest Airlines, WWLP-TV Channel 22 News.

WORCESTER

Committee: Dr. Nancy Said, Honorary Chair; Tamara Sfeir and Melissa DesJardins, Site Coordinators; Jeanine Alton; Faith Bandama; Deborah Beiten; Sue Corbett; Pat Daly; Cathy Dionne; Peter Donaty; Tim Maher; Rosemary Murphy; Sue Nolan; Karen Pohl; Jennifer Rau; Karen Stefanock; Faith Trudel.

Special thanks: Adesso Hair Salon & Day Spa; The Alzheimer's Partnership; Aventis Pharmaceuticals; Bancroft School of Massage Therapy; Beverly Healthcare/Hermitage Home; Blaire House of Milford; Blaire House of Worcester; Bristol-Myers Squibb; Central MA Search & Rescue Team; Dr. Harriette L. Chandler; Channel 3 News; Chiropractic Assoc. of Worcester; Chuck &

Mudd; City Trends Beauty Salon; Claire's Bakery; Clark Manor/Landmark; Clearview Ice Co.; Community Health Link; Compaq; Gary Davis, Eisenberg Assisted Living; Dan Dimezza, LMI; Dunkin' Donuts; Eisai Inc.; Elder Service Plan – Fallon Healthcare; Essex Management; GlaxoWellcome Inc.; Grace Episcopal Church; GE Long Term Care Division; Guertin's Graphics; Hallsmith Sysco; Holy Trinity Eastern Orthodox Nursing and Rehabilitation Center; Jolly Jills; KTN Video; Dawn Karolides, Massage Therapist; Donna Kay Rest Home; Keystone Center; Lanessa/Landmark; Life Care Center of Auburn; Eli Lilly & Co.; Merck & Co., Inc.; Kerri Monahan; Notre Dame Long Term Care Center; Novartis Inc.; 111 Chop House; Pfizer Inc.; Polar Cap Ice Company; Polar Corporation; Price Chopper; Pro Nails; Ortho-Tec Medical; Dr. Nancy Said's office and staff; Saint Steven's Church; Sam's Club; Robert Shortsleeve; The Skowrya Family; Sole Proprietor; Stephano's Restaurant; Struck Café; SunBridge of Millbury; United Way of Worcester; Dr. Christopher Van Kleek; Elder Service Net; Webster Manor/Landmark; Webster Square Medical; West Side House; Whitney Place/Beaumont; Woods at Eddy Pond; Worcester County Church of Christ; Worcester County Sheriff's Office; Worcester Fire Department; Worcester Ice Cats; Worcester Medical Center; Worcester Medical Center Audio-Visual Department; Worcester Police Department; Worcester Regional Transit Authority; Worcester Senior Center; Worcester Telegram & Gazette; WSRO-AM radio; WTAG-AM radio.



At Stanley Park in Westfield, emcee and WWLP-TV Channel 22 meteorologist Nick Morganelli stands with his dog, Zada and three young fundraisers (L to R): Kelsy Lavoine, 8; Courtney Wallis, 12; and Jennifer Lavoine, 11. (Photo by Royster Hedgepeth)

ALZHEIMER'S EDUCATION CALENDAR

Family Orientation

A two-hour education meeting for family members. Topics include diagnosis, treatment, medications, planning, home management, and more. The program is free of charge.

Locations, dates, and times are listed below:

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.

■ **February 5, March 5, April 2. (2:00-4:00 p.m.)**

Lowell: Held at Alzheimer's Association, Lowell Area Office, 133 Market St., Lowell. Presented by Harriet Udoff. Pre-registration is not necessary and the program is free of charge.

■ **February 14, March 14, April 11. (10 a.m.-12:00 p.m.)**

Longmeadow: Held at Jewish Geriatric Services, 770 Converse St., Longmeadow. / Pre-registration is recommended. Free of charge. Phone 413.527.0111.

■ **February 14, March 14, April 11. (4:00-6:00 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.

■ **February 14, March 14, April 11. (6:45-8:45 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.

■ **February 15, March 15, April 19. (1:30-3:30 p.m.)**

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.

■ **February 15, March 15, April 19. (10:00 a.m.-12:00 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.

■ **February 27, March 27, April 24. (1:30-3:30 p.m.)**

Taking Control of Alzheimer's Disease: Home-Based Care Techniques for Families

Alzheimer's Association, Cambridge Office, 36 Cameron Ave., Cambridge. This free six-part seminar will teach families a new therapeutic approach to caregiving. Family caregivers will learn how to work with the person with Alzheimer's disease in order to take more control over the often-difficult symptoms of the disease. This course will continue through April, with dates listed below. Families must plan to attend all six sessions. Presented by Dr. Paul Raia. / Pre-registration is required. There is no charge for the course. Call Donna Smart-Gorham at 617.868.6718.

■ **March 13, 20, 27 and April 3, 10, 17 (6:00-8:00 p.m.)**



Alzheimer's Research: Expanding Knowledge, Enhancing Caregiving

Sheraton Hotel, Springfield. The 10th Annual Western Massachusetts Professional Caregivers Conference with keynote address by Dr. Rudolph Tanzi. Conference also offers a networking lunch, and a vendor and book fair. ○ / Pre-registration is required. For more information, contact Jeannie Banas at 413.527.0111 or see the conference announcement on the Chapter's web site at www.alzmass.org.

■ **Wednesday, March 14 (8:30 a.m.-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



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 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 charge 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.

■ February 6, March 6, April 3

Basic Training for New Support Group Leaders

Training sessions for 52 new and prospective support group leaders for the Massachusetts Chapter took place during October and November. **Pre-registration is required.** The sessions were free of charge. Training for prospective family support group leaders was held at Lahey Medical Center in Burlington; Pilgrim Manor in Plymouth; Worcester Senior Center, Worcester; and at The Atrium in Agawam. At our Cambridge Office, a special three-hour training session was held for prospective leaders of *patient support groups*.

Watch for more information on our spring training dates! Facilities interested in hosting an upcoming training session are encouraged to contact Harriet Udoff at 978.937.5576 or e-mail at

harriet.udoff@alz.org.

■ Dates and times to be announced.

