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 Fall 2002
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ALZHEIMER'S ASSOCIATION



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Mark Your Calendars Now!

Annual Family Conference
Saturday, November 9

Families, friends, and persons with AD are invited to come together for learning and fellowship at the Westford Regency Hotel. See page 9.

Western MA Conference
Wednesday, November 13

Professional caregivers won't want to miss Joyce Simard's keynote address at the Springfield Sheraton, Springfield. See page 9.

Simons Symposium
Thursday, November 21

Join us at the Charles Hotel in Cambridge to learn more about the potential Alzheimer "vaccine". Dr. Bradley Hyman of MGH and Harvard Medical School is this year's Simons Lecturer. See page 9.

DON'T MISS the Winter 2003 Newsletter for complete coverage of Memory Walk 2002!

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Encircled by Grief: A Caregiver's Journey

By *Wendryn Case*

During our journey of caring for someone with Alzheimer's disease, our grief may come to us gradually, not unlike poet Carl Sandburg's description of "Fog..." coming "on little cat feet."

Caregivers experience a kind of grief-in-waiting, a periodic and repetitive response to the steady progression of losses caused by the disease. The caregiver's experience of loss begins at the diagnosis. Each loss experienced by our loved one brings with it a corresponding loss for us.

Our loss is not of memory, sight, or speech. Caregivers lose intangible parts of a relationship that had been developed mutually. Each subsequent interaction reveals further loss, as what remains of our relationship becomes more one-sided between our loved one and us. We grieve the passing of what had become familiar and expected over years of sharing.

Ebb Tide: Anticipatory Grief

We are unaccustomed to sorrow in this form, since few have borne witness to the persistent diminishing of another person. Little allowance is made for our anticipatory grief. Some of our friends and family may not understand our feelings.

Mourning and celebrating the fullness of our relationship prior to the disease frees us to create space for the fullness of the relationship we have now.

Family members and friends may even act nervous or uncomfortable around us. After all, our loved one is still living. Despite this complex irony, it is important for us to be aware of what we are feeling. The old proverb, "Beware the naked man who tries to give you his shirt," can speak to us here, for we cannot continue to provide loving care if we do not also take loving care of ourselves.

Paradox. How do we care for ourselves when we cannot stop anticipating the every need of the

continued on page 4

Massachusetts Chapter

Photo by Art Falbo



Joy triumphs over grief for family caregivers and other participants at Alzheimer's at Tanglewood: an Encore, where Co-Chair Karen Gold (L) greeted Honorary Chair Tina Packer (R), Founder and Artistic Director of Shakespeare & Company, Lenox. (See story, page 7)

The Massachusetts Chapter serves the entire state from Cape Cod to the Berkshires.

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From the President: Recalibrating Our Reach across the Bay State

The Alzheimer's Association is dedicated to doing everything within our means to extend services and programs to all parts of our state. We understand the challenges experienced by families, including the difficulties of traveling long distances to participate in education and training programs. In recent months, we have taken steps to expand our capacity to provide more in-depth programs to the families and professionals of Worcester County, and of Cape Cod and the Islands.

This summer, the Chapter received a two-year grant from the **Fairlawn Foundation**, enabling us to hire a staff person and to open a small office in Worcester County. We are very excited about the prospect of expanding programs and services for families and professionals in Worcester County. We are also very appreciative of the support and encouragement from both the Worcester and the North Worcester Alzheimer's Partnerships in our pursuit of funding for Worcester County.

On board. Our Massachusetts Chapter is now delivering services to the entire state of Massachusetts. Last summer the Board of the former Cape Cod and Islands Chapter decided to leave the Alzheimer's Association. Our Massachusetts Chapter will continue providing services to families and professionals living and/or working on Cape Cod and the Islands, as we have been doing for the past 22 years.

As part of our integrated network of services, our (800) Helpline phone number is open and available, and staffed by trained counselors to answer the questions of any Massachusetts resident 24 hours/day, 7 days/week (see page 8). During the coming months, many of the core programs and services of our Chapter will be available to the Cape and Islands.

Staff transitions. We were very saddened at the loss of staff member **Geraldine (Geri) Lindsey**. Geri provided



Geri Lindsey (far R), with Chapter colleagues, in file photo.