Community Care Training

A professional education program designed to teach participants to become trainers within their community agencies or facilities. One or two representatives come 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 charge is \$500 for two representatives from an agency.**

Cambridge Office: Alzheimer's Association, 36 Cameron Ave., Cambridge. Call Donna Smart-Gorham at 617.868.6718.

■ February 14, March 14, April 11

Lowell Office: Alzheimer's Association, 133 Market St., Lowell. Call Harriet Udoff at 978.937.5576.

■ Spring 2001, dates to be announced.

Conference for Professionals

MARK YOUR CALENDAR!!! Our annual conference for professionals, *A Map Through the Maze*, will be held at the Royal Plaza Hotel in Marlborough, MA. **Pre-registration is required.** The conference will feature a full day of speakers and workshops, as well as an exhibitor's fair and poster session. Brochures will be available by early March. For exhibitor or poster information call 617.868.6718, or refer to our web site at www.alzmass.org.

■ Wednesday, May 9

BRAND NEW!!!

Living with Early-Stage Alzheimer's Disease

A new education series for people with early-stage Alzheimer's disease and their family members. **Pre-registration is required.**

■ For more information, call Harriet Udoff at 978.937.5576.



36 Cameron Avenue
Cambridge, MA 02140

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Advocacy

An overwhelming majority of survey responses identified nursing home quality of care issues as the number one advocacy priority.

Visit our website at www.alzmass.org to place your vote on advocacy issues!



Advocacy Priorities Survey Targets Nursing Home Quality of Care Issues

By Deborah Thomson, JD

During the months of October and November, the Alzheimer's Advocacy Committee circulated a survey requesting input on advocacy priorities for the coming year. We received many responses from family members and health care professionals. The results are in, and unlike the situation in the Florida election there is a clear winner!

An overwhelming majority of survey responses identified **nursing home quality of care issues** as the number one advocacy priority. In recent years we have seen a disturbing decline in the quality of care provided to nursing home residents. The Massachusetts and Cape Cod & Islands Chapters have devoted a significant portion of their recent advocacy efforts to addressing these concerns. Our efforts culminated in the passage of a Nursing Home Quality Initiative in the Fiscal Year 2001 Budget, which focused on staffing shortages as the primary obstacle to quality care. The Quality Initiative included a wage pass-through for certified nurse aides who are the front line caregivers in nursing homes. It also implemented a number of measures designed to improve job quality for nurse aides.

In the coming legislative session we will support legislation increasing nursing home staffing levels, as well as legislation establishing a Nursing Home Quality Advisory Council and a bill authorizing a study of the health insurance needs of direct care workers. We will continue to work with the CORE Coalition and the Direct Care Workers' Initiative in support of these measures.

The second-ranking issue in our survey results was that of **adult day health**. Adult day programs are a critical component of the community-based care system for dementia patients. Over the past two years, the Chapters have successfully worked to increase payments for dementia-specific day care services. In the coming legislative session we will support legisla-



Dr. Lillian Glickman, Secretary of the State's Office of Elder Affairs, accepts the Chapter's 2000 Advocacy Award from outgoing Board Chair Dr. Nina Silverstein at the Annual Meeting (see story, page 4).

tion to implement the recommendations of the Adult Day Study Commission. The Commission has endorsed a three-tiered system of adult day services with appropriate regulatory standards for each level and a state oversight function for all adult day programs.

Following these two issues in close order of priority were **federal Medicare issues, community care expansion, guardianship and competency issues, prescription drug coverage, the Alzheimer's Advisory Council and Vision 20/20**. All these issues are important to Alzheimer patients and their families, and we will undertake appropriate advocacy on all of them over the coming year.

A closing piece of good news is that on November 13th President Clinton signed the reauthorization of the Older Americans Act. This act contains \$125 million to fund a national respite program for caregivers and was a priority of our national legislative agenda. Hopefully, this small program will serve as the seed for a growing model of caregiver support. □

Deborah Thomson is the Massachusetts Chapter's Director of Public Policy.

Multicultural Outreach Program Reaches Seniors

By Michael Kincade, Sr.

We're on our way! One important priority for our Massachusetts Chapter's multicultural outreach program includes working closely with organizations throughout metropolitan Boston either currently serving or targeting predominantly African-Americans, with the goal of bringing the Association's services more effectively to this community. The agencies provide services such as senior day care, transportation, and meals as well as on-site and home health care. In collaborating with these agencies, we are able to build on established relationships as well as forge new bonds.

In addition, Dr. Pamela Sheridan has agreed to participate in the first of a series of community forums in Roxbury. She will discuss dementia and its impact upon the Black communi-

ty. Other forums being planned to expand outreach efforts will focus on legal issues, financial concerns, and home care for people with dementia. As a peer education specialist, my goal is to include as many experts of color as possible for each panel. The success of the daytime support group has also led to early steps in beginning an evening support group within the Roxbury/Dorchester community.

Finally, our participation on the Multicultural Coalition on Aging has led to an opportunity for the Association to take part in a newly formed Community Advisory Committee targeting Black seniors. The committee will conduct a needs assessment to address barriers Black seniors encounter in receiving services, as well as identify outreach and educational strategies. □

Michael Kincade, Sr. is the Massachusetts Chapter's Outreach Manager.

Exhibit, Reception Planned for Art Treasures

By Heidi Ganss

Rose de Smith Greenman, who suffered from Alzheimer's disease, died in 1983 at age 84. Sixteen years later, in December, 1999, Betty Avruch, Rose's only daughter, re-discovered three large cartons of artwork that her mother had produced. The first public showing of a small fraction of this prolific, self-taught artist's evocative work will take place at the Berenberg Gallery, 4 Clarendon St., Boston from February 28 through April 14, 2001.

Her collective works — close to 2000 drawings, from small sketches to large landscapes — were created during a seven-year period, 1970 to 1977. The actual time frame was easily determined, since Rose carefully signed and dated each piece. One can visually chart her slow deterioration dating from 1970 forward as her style became freer and more abstract in the later years. Ironically, as Rose's memory and other capabilities diminished, her output of art increased.

Her sketches are filled with beauty, passion and humor, and her love for life. The drawings appear on the backs of posters, old calendar pages, and envelopes; whatever was available to her the moment inspiration struck. Rose used pencils, pens and colored markers to create her "doodles" — scenes of home and family, gardens and flowers, sometimes 10 or more in one day. Her innate sense of color and design, reflected in her artwork, must have helped carry Rose through endless days and nights.

A very special private Alzheimer's Association reception honoring Rose's life and artwork, hosted by Betty and Frank Avruch, will be held Thursday, March 15 at 6:30 p.m. For more information, please call the Development Office at (617) 868.6718, ext. 207. A Rose deSmith Greenman sampling can also be seen on the web at www.bostonman.com. ☐

Heidi Ganss is the Massachusetts Chapter's Director of Development.

Development



View full-color artwork at www.bostonman.com/rose/rosethumb1new.htm

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Book Review: A Researcher's Diary

By Paul Raia, Ph.D.

Decoding Darkness: The Search for the Genetic Causes of Alzheimer's Disease by Rudolph E. Tanzi and Ann B. Parson. Perseus Publishing, Cambridge, Massachusetts (2000): 247 pages.

I felt sad when I finished this book. Sad for families such as the Noonans, who anxiously await a cure. Sad that world governments do not adequately support and coordinate research on the cure and treatment of Alzheimer's disease. But I was also sad because this was one of the most enjoyable books that I have read on this, or any other subject and I wanted more. Tanzi and Parson weave a story with delicate strands of history, colliding egos, ethics, science, politics, and mystery with the right mix of journalistic matter-of-factness, human interest, and poetic prose.

This book flows in a manner reminiscent of an Agatha Christie mystery, yet it also gently educates the non-scientifically minded. Chapter 2, "The Core of the Matter" is the best explanation of genetics and the history of the race for a cure that I have read. Chapter 7, "Mutations, Revelations" discusses the decision for some of the scientific community to focus on mutated genes characteristic of the rare familial form of Alzheimer's disease as a way of understanding the underlying mechanisms of the more common form of the disease.

High stakes. At the time, this was a controversial decision that since has revealed much of our present understanding of the disease. Tanzi and others risked their careers on the possible heuristic impact of that choice and as they thought, it paid off big-time. We now know the enzymes that are involved in cutting amyloid into the dangerous form and because of this there may be a drug or drugs that could be developed to halt the process—good news, good choice.

There is a remarkably honest theme, conflicted emotions, running through this book. Tanzi and others involved in "the chromosome 14 race" clearly want the fame associated with being first to find a cure while also hoping that a colleague will

develop something sooner to alleviate the suffering. Listen to Tanzi's angst in these lines:

On the one hand, I was very let down; we'd missed the gene by the narrowest margin. On the other hand, there was a sense of relief. The long search was finally over, another crucial piece of the puzzle was locked into place and we could get on to something new, something all the closer to a full picture of what caused Alzheimer's.

Researchers don't get the immediate gratification a physician receives by helping people every day. What we do get, in the long haul, is the gratification of knowing that through our own very occasional breakthroughs, and through the field's collective bent, we can positively affect humanity forever, and that's a large, very large privilege.

I should point out that I was honored to have been quoted in this book, so mine is not an entirely unbiased opinion. However, let me offer support to my view by quoting William Beatty's review from *Booklist*:

Tanzi and Parson tell a lively, scientifically solid detective story about the discovery of the . . . search for genetic elements in the causation of Alzheimer's . . . The science is rigorous, but the authors brighten the book with their perceptive perspective on the political and horse-race elements in scientific pursuits, which nonscientists seldom consider when they read about the progress of science.

Decoding Darkness is like having an all-access locker room pass at the Genetics Olympics. Through its pages the reader is afforded a rare, up-close and personal view of the Olympians with their towels down and their humanity showing. I enthusiastically urge that this book be read twice; once because it's such fun, and once because the information is so vitally important. ☐

Dr. Paul Raia is the Massachusetts Chapter's Director of Patient Care and Family Support.

Medicine & Science



Decoding Darkness is like having an all-access locker room pass at the Genetics Olympics.

Medicine and Science



Roberta Rosenberg, MEd.

Roberta Rosenberg Receives Cooper Award

The Massachusetts Chapter is pleased to announce that the Chair of our Medical and Scientific Advisory Committee, Roberta Rosenberg of the Research Institute at the Hebrew Rehabilitation Center for Aged in Boston, was the co-recipient, with Joanne Prince, of the 2nd Annual Ed Cooper Award for community service. Ms. Rosenberg, of Newton, received the prestigious Cooper Award from the Boston Commission on Affairs of the Elderly for her work in founding and co-chairing the Multi-cultural Coalition on Aging in Boston. The award ceremony at Boston City Hall October 5 was attended by Boston Mayor Thomas Menino and Elder Affairs Commissioner Joyce Williams.

Gathering Draws Top Area Researchers, Clinicians Dr. Jeffrey Cummings Honored by Massachusetts Chapter

by Gerald Flaherty

On the 10th Anniversary of our annual Simons Research Symposium, we were delighted to feature Dr. Jeffrey Cummings of the UCLA Alzheimer's Disease Center. Dr. Cummings trained at Boston University, and his seminal work has been followed closely by his many friends and colleagues here, including Chapter Board Chair Dr. Sanford Auerbach.

In appreciation of Dr. Cummings' return to Boston to deliver the year 2000 Simons Research Symposium lecture, our Massachusetts Chapter hosted a dinner in his honor November 13, the evening before his lecture. Two dozen Boston-area researchers and clinicians, along with representatives from the Chapter's staff, met with Dr. Cummings at Henrietta's Table at the Charles Hotel in Cambridge. The function provided a forum for informal discussion about a range of exciting developments in the accelerated hunt for a cause and cure for Alzheimer's disease.

As many of our readers who have attended previous Simons Lectures know, the Chapter's Medical and Scientific Advisory Committee each year selects the Simons Symposium Lecturer. While we've had a long list of eminent lecturers in this series—such as Dr. Marilyn Albert of MGH and Harvard Medical School in 1999—Dr.



Dr. Jeffrey Cummings of UCLA, the year 2000 Simons Research Symposium Lecturer.