In recent months, we have taken steps to expand our capacity to provide more in-depth programs to the families and professionals of Worcester County, and of Cape Cod and the Islands.

administrative and bookkeeping support, and was a very dedicated and talented member of our team. Geri's daughter, **Donna Smart Gorham**, serves as Office Manager for the Association. We are fortunate to have known and worked with Geri... and we miss her.

It is our pleasure to welcome **Sandra DeOliveira** as our newest employee. She will work as a much-needed bookkeeper, adding capacity to our finance staff. Prior to joining the Alzheimer's Association, Sandra worked as an accounting assistant for EnviroBusiness, Inc.

in Cambridge.




Sen. Royal L. Bolling, Sr.

And a sad note: Former State Senator **Royal L. Bolling, Sr.** died July 16, of cancer. He was 82. In the 1980s, Sen. Bolling was the Alzheimer's Association's chief supporter in the Legislature, and also served on our Chapter's Board of Directors. A highly decorated WWII veteran, he is recognized as having played an historic role in the evolution of African-American politics in Greater Boston.


—Jim Wessler

National Alzheimer's Association Selects Massachusetts Chapter Program

Basic Training For New Support Group Leaders, a workshop offered by the Massachusetts Chapter several times each year, has been identified by our national office as worthy of replication by Alzheimer's Association chapters across the country. We are pleased to have this successful program recognized! See page 8 for details. 

A Reminder

Many companies attempt to capitalize on the public's concerns about Alzheimer's disease and other dementias. Some try to mimic the look of the Alzheimer's Association so that donors will think their money is going toward the Association's work, when it's really not.

All mailings from the Alzheimer's Association carry the "Stand by You" logo. Any solicitation that does not bear this logo is NOT from the Alzheimer's Association. Please call (617) 868-6718 if you have questions about something you receive. 



Book Review: A Chaplain's Voice

Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-Threatening Illness, 4th Edition

By Hank Dunn

A&A Publishers, Herndon, VA (2001): 80 pages.

Reviewed by Betsy Peterson

This little book by a hospital and nursing home chaplain packs an enormous amount of useful information into 80 pages. Best of all, it helps us to think clearly about the difficult decisions that may be needed as a terminal illness progresses, and to recognize some of the emotional and spiritual dynamics that often complicate those decisions.

Goals. Dunn first reviews three possible goals of medical care—cure, stabilization, or preparing for a comfortable and dignified death. Each chapter identifies key questions, e.g., What are the benefits and hazards of artificial feeding tubes? and concludes the discussion with a pithy summary.

He gives the fullest discussion to the four most common major treatment choices—cardiac resuscitation; artificial hydration and nutrition; whether to hospitalize someone who has been ill at home or in a nursing home; and whether to shift from cure to comfort care—but also considers related issues, such as the use of antibiotics and pain control.

Dunn is clear that these decisions depend a great deal on the specific medical circumstances at the time. He suggests how to get help with making end-of-life decisions, and offers considerations that may help in “the journey to letting go”.

Beacon. Anyone who has made that journey, and has had to make any of these decisions, knows that information is only part of the process. But good information can help a lot. This book clarified many issues for our family, first as we chose a comfort care directive, and later as my husband was admitted to hospice care and became unable to swallow.

The new 4th edition expressly discusses the hard choices within the context of dementia, especially the choices of artificial hydration and feeding for an end-stage patient. Dunn also summarizes signs by which professionals judge that dementia has reached the end-stage. (For a fuller discussion, designed primarily for professionals, I recommend *Hospice Care for Patients with Advanced Progressive Dementia*, by Volicer and Hurley, available from the MA Chapter.)



Book Review: Honoring the Farewell Process

Matters of Life and Death: Finding the Words to Say Goodbye

By Carol Wogrin, R.N., Psy.D.

Broadway Books, New York, NY (2001): 189 pages.

Reviewed by Betsy Peterson

Dr. Carol Wogrin has filled this book with common sense, practical suggestions, and insights that will help anyone facing a terminal illness—including the long slow loss of dementia, even though most of her remarks are addressed to a general audience. There are lots of books on grief, and many on Alzheimer's, but very few that consider both issues together.

And in fact, Dr. Wogrin helped some of us family caregivers before this book was published. She met with a small group of Alzheimer's caregivers, helping us to explore and understand the complications of grieving a dementia patient. I had the privilege of being in that group, and feel thankful that others can now benefit from her calm voice and well-grounded perspectives.

Commitment. Dr. Wogrin became a psychotherapist after ten years as an oncology nurse. In addition to her private practice, she is Executive Director of the National Center for Death Education and Director of Bereavement Studies at Mount Ida College in Newton, MA. She is also Director of the Massachusetts Compassionate Care Coalition, a grassroots organization dedicated to improving end-of-life care.

She invites readers to use the book as a guide that “can help you manage your fears—the fear of saying the wrong thing, of upsetting others, of facing overwhelming feelings.” She suggests words and phrases for specific situations, but always with

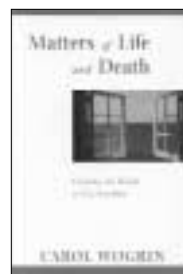
a keen awareness that people vary enormously, that there is no one type of “good death”, and there are many good ways to say goodbye.

It may not be necessary to speak of death. But Dr. Wogrin is convinced that saying goodbye, in words or actions—“to share your love for another clearly and deliberately”—is worth the effort and risks. If we let fears prevail, we may “miss the opportunity of a lifetime”.

One chapter, *The Long Goodbye*, discusses long illnesses and especially dementia. That phrase, the long goodbye, is one I came to dislike over the years I cared for my husband: it fed my tendency to focus on the losses instead of learning to treasure what's there.

Reaffirmation. But Dr. Wogrin gives us an expanded definition of saying goodbye—showing our love for another clearly and positively—and thus provides a strategy that honors the past without distorting the present. Several stories in this chapter came from our group meetings, including some from our family—I'm “Pat”, and “Jan” is our daughter.

The book opens with a general discussion of difficulties we may face in talking with dying people. Successive chapters recommend advance care planning, briefly review the dying process, focus on difficult relationships, and provide help for children in saying goodbye. The final chapter speaks of lessons Dr. Wogrin has learned from those who are dying.



Education

Elisabeth T. Peterson, a former family caregiver, was a Visiting Research Associate, 2001-2002 at the Women's Studies Scholars Program, Brandeis University, Waltham, MA.

These books are on our Chapter's 2002 Publications List. Call (617) 868-6718 or see our website at www.alzmass.org/publications for ordering information.

Dr. Wogrin gives us an expanded definition of saying goodbye—showing our love for another clearly and positively—and thus provides a strategy that honors the past without distorting the present.

Patient Care and Family Support

For more information about grief and bereavement groups, please contact the Helpline at (800) 548-2111.

Encircled by Grief...

continued from page 1

one for whom we care? Self-care is a very individualized endeavor. Start simply. Take a few moments to listen to your emotions. You have become an expert at gauging the emotional state of others; now you can use your ability to discern your own emotional state.

Notice the tensions you hold in your body. Breathe. Reflect on your day and the feelings it triggered.

Did Mom forget how much she used to like apples? Can you vividly remember how carefully she removed the skins, cut them into eighths, sprinkled them with sugar, and shared them? Does remembering her before the disease and watching her now, cause your tears to surface?

Bittersweet. Or maybe you smile, savoring this special memory. Whatever your response, trust and value it. Each of us needs to trust in our feelings and give ourselves the space to acknowledge and safely express them.

How we choose to do this processing will vary. Crying, laughing, yelling, singing—each of us must discover our own form of release. Experiment! Hobbies, puzzles, art, massage, concerts, meditation . . . there is no single

right way to recognize and respect your feelings. What works today might not work as well tomorrow. Listen to yourself and seek the support of others.

When grief laps at our toes, coming toward us like so many small waves, we need to be very patient with ourselves. Like water slowly pulling the sand out from under our feet, our grief can leave us unbalanced and changed. We must make an extra effort to be present to ourselves and to our needs.

Stargazing. Writing in a journal or stepping outside to view the night sky might bring us back “home” to ourselves. Schedule respite care and go shopping or out to lunch with a friend. Rake the first leaves of autumn or put your garden to bed. Whatever ways we find to care for ourselves, this self-nurturing will enable us to be more fully present to our loved one.