Dr. Cummings' November 14 lecture was the first to directly address the neurological basis of specific behavioral disturbances associated with the disease. (The highlights of Dr. Cummings' lecture will be featured in our next Newsletter.)

Clearer pathways. The informal gathering provided our Chapter a superb opportunity to hear directly from Dr. Cummings and others doing "bench science" on Alzheimer's disease, who also work closely with patients and families. We were most interested in learning from the scientists how we can best support their efforts to educate the public about research advances, and how they can best support our efforts to advocate on behalf of the Alzheimer community.

Because we've learned more about this disease during the past few years than in the last century, events such as the pre-Simon's dinner gathering are especially helpful in guiding our Chapter's efforts to educate family and professional caregivers. This educational mission encompasses topics such as scientific



Drs. Sally McNagny, Robert Green and Lewis Lipsitz compare notes at the reception.

advances and the workings of the brain, but also addresses the pressing need to provide help in preparing families for the kinds of decisions—about therapies, medical treatments, and testing—that we all need to understand to make informed medical decisions.

Despite the consensus that the accelerated pace of scientific advancement is truly breathtaking, the group sounded several notes of caution. As Dr. Cummings said in general remarks to his colleagues, any potential cure will take some years to properly evaluate. With the Chapter's Medical/Scientific Advisory Committee Chair Roberta Rosenberg leading the discussion, other scientists commented on our collaborative need to:

- Reach overworked primary care physicians, so that they make referrals necessary for a proper diagnosis and follow-up care in the community;
- Reach under-served and minority populations;
- Address the increasing level of misinformation reaching the public— a common phenomenon in this age of instant information — which promotes the growth of "pseudo-science" over substantive scientific research such as that funded by the National Institutes of Health, the national Alzheimer's Association, and other groups;
- Clear up some of the confusion about the usefulness of dietary supplements;
- Address, as a serious policy issue, the real danger of a shrinking caregiver pool resulting from the aging of the baby-boomer generation—the largest in our nation's history, which numerically will not be replaced;
- Finally, to "calm the angst" among elders about memory loss associated with normal aging.



Dr. Alvaro Pascual-Leone of Boston University. Photo by Jaime Ferguson

Spanish-Speaking Caregivers Conference Breaks New Ground

By Roberta Rosenberg, M.Ed.

Sixty Spanish-speaking caregivers of family members with Alzheimer's disease gathered at Curtis Hall in Jamaica Plain October 11 to learn more about this devastating illness, and to share their experiences as caregivers. *Pasajes a lo incierto* was the first conference planned with the needs of this unique group in mind.

Massachusetts Chapter Hispanic Outreach Coordinator Conchita Rodriguez designed the program to be conducted entirely in Spanish, located in a neighborhood where many of these families live, and low-cost enough to be affordable. News about the conference was spread through area agencies serving Latino elders, Spanish radio, Spanish newspapers, and Conchita's personal contact with families.

Featured speakers included Dr. Alvaro Pascual-Leone, Associate Professor at Boston University and Associate Director of the Center for Clinical Investigation at Beth

Israel Deaconess Medical Center and Harvard Medical School; and Dr. Antonia Coppin, a specialist in geriatrics and gerontology who studied at the School of Science and Health at Francisco Miranda University in Venezuela. These two bilingual, bicultural doctors spoke to attendees about the difference between normal changes in memory as we age, and home safety when caring for someone with Alzheimer's disease. Following the presentations, a panel of caregivers moderated by Elena Ortiz-Villon talked about their experiences and encouraged audience questions.

Model for outreach. The conference served as a successful model for groups that often miss out on the benefits of new health care practices, research findings, and programs when these are publicized only in English. Audiotapes of the two speakers' presentations will be available for families caring for Alzheimer's patients at home. Once prepared, these tapes can be obtained by contacting Conchita at 617.868.6718.

The conference was funded by the Alzheimer's Association, Massachusetts Chapter and a grant from the National Institutes of Health to the Massachusetts General Hospital Alzheimer's Disease Research Center. Both organizations are committed to helping families care for their loved ones at home with plenty of support, information, and resources, and assisting these families to get the medical care they need. ◻

Roberta Rosenberg, M.Ed. is Chair of the Massachusetts Chapter's Medical/Scientific Advisory Committee.



Jaime Bernal, Sarah Fallas, Conchita Rodriguez, Carlos Rodriguez, Vilma Rodriguez-Andrade and Jaime Ferguson made the conference a success. Photo by Rachel Hawk

Working in harmony. It was also rewarding for Chapter representatives to hear scientist after scientist express appreciation for all of the Association's chapters and our collaborative work on behalf of our Alzheimer families. As a result of the dinner gathering, we gained a clear agenda for our future working relationship with the local research community. We will follow it in our goal to provide the very best advice, and the most comprehensive support possible, to the thousands of families in our Chapter who most need it.

The Massachusetts Chapter is grateful to its Board and staff members who helped organize the dinner meeting so successfully. We offer special thanks to the Boston University Alzheimer's Disease Center; Pfizer, Inc.; and Novartis for their support in this event, which we hope to replicate on some regular basis. Among those able to attend were Drs. Marilyn Albert, Sanford Auerbach, Deborah Blacker, Jeffrey Cummings, Kirk Daffner, Donald Davidoff, Stephen Fink, Robert Green, Sally McNagny, John Growdon, John Hennen, Neil Kowall, Helen Kyomen, Lewis Lipsitz, Nancy Emerson Lombardo, Alan Mandell, Margaret O'Connor, Paul Raia, Roberta Rosenberg, Nina Silverstein, Reisa Sperling, Rudy Tanzi, Inese Verzemnieks, and Ladislav Volicer. ◻

Gerald Flaherty is the Massachusetts Chapter's Director of Special Projects.

Education



Guest Speaker Dr. Antonia Coppin is interviewed by radio producer Benito Martinez. Photo by Jaime Ferguson.

Despite the consensus that the accelerated pace of scientific advancement is truly breathtaking, the group sounded several notes of caution.