Our grief-in-waiting allows us to experience the fullness of ourselves in our relationships with others. Mourning and celebrating the fullness of our relationship prior to the disease frees us to create space for the fullness of the

*“The act of living is different all through.
Her absence is like the sky, spread over everything.”*

—C.S. Lewis



Photo by Wendryn Case

relationship we have now. Just as our loved one with Alzheimer's disease must live in the moment, our experience of grief enables us to share these moments with them.

Our lives are thus distilled to their most basic and elemental aspects. It is as if, in the words of poet William Blake, any of us might see “. . . a world in a grain of sand, And a heaven in a wild flower, Hold infinity in the palm of your hand, And eternity in an hour.”

The next time you stand on a beach and watch the tide going out, look at the sand being pulled out from between your toes. Look at the patterns of the sand; the rivulets that host a collection of tiny creatures—snails, sand shrimp, little fish. These lives exist completely in the present, following paths mapped out for them by the movements of our vast planetary waters. They are held and sustained by the presence of the salt sea.

Communion. We, too, are held and sustained. Regardless of the particular spiritual path we have chosen to follow, a part of us knows that the love we have shared will always be held in a special place of communion, where nothing can take it away. And though we lose each other to disease and ultimately, to death, our love is transformed but not lost.

Some call this transformation an experience of mystical hope, the kind that does not depend on the fairy tale outcome of “happily ever after.” This hope goes beyond expecting a cure. This hope knows that all will be well, even as we rail against the universe and weep at our losses.

Rip Current: Bearing the Loss

Later in our experience as caregivers, our grief may come to us quickly. Like a crashing wave, terrifying in its fierceness, it sweeps away our breath and knocks us senseless. This is the type of grief that our culture knows. This is the grief that batters us when our loved one has died. It carries us far from familiar shores into colder, deeper waters.

People send flowers, casseroles, and cards. Friends struggle to find something comforting to say. We often do not recall what was said; we just know that someone had come to stand beside us.

Alone in deep waters, we may be isolated by the intensity of our numbness, pain, or anger. We may find ourselves walking through our days as if encased in a bubble, doing things auto-

Photo by Eric Johnson



Russell and Gladys Case with great-granddaughter, Lilli.



Enjoying a late summer morning.

matically, without being aware. We may wonder how we just arrived home from the store with no recollection of having driven there.

It may take great energy to move around at all. C.S. Lewis describes life after the death of his wife in two simple sentences. "The act of living is different all through. Her absence is like the sky, spread over everything."

Mapping. We need time to explore this new landscape. There is no standard formula that neatly predicts how long it will take. It is more than the time we may take off from work or from regular social engagements.

Our feelings may be raw and ever present for many weeks or months. We may find ourselves on the verge of tears or suddenly laughing. We might crave silence. Or, we might despise the quiet places, hoping to contain our pain within the pages of dizzying to-do lists.

Grief is a process that is particular to the one who bears it. There is no right way or right time. There is only our steady movement in the direction of a new and changed life, carrying with us the essence of the life we once shared with another. We may encounter feelings we thought we had already left behind.

Undertow. Like a spiral, we come around to them again and again. Meeting these feelings may still be like being surprised by a crashing wave. It is difficult to function amidst such intensity.

For a closer look at the subject of grief:

- A Grief Observed* by C. S. Lewis
- Necessary Losses* by Judith Viorst
- A Pilgrimage through Grief* by James E. Miller
- Matters of Life and Death* by Carol Wogrin
- Life Lessons* by Elisabeth Kübler-Ross & David Kessler

But eventually, though they splash over and through us again, our feelings change. The intensity is with us for shorter intervals. Our feelings touch us more gently and then move on. We are transformed.

Remember that it is important to discern what *you* need throughout this grieving process.

By exploring the moments in which you find yourself, you may discover healing in the broken places. Hear the small voice in the silences that can guide you to a new way of being. You may benefit from sharing your feelings with a trained grief counselor or someone experienced in pastoral care.

Give to yourself the gift of self-care . . . the love and tenderness that you so generously showered on another will now be showered on you. Accept this caring. It may come from within you or may be offered to you through friends, family, or even strangers.

You have been a caregiver through a multitude of 36-hour days. It is now your turn to be accompanied on your new journey by the caring presence of others. **■**

Wendryn Case is Administrative Assistant for the Massachusetts Chapter's Western Regional Office in Springfield.

Patient Care and Family Support



Photo by Catherine Votaw

Pets encircle caregivers with comfort throughout the grieving process.

Support Group Forum Invigorates Leaders, Trainers

By Debra Katt-Lloyd

On June 13, more than 70 support group leaders gathered at Whitney Place in Natick to participate in a half-day forum titled *Support Group CPR: Breathing Life Into Your Group*. The program consisted of a panel presentation followed by small group discussions with two volunteer facilitators.

The panel of four experienced support group leaders—**Judy Antonangeli, Joanne Chaulk, Phyllis Scanzani-Smith, and Judy Sabol**—was moderated by **Joanne Koenig-Coste** and covered the topics of recruiting new members, sustaining a group, common leadership problems, and dealing with losses.

Giving back. The program also gave us an opportunity to show appreciation to support group leaders. Thanks to the generous contribution of gift baskets by several organizations, we were able to recognize five people who have been support group leaders for at least 16 years. Several other leaders received a basket as part of a raffle.

Lois Pecora received a special certificate of appreciation for her work as a support group leader and past Chairperson of the Support Group Committee. Our thanks to all of those who participated, and to the Tapestry Program at Whitney Place Assisted Living Residences in Natick, Northbridge, and Westborough which generously underwrote the forum. **■**

Gift baskets to recognize the five leaders for 16+ years of service.



All Forum photos by Rachel Hawk

Lois Pecora receives a certificate of appreciation for her collective works on behalf of the Association.



Participants were inspired by the panel presentation.



Advocacy

The payoff for all our hard work has been phenomenal to date: substantial increases in federal research funding, growth in state-supported services, and improvements in the quality of care for those in nursing homes.

The results of our 10th Annual Memory Walk will be announced in the next issue of our Newsletter! Stay tuned. Shown in photo is U.S. Congressman Edward Markey, leading walkers at our 2001 Greater Boston Walk.

Public Policy Review: Fall Update

By Kate Doyle

Advocacy is a key component of our identity as the Alzheimer's Association. We have emerged as an authority on the issues that affect people with Alzheimer's disease and their families; we have become their voice. But more importantly, we have helped people with the disease, family members, friends, and others become advocates themselves.

Our Philosophy

Our work in public policy moves our concern for individuals with Alzheimer's disease and their families out of our homes and into the capitals of every state, the offices of virtually every senator and representative, and even the White House. In coalition with other elder advocacy organizations, Alzheimer's Community Partnerships, and the national Association, our Chapter's public policy goals—long term care policy reform, and compassionate care and equal access to quality services—were successfully accomplished during this fiscal year, even in this difficult economic climate.

The payoff for all our hard work has been phenomenal to date: substantial increases in federal research funding, growth in state-supported services, and improvements in the quality of care for those in nursing homes. Your involvement has been a critical component of our success to date.

Engagement. Many would-be advocates have reservations about their ability to undertake advocacy activities. However, telling legislators and lawmakers what we want for our loved ones with Alzheimer's is not only doable, it is necessary.

If you are a caregiver, who better than you to illustrate the need for home- and community-based services? Who is better than you to explain the need for adequate training for skilled caregivers or law enforcement personnel? Although our advocacy is rooted in the reality of caregiving for our family members, we welcome the participation of anyone committed to the Association's mission of a world without Alzheimer's disease.

Our Results

As an example of the pathway your involvement as an advocate can take, our efforts resulted in the passage of a Senate Appropriations Committee Bill, including full funding for the Safe Return Program. This translates into \$900,000 allocated



Photo by Ellen Shub

in the federal budget for Safe Return.

Steep climb. As we reported earlier this year, however, President Bush's budget proposal cut funding for Safe Return. The House Appropriations Committee has not completed action on the House Commerce/Justice and State Appropriations bill at this time.