Development

Alzheimer's Family Member, Triathlete Strides Toward Fundraising Goals

Joe Klejna of West Springfield has a strenuous year ahead! He plans to compete in the 111-mile Sea to Summit Triathlon in New Hampshire in July, 2001 and to circumnavigate Cape Cod in a sea kayak in October. Joe will be the first person to make the three-day, 150-plus-mile water journey by kayak. He needs sponsors, both corporate and individual, to help him raise critical funds for the Alzheimer's Association in honor of his mother, Beverly Klejna. For more information and/or to sponsor Joe, please contact him at 413.734.2204 or e-mail Joe at jaka3@mediaone.net



First-graders at Solomon Schechter Day School in Stoughton raised money for Association programs and services. School file photo

Children Turn Lesson Into Action

First-graders at the South Area Solomon Schechter Day School, an independent Jewish day school in Stoughton, MA, don't just learn about doing good deeds. They put what they learn into action.

During the past school year, as part of a tzedakah (Hebrew for "charity") project, the children saved nickels from bottle and can deposits. At year's-end, when their teachers asked for suggestions about how to use the money to help others, one student suggested they donate it to try to find a cure for what was affecting an adjacent classroom teacher's parent — Alzheimer's disease. His classmates agreed and a contribution was sent to the Alzheimer's Association, Massachusetts Chapter.



Henry Staines after completing the Marine Corps Marathon in Washington, DC. Photo by Tracy Staines

Staines Triumphs in Marathon

Congratulations to Henry Staines of West Roxbury, who raised nearly \$2600 for the Alzheimer's Association, Massachusetts Chapter while running in the Marine Corps Marathon October 22 in Washington, D.C. On a very warm, humid day, Henry, a Boston Police Officer, persevered in loving memory of his grandmother, Mary G. Staines and his wife Tracy's grandmother, Herma Stancill, both of whom died from Alzheimer's disease. Special thanks to the Boston Police Patrolmen's Association for their generosity.

We also express appreciation to new Board member, Barbara Milensky, who made a donation in response to our web site promotion.

Special Events, Special People

Many thanks to the amazing Noonan Family! Their 4th Annual Memory Ride, held August 26 and 27, raised over \$74,000 for Alzheimer's research. For information about the 2001 Memory Ride, please visit www.memoryride.org or call 508.564.5700.

Thanks to David Jasinski and Sharon Jensen from Nichols House, Carolann Mahon from Oak Hill, and Tadd Clelland from Marriott MapleRidge of Dartmouth who organized the 2nd Annual Bristol County Alzheimer's 5K Road Race. On September 17 at Fort Phoenix in Fairhaven, 175 runners helped raise \$1,000 for Chapter programs and services.

Thanks to Julie Hannon and the Wayland Women's Inner

Club for their 1st Annual Charity Golf Tournament, held September 9. Eleven teams participated and helped to raise over \$1,200 in honor of Ruthie Cedrone.

Thanks to Landmark Health Solutions for their 2nd Annual Charity Golf Tournament, held September 13 at Townsend Ridge Country Club, Townsend. Over 140 participants helped raise \$3,000 for Association programs and services.

Thanks to Dorothy Ahle and the Parody Players for "Is That Your Final Answer?" a musical parody revue written by Dorothy. A performance was held October 27 at the Unitarian Universalist Church of Reading and more than \$1,100 was raised for Association programs and services.

Thanks to Joe Hope of Auburndale for organizing the 11th Annual Great Allston Pub Crawl August 9. More than 150 people and 15 taverns participated in the event, which raised over \$1,600 for the Alzheimer's Association.

Help Your Gift Make An Even Bigger Impact!

Analog Devices, Fleet, Cisco Systems, Coca-Cola, Eastern Mountain Sports, IBM, Deloitte & Touche, Delta Air Lines, Fidelity Investments, Stride Rite Corporation, 3Com, United Parcel Service, Merrill Lynch & Company and John Hancock . . . What do these companies have in common? They all offer a matching gift program for their employees. Thousands of corporations will double or, in some cases, triple the size of employees' charitable gifts. Check with your human resources department and make an even greater difference to Alzheimer's patients and their families.

New Massachusetts Chapter Giving Society Established

The Alzheimer's Association, Massachusetts Chapter is pleased to announce the formation of our new Leadership Circle, comprised of annual donors of \$1,000 or more. As a reminder, all Friends (individual/family members/donors of \$30 - \$49) receive our quarterly newsletter, discounts on publications and notification of events. Sponsors (members/donors of \$50 to \$99) receive the above and discounts on publications and family conferences. All donors of \$100 or more receive the above and are acknowledged in our Annual Report. Leadership Circle members (members/donors of \$1,000 or more) receive all the above, plus invitations to exclusive events and special acknowledgment in our Annual Report.

If you would like more information on how to make a gift to support Chapter programs and services, please call the Development Office at 617.868.6718.

"I REMEMBER..."

The Maine Chapter of the Alzheimer's Association has produced a 416-page cookbook of 385 recipes and assorted memories. All recipes are tested and carefully edited, and range from quick-and-easy comfort food to elegant dinner party fare. Recipes are derived from 252 individual contributors in 88 Maine towns and 18 states.

The cost is \$20 (includes tax), plus shipping. Please call the Alzheimer's Association, Maine Chapter at 1.800.660.2871 to order your copy.

Watch for these Upcoming Events:

Art Reception: THURSDAY, MARCH 15

Reception and showing of Rose deSmith Greenman's work at the Berenberg Gallery, 4 Clarendon Street, Boston, MA. Hosted by Betty and Frank Avruch. See page 13 for more details, or for more information call 617.868.6718 ext. 207.

Springfield Symphony Concert SATURDAY, APRIL 28

Springfield Symphony Concert, Symphony Hall at 8:00. Western Regional Office Open House and Dessert Reception, 1600 East Columbus Ave., Springfield, 5:00-8:00 p.m. For more information call 413.527.0111.

Night at the Pops: MAY 2001

Second Annual Night at the Pops, chaired by Stanley Solomont. For more information, including corporate sponsorship opportunities, please call 617.868.6718.

Al Dente Road Race SATURDAY, MAY 5

The 5th Annual 4-mile Al Dente Road Race – come join the fun, food, prizes at the Medford VFW Post 1012. For more information, call Ed Nolan at 781.396.6058 or e-mail him at denterace@aol.com.