On the research front, federal funding for Alzheimer research would jump to an estimated \$670 million in fiscal year 2003, an increase of \$71 million or close to 12% over the current research investment (\$598.9 million). Although this figure is less than the \$200 million increase sought by the Association, it is a big step forward to the Alzheimer's Association's \$1 billion goal, especially during tight fiscal times.

Our Commitment

We pledge to work together with our advocates and related service organizations at all levels to increase public awareness, and legislative action to support research related to Alzheimer's disease. It's clear that public awareness and media coverage of dementia-related issues are more prevalent than ever before. We care about keeping the news agenda focused on our goals and programs.

In addition, the groundswell of support for Memory Walk and fundraising achievement is growing each year! Research breakthroughs are acknowledged in the general as well as technical media outlets, and legislators are more concerned than ever about drafting Alzheimer-friendly policies and laws.

Advocacy for dementia issues is also growing. Our public policy advocate list now tops 1,000 individuals, and our outreach to family members and professionals helps to enlist new advocates every day.

Join us! We also need people who can write letters and make phone calls to legislators. And we certainly need individuals who can go to the State House and to congressional district offices for meetings.

We recently had a very successful series of congressional meetings, and our success was due in no small part to the numbers of dedicated family members and professionals who came out to attend these meetings. Agenda topics included federal priorities, such as research funding, Safe Return, Medicare/Prescription Drugs, quality of care issues, and the family caregiver program. In addition, we have met with the Massachusetts Congressional delegation: Stephen Lynch, James McGovern, Barney Frank, and John Tierney.


If you would like to become more involved in the Association's advocacy efforts, we want to hear from you! Please call Susan Kelley-Grasso at (617) 868-6718. 



Photo by Kate Doyle

Advocate Lewis Law (holding sign) and others formed the Massachusetts delegation at the National Public Policy Forum in Washington, DC in April.


Tanglewood Encore Delights Guests, Supports Mission

On a hot August afternoon, *Alzheimer's at Tanglewood: An Encore* raised \$28,000 for caregiver education and support programs as 125 guests celebrated the work of the Massachusetts Chapter. Enjoying the beautiful summer day, many guests came early and picnicked on the Tanglewood grounds before joining co-chairs Karen Gold and Fredrica Sloan for a pre-concert dessert reception in the Hawthorne Tent.

Leadership. Classical guitarist Jason Ennis entertained, and a brief program highlighted the accomplishments of the event's Honorary Chairs: Benjamin Liptzin, M.D., Chair of the Department of Psychiatry at Baystate Medical Center, Springfield; Tina Packer, Founder and Artistic Director of Shakespeare & Co., Lenox; and Paul R. Solomon, Ph.D., Founder and Clinical Director of the Memory Clinic, Bennington, Vermont. Ms. Packer spoke movingly of her experiences as a caregiver for her mother.

Sponsors for Alzheimer's at Tanglewood were AmeriCare Associates, Berkshire Healthcare Systems, the Harold Grinspoon Foundation, Charles Magriel, EPOCH Assisted Living at Melbourne, Novartis Pharmaceuticals, Pfizer, and Quabbin Valley Healthcare.

Other supporters included AmeriCare Associates; Baystate Medical Center; East Village Park; Hadley Printing; Health New England; Royster and Kathryn Hedgepeth; Hearthstone Alzheimer Care; Janssen Pharmaceutica; Mental Health and Substance Abuse Service of the Berkshires; Mercy Medical Center; Neuro-Psychology Associates; Northern Berkshire Health Systems; Rosenberg, Freedman & Goldstein; Shatz, Schwartz & Fentin; Stanley Solomon; Tanglewood; and The Arbors at Amherst and Chicopee.

Special thanks to the members of the organizing committee—Mark Ailinger, Sue Jones, Karen Gold, Deborah C. MacDonald, Catherine May, Susan Megas, Barbara Milensky, Beth Parker-O'Brien, Fredrica Sloan, Suellen Solomon, Jean Tyler and Diane I. Weinstein — for creating such a beautiful, memorable event. 

—Kathryn Hedgepeth



Co-Chairs Karen Gold (L) and Fredrica Sloan (R) announce good news—the Tanglewood Encore raised \$28,000!

All Tanglewood photos by Art Falbo



Norma Solomon combined her birthday celebration with the Tanglewood event.



Benefactor Charles Magriel (L) and daughter Laurie (R) enjoy the pre-concert reception.

Western MA News




Honorary Chair Dr. Paul Solomon.

Springfield Multicultural Training

Targeting Springfield's largest ethnic communities, Latinos and African-Americans, the Springfield Multicultural Alzheimer's Services (SMAS) project connects families with local agencies providing an array of support services. Partners in the project are the Alzheimer's Association, Greater Springfield Senior Services, the Spanish American Union, and the VNA and Hospice of Western New England. Marcia McKenzie is the SMAS Coordinator in the Western Regional Office.

Outreach. Under an Administration on Aging Alzheimer's Demonstration Grant, SMAS is assisting families and training community outreach and healthcare workers on culturally appropriate Alzheimer's care. During the spring, the Alzheimer's Association provided training sessions on Alzheimer's disease and its effect on people with the disease and their caregivers.

The Association and the Spanish American Union also collaborated on cultural competency training; i.e., how one's culture (race, religion, country of origin, etc.) affects acceptance or rejection of assistance, and understanding of differences between dementia and normal aging. Health care professionals and outreach workers from Greater Springfield Senior Services, the VNA, and Stavros Center for Independent Living participated.

To arrange for cultural competency training or to refer families to SMAS, please contact Marcia McKenzie at (413) 787-1113 or marcia.mckenzie@alz.org. 



Chapter President Jim Wessler (L) welcomes Jeff (C) and Carrie (R) Graham. Jeff is Co-Chair of the Pioneer Valley Memory Walk.

Alzheimer's Education/Event Calendar:

Family Orientation

An education meeting for family members. Topics include diagnosis, treatment, medications, planning, home management, and more. *Each Family Orientation session is repeated on a monthly basis.* The program is free of charge. Locations, times, and dates are listed below.

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

Nov. 21, Dec. 19, Jan. 16 (10:00 a.m.-12:00 p.m.)

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

Nov. 13, Dec. 11, Jan. 8 (10:00 a.m.-12:00 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.

Nov. 13, Dec. 11, Jan. 8 (6:45-8:45 p.m.)

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

Nov. 13, Dec. 11, Jan. 8 (3:30-5:00 p.m.)

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

Nov. 21, Dec. 19, Jan. 23 (6:00-8:00 p.m.)

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

Nov. 13, Dec. 11, Jan. 8 (3:30-5:00 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.

Nov. 26, Jan. 21 (1:30-3:30 p.m.)

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

Nov. 21, Dec. 19, Jan. 16 (1:30-3:30 p.m.)

Helpline Available 24/7!

Our Helpline phone service, 1-(800) 548-2111, is now available around the clock, seven days per week, to accept your calls and answer your questions. We are also able to offer translation services in many languages. To reach our national office in Chicago during regular working hours, it is necessary to call (312) 335-8700.



SAVE THE DATES!!!

Basic Training for New Support Group Leaders

Free training workshops offered to new and prospective leaders of Alzheimer family and patient support groups in our Chapter area.

Contact Debra Katt-Lloyd for further information and dates at (978) 937-5576.

Friday, Nov. 1 Benefit Concert by Gifted Pianist Elliot Steger, M.D.

National Heritage Museum, Lexington, 6:30 p.m. Ticket price is \$15 and includes refreshments.

Sponsored by the Liberty Alzheimer's Partnership; all proceeds to benefit the Alzheimer's Association. For tickets or sponsorship information, please contact Joanne Chaulk at (978) 486-0590 or proeldercare@aol.com.

January, 2003 Second Annual Clergy Conference

"Alzheimer's Disease, A Spiritual Journey". Conference site to be announced. For further information please contact Jeannie Banas at (413) 787-1113 or Jeannie.Banas@alz.org.

Saturday, Feb. 1 11th Annual James V. Jordan Winterfest Benefit The International, 184 High Street, Boston

Don't miss this festive and spirited annual event—a great time for a great cause! For more information on sponsorship opportunities or getting involved, please contact Heidi Ganss, Director of Development at (617) 868-6718 ext. 207 or heidi.ganss@alz.org.

Photos by Janet Taylor



Mark Your Calendars Now!