Make the Link Golf Tournament MONDAY, JULY 16

Fourth Annual Make the Link Golf Tournament at the scenic Andover Country Club. This 75-year-old, Donald Ross-designed course is an outstanding venue for a wonderful cause. Corporate sponsorship opportunities are available. For more information, contact Dick Fleiss in the Development Office at 617.868.6718. b

New Publications List

An abundant harvest of Alzheimer-related educational materials—books, brochures, and fact sheets—is now available through our offices. Among other new items, the 2001 edition of our Publications List includes three new books: *Decoding Darkness: The Search for the Genetic Causes of Alzheimer's Disease* by Rudolph E. Tanzi, M.D. and Ann B. Parson; *Management of Challenging Behaviors in Dementia* by Ellen K. Mahoney, D.N.Sc., Ladislav Volicer, M.D. and Ann C. Hurley, D.N.Sc.; and *Hard to Forget, An Alzheimer's Story* by Charles P. Pierce.

We also offer several new brochures, including a new *Guide for Clergy, Are You a Healthy Caregiver?* (a self-help health promotion card); and our *Nursing Home Consumer Guide*. Some materials are free of charge and most others offer a discount to Massachusetts Chapter members. We try to provide a balance of materials for family members, people with dementing illnesses, and for professionals. Our list is revised each year.

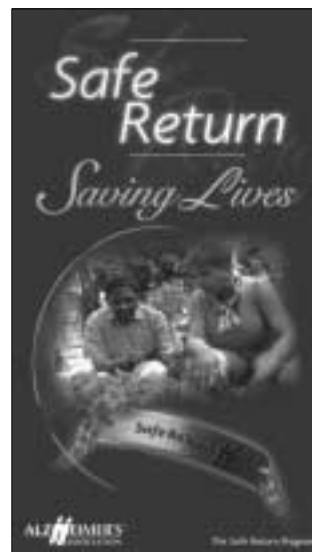
For a copy of the Publications List, which includes the order form and membership information, call 617.868.6718. From outside the 617 area code, phone (800) 548.2111. The list is also available on-line at www.alzmass.org.



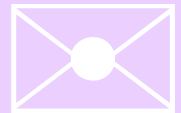
Safe Return Program Releases New Caregiver Video

The national Alzheimer's Association has released a new video designed specifically for family and professional caregivers, *Safe Return—Saving Lives*. The 12-minute video, developed with the assistance of our Massachusetts Chapter, has three goals: to educate people with dementia and their family and professional caregivers on wandering behavior; to demonstrate how the national Safe Return Program works; and to register potential wanderers.

Safe Return—Saving Lives, which made its debut in October at Old Colony Elder Services in Brockton, complements the award winning Safe Return police training video developed by our Massachusetts Chapter in 1996. It has been very well received in the Chapter's current in-service training series for case managers in the state's network of home care agencies. For more information about Safe Return or about any of our many videos, please call (800) 548-2111.



Save the Dates!



The Alzheimer's Association needs *your* support!

We rely on private contributions to provide the 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. In an effort to be fiscally and environmentally responsible, we are using "Eastern Massachusetts" envelopes for the entire state, including Western Massachusetts, because we had a large number of them in stock, printed before last year's merger. However, contributions raised will be used for programs and services throughout the **entire** Massachusetts Chapter area, including Western Massachusetts. b

Western MA News

Western Regional Office Moves to Springfield in January

After 14 years in Hampshire County, the Chapter's Western Regional Office is relocating to downtown Springfield. The office is subletting space from Springfield's Department of Elder Affairs in the City Hall Annex, former home of the Department of Public Works and Springfield District Court. In addition to the Chapter office, the building will house the Springfield Council on Aging, Golden Age Club, the Senior Aide Program and the Department of Elder Affairs office.

"This is an excellent opportunity for the Association to increase its collaboration with other agencies that assist seniors living in Springfield," said Kathryn Hedgepeth, Director of the Western Regional Office. She noted that a 1998 University of Massachusetts study on the prevalence of Alzheimer's disease estimated that more than 10,000 people living in Hampden County are affected. Increased space available in the new office permits expansion of the Caregiver Library and on-site support groups and caregiver training programs.

To celebrate its move, the office is planning an Open House and Dessert Reception on Saturday, April 28, 2001. The festivities will conclude with a concert by the Springfield Symphony

Orchestra. The Symphony Hall program features Myron Romanul, a finalist in the Orchestra's search for a permanent conductor; and guest violinist Livia Sohn. Please call 413.527.0111 for ticket information and an Open House invitation.

March Professionals Conference Features Research

Professional caregivers, take note! The 10th Annual Western MA Professional Caregivers Conference has been rescheduled. "Alzheimer's Research: Expanding Knowledge, Enhancing Caregiving" will be held at the Sheraton Hotel at Monarch Place, Springfield, MA on March 14, 2001. Continuing education credits will be offered.

Dr. Rudolph Tanzi, world-renowned neurogeneticist, will deliver the keynote address and discuss his recently published book, *Decoding Darkness: The Search for the Genetic Causes of Alzheimer's Disease* (see book review by Dr. Paul Raia, page 13). In addition, Dr. Sanford Auerbach will discuss research into the correlation between Alzheimer's disease and mental

retardation; and Dr. Alice Cronin-Golomb will share her studies on "Vision and Cognition in Alzheimer's Disease and Related Disorders." Dr. Jay M. Ellis and Dr. Benjamin Liptzen will co-present an update on Alzheimer's drug therapies.

Conference sessions will be presented as a series of plenary meetings. A vendor and book fair and a networking lunch will round out the day's events.

Registration materials will be available in early January 2001. For further information or a conference brochure, call Jeannie Banas at 413.527.0111 or refer to the announcement on the Chapter's web site at www.alzmass.org.

SAVE THE DATES!

March 14. (8:30 a.m.-3:00 p.m.) "Alzheimer's Research: Expanding Knowledge, Enhancing Caregiving." Professional Caregivers Conference, Sheraton Hotel, Springfield.