All meetings are free of charge and marked by . Times are subject to change. Please call for details for each program. Pre-registration is required. Helpline at 617/868-6718 for up-to-date information.

November, December, January 2003


November: Alzheimer's Awareness Month

Against the lovely backdrop of autumn, we look forward to Alzheimer's Awareness Month! Each year, the chapters of the Alzheimer's Association across the country offer special educational programs.

Although our collective efforts certainly are not limited to November, we do focus on that month for outreach in encouraging others (the media as well as libraries, support groups, diagnostic centers, etc.) to offer programs or displays. Please take a look at our Education Calendar for the programs we are offering, and as November approaches, check your local paper for program notices.



Hope. We cannot yet say that there is a cure, but we can say that we are steadily learning more and more about how to make life better, both for people with a dementing illness and for their families. Please know that there is help—and there is hope.

Find a program that interests you and make a point of attending.

If you have not yet attended a support group, please consider doing so—many have found a support group to be literally lifesaving. Every group is different; finding the right fit may not happen the first time, but is well worth the effort. Support groups offer a chance to talk with others in the same circumstances, and for some reason related to being human, this exchange can be very helpful and comforting. 



Train the Trainer Program for Dementia Care Professionals

A professional education program designed to teach participants to become trainers within their community agencies or facilities. One or two representatives attend in order to learn about Alzheimer's disease and dementia, Habilitation therapy, behavior issues, activities, and more. After the program, the representatives return to their facilities to teach other staff members.

  Pre-registration is required for this full day of training. 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.

Nov. 5, Dec. 3, January 7

19th Annual Family Conference


Living with Alzheimer's, our annual conference for family members and friends of people with Alzheimer's disease (AD) or other chronic, progressive memory disorders, will be held at the Westford Regency Hotel (just off Route 495, near Routes 3 and 2). The conference includes workshops for people with AD, as well as discussion groups for others on topics such as *Activities of Daily Living*, *What to Look for When Evaluating a Nursing Home*, and *Home Modification*.   Prior registration is necessary. The fee is \$25 for the first family member, and \$20 for each additional member. Lunch is included. Call (617) 868-6718 for a brochure or visit our web site at www.alzmass.org.

Saturday, Nov. 9 (9:00 a.m.-4:00 p.m.)

Annual Simons Research Symposium

The 12th Annual Simons Symposium, featuring a scientific lecture on Alzheimer's disease, will be held at the Charles Hotel, Cambridge (convenient to the Harvard Square T-stop and buses). This year's lecture

will feature the cutting-edge work of **Bradley T. Hyman, M.D., Ph.D.**, senior researcher at the Massachusetts General Hospital Alzheimer's Disease Research Center and Professor of Neurology at Harvard Medical School.

Dr. Hyman will present "New Ways to View Alzheimer's Disease". His work bears on the potential "vaccine" for AD, and has generated much attention in both scientific and public media.  There is no charge for the lecture or coffee and dessert reception that follows, but prior registration is necessary.

Parking is \$5 with validation. Call (617) 868-6718 for a brochure or visit our web site at www.alzmass.org.

Thursday, Nov. 21 (7:00-8:30 p.m.)

Western MA Regional Professionals Conference

Our 12th Annual **Western Massachusetts Professional Caregivers Conference**, *Empowering the Patient*, features a keynote address by **Joyce Simard, M.S.W.** The Conference will be held at the Springfield Sheraton, One Monarch Place, Springfield, MA. For further information, call Jeannie Banas at (413) 787-1113 or e-mail jeannie.banas@alz.org.

Wednesday, Nov. 13 (8:00 a.m.-4:00 p.m.)

Activity-Based Alzheimer's Care Training

A new training program for activity and program professionals. Topics covered include activity-based care for persons with AD, assessment and care planning, program design, quality activities, program evaluation, and teamwork. Alzheimer's Association, Cambridge Office, 36 Cameron Ave., Cambridge. For more information, contact Erin Whalen at (617) 868-6718, ext. 213.

Thursday, January 23




Readership Poll: Do You Use Our Web Site?

PLEASE LET US KNOW! Just clip this section and mail to Newsletter Poll, Alzheimer's Association, 