April 28. (5:00-8:00 p.m.) Western Regional Office Open House and Dessert Reception, 1600 E. Columbus Ave., Springfield. Followed by Springfield Symphony Concert, Symphony Hall, 8:00 p.m.

Support Group Leaders Convene

By Bonnie Haley, LSW

Whitney Place in Westborough was the setting for the 6th Annual Forum for Support Group Leaders Friday, October 6, 2000. The Forum offered the opportunity for more than 65 facilitators from all points across Massachusetts to renew their sense of commitment and enthusiasm. The group gathered to listen to Dr. Paul Raia's keynote address, "Unmasking the Feelings Behind the Issues."

Dr. Raia, the Chapter's Director of Patient Care and Family Support, offered valuable advice on how group facilitators can help family members get past the superficial issues and deal with the feelings beneath them. Most support groups, he noted, don't ask the really important questions, such as "What are you afraid of?"

Dr. Raia encouraged participants to help people identify what principles or values they're committed to and which commitments they're actually holding onto out of cultural compliance or fear. Once people recognize the

source of their private fears, he explained, they are ready to consider what might happen if they changed their own behaviors and approaches to care. Focus groups to discuss these intriguing issues followed the presentation.

The Support Group Leaders Forum was generously underwritten by The Tapestry Program at Whitney Place Assisted Living Communities in Westborough and Natick. □

Bonnie Haley, LSW is Special Care Manager, Brighton Gardens of Dedham.



Keynote address by the Association's Dr. Paul Raia.



Bonnie Haley and Paulette Masse facilitate a small group discussion. Photos by Sam Laundon, Natural Light Studios

Support Group listing continued from back cover

Hingham: Jo Ann Mitchell	781/749-5417	Susan Kleczka	508/248-7344
Eleanor Blair	781/749-4774		
Michelle Hollands	781/749-1310	South Lancaster: Harriet Klayman	978/368-6414
Holden: Naomi Sohlman	508/829-0270	Springfield: Ellen Nepomuceno	413/781-5070
Holliston: Lynette Dunn-Nastasi	508/429-3568	Stoughton: Sandy Putney	781/821-4990
Hopedale: Charlene Machnik	508/473-2992	John Scott	781/344-7300
Hopkinton: Pat McKinney	508/435-0222	Christine Bonfiglio	781/297-8211
Kingston: Gerry Menard or Susan Gates	781/585-4100	Carol McLaughlin	781/230-2100
Lee: Jennifer Pilcher	413/243-4747	Taunton: Barbara Richards	508/823-4493
Leicester: Eva Dawson	508/987-8056	Tewksbury: Elaine St. Cyr	978/657-0800
Longmeadow: Jay Brumberg	413/567-6212	Turners Falls: Molly Chambers	413/773-5555
Lowell: Daphne Dumont	978/458-8773	Wakefield: Lynn Zaloga	781/224-2800
Ludlow: Barbara Messler	413/589-7581	Ware: Stasia Wozniak	413/967-2245
Lynn: Harriet Udoff	978/937-5576	Wareham: Carolyn Cardoza	508/758-2173 or 508/991-5015
Lisa Mercurio	781/596-2992	Watertown: Ruth Gordon	617/491-1823
Malden: Jolyn Ek	781/324-4999	Wayland: Candace Steingisser	508/358-3000
Marlboro: Sean Caulfield	508/481-9898	Webster: Carolyn Racicot	508/949-3598
Joyce Henderson	508/485-4040	Wellesley: Amy Beck	781/237-6400
Medford: Douglas Lloyd	781/324-5759	Cathy Buckley	781/431-5337
Mendon: Marlene Fregeau or Caroline Prout	508/473-0862	Peggy Mullen	508/533-7020
Merrimac: Patricia Lavoie	978/803-3296	Westboro: Julie Palmieri	508/836-4354 x706
Methuen: Donna Koski	978/682-3582	Westfield: Ellen Nepomuceno	413/781-5070
Middleboro: Robella Coates	508/946-2490	Weston: Shirley Earle	781/893-0154
Milford: Marlene Fregeau	508/473-0862	Westwood: Peter Byron	781/326-5652
Millbury: Pat Clark	508/793-0088	Weymouth: Kerry O'Malley	781/337-3121
Nahant: Rev. David Dodge	781/581-1201	Marsha Frankel	781/340-9100
Natick: Jan Chiampa	508/655-1000 x21	Williamstown: Fredrica Sloan	413/458-8127
Judy Sabol	508/650-9003	Winchester: Valerie Gramolini	978/897-7455
or Susan Scheib	508/653-3081	Woburn: Jennifer Jaroch	781/932-0350
Lois Pecora	508/655-5000 x3988	Worcester: Dianne Protano	508/756-7176
New Bedford: Judith Wilde	508/997-9396	Mary Poulin	508/852-0600
Jenny Nelia	508/998-7807	Faith Bandama	508/791-5543
Newburyport:		Ann Fitman	508/753-4791
Patricia Lavoie	978/803-3296 or 465-5361 x25	Worthington/Cumington:	
Newton: Kathleen Connolly	617/630-2743	Lucille Temple or Sandra Epperly	413/238-5584
Emily Saffer	617/558-6443	Specialized Groups	
North Adams: Beth Hinkley	413/664-4536	<i>Caregivers of Mentally Retarded Adults with AD</i>	
North Easton: Marsha Shalek	508/238-7053	Kevin Leahy	781/324-4303
Norwood: Diane Simoni	781/769-4495	<i>People with Early Stage Alzheimer's and Their Caregivers</i>	
Palmer: Carol Coiz	413/283-8361	Cambridge: Elaine Silverio	508/429-1577
Peabody: Linda Smith	978/531-2254 x137	Danvers: Carol Owen or D'arcy Adams	978/774-4400 x3064
Pittsfield: Beth Cerow	413/445-2300	Natick: Joanne Koenig-Coste	508/879-5338
Robert Hamilton	413/499-0524	or Lois Pecora	508/655-5000
Beth Hinkley	413/499-1992	Weymouth: Julie Barcelo	781/340-9100
Ann Maynard	413/442-4978	<i>People with AD and Their Caregivers</i>	
Plymouth: Tina Tasker	508/746-7016	Wellesley: Peggy Mullen	508/533-7020
Quincy: Kathy Prince	617/471-5712	<i>Families of VA Patients with AD</i>	
Reading: Anne Marie Bourque	781/944-1132	Bedford: Jennifer Hill	781/687-2701
or Marie Ammer	781/942-9059	<i>Spanish-language Group/En Español</i>	
Rockland: Laureen Walsh	978/878-0099	Boston: Conchita Rodriguez	617/868-8599
Scituate: Marla Kaplan	781/681-1065	Springfield: Lydia Serrano	413/781-8800
Somerville: Sara Demetry	617/868-6323	<i>Spouses' Group</i>	
Somerset: Bernadette Mackin		Brockton: Geralann DiDomenico	508/427-6099
or John Rogers	508/679-2240	<i>Younger Adult Caregivers:</i>	
Southbridge: Roger LaMontagne	508/765-9771	Erin Whalen	617/868-6718

Support Groups

Basic Training for New Support Group Leaders

The Support Group Leaders Committee is pleased to offer workshops for new and prospective leaders of Alzheimer's support groups. Each workshop is designed to cover important basic information about starting and leading an Alzheimer family support group, and features our Support Group Leaders' Manual. Advance registration is required. For more information, call Harriet Udoff at 978.937.5576 or e-mail harriet.udoff@alz.org.

Reunión Mensual de Familias

Si desean información sobre reuniones mensuales de familias, por favor llamen a Conchita Rodriguez al 617.868.8599.

Support Groups

Support groups provide a forum for family members and friends of people with Alzheimer's disease to share feelings, concerns and information, and to support each other in coping with the effects of Alzheimer's disease or one of the related disorders. Each group varies in size and frequency of meeting. Please call the support group leaders listed on this page for further info.

For information on support groups on Cape Cod, call the Alzheimer's Association of Cape Cod and the Islands at 508/775-5656.

These groups are open to the public. In addition, many day programs and nursing homes offer groups open to the families of their patients. Support groups are independently run and this listing should not be construed as a recommendation.

Early Stage Patient Series

We are now recruiting participants for a new three-part education series specifically for early-stage patients. Dr. Paul Raia and Harriet Udoff will facilitate the meetings in our Cambridge office. For more information, please call 617.868.6718, ext. 214.

We are a member of



Thank you for your payroll deduction contribution.

Abington: Sharmila Biswas	781/871-0200	Ellen Foley or Ruth Gordon	617/491-1815
Acton: Joanne Chaulk or Jean Fleming	978/486-0590 978/264-9643	Canton: Susan Brady	781/828-7450x307
Agawam: Judy Pothul	413/821-9911	Chelmsford: Pat Keene Sandy Simon	978/251-8491 978/250-6122
Amesbury: Patricia Lavoie	978/803-3296	Susan Antkowiak	978/934-0000
Amherst: Shirley Crites	413/548-6800	Chelsea: William Nadler	781/284-2872
Andover: Rachel Zalvan	978/623-8321	Chicopee: Elaine Mitchell Judy Pothul	413/592-7738 413/821-9911
Arlington: Laurie August	781/316-3400	Debbie Ryan	413/536-2540
Athol: Linda Duffy	978/249-3717	Clinton: Laura Beckman-Devik	978/365-7376
Attleboro: Annie Sirois or Patsy Daniels or Ginny McDermott	508/222-6655 508/222-0118 x2122	Concord: Arlene Parillo or Nancy Crowley	978/897-2569 978/371-3400
Sharon Leary	978/226-6150	Danvers: Lois Stern	978/750-4540
Mary McCormack	508/222-6655	D'arcy Adams	978/774-4400 x3064
Ayer: Jeannette Coutu or Gary Davis	978/772-1704	Jeanne Parent	978/777-5717
Boston:		Duxbury: Nancy Lee Strowasser or Sandi Wright	781/585-2397
Brighton, Mary Ellen Peters	617/789-2618	East Longmeadow:	
Dorchester, Donna Allen	617/474-1194	Ellen Nepomuceno	413/781-5070
Downtown, Barbara Hawley	617/726-2639	Mary Anne Stout	413/525-8150
or Maureen Tardelli	617/391-7878	Easton: Karen Sprague	508/230-2100
Hyde Park, Carol Westheimer or Wendy Marks	781/455-8588	Fairhaven: Sharon Jenson	508/997-3193
Jamaica Plain, Denise Reichenbacher	617/983-2300	Fall River: Nancy Reed	508/679-0011
Roslindale, Lisa Talayco	617/363-2329	Paulette Masse	508/379-9700
Roxbury, Ilene Marsh	617/361-7486	or Judy Elste	508/675-2101
or Michael Kincade	617/868-6718	Fitchburg: Alice Murphy or Joanne Harris	978/343-5368
West Roxbury, Susan O'Connell or Stephanie Brinkhaus	617/325-1230	Ellen Sparrow	978/632-1230
Bourne: Judy Anthony	800/870-1800	Florence: Sheri Weintraub	413/584-1060
Braintree: Alisa LaCoste Denise Hughes or Chris Togneri	781/843-1860 x629 781/848-2714	Foxboro: Diane Caldwell	508/543-7336
Bridgewater: Jean Giguere	508/697-4368	Framingham: Deborah Young	508/879-8000
Brockton: Nancy Bresciani	508/583-2517	Jayne Goldman	508/788-6050
Lorraine Lopes	508/587-6556	Franklin: Linda Bonneau	508/528-4600
Brookline: Pattie Chase	617/232-0291	Gardner: Chris Santum	978/632-5477
or Howard Block	781/455-8588	Gloucester: Janett Lavender or Mary Spittle	978/281-1750
Burlington: Sue Mike	781/272-2857	Great Barrington: Kelly Thom	413/528-2650
Stacey Kohler	781/744-8114	Hadley: Beth Rosati	413/584-5057
Cambridge: Alice McCarter, Mary Costello	617/547-3543x22	Haverhill: John Freeman	978/346-4743
		or Nancy Savarese	978/683-2771
		Fran Eisenman or Pam McCallum	978/469-0169



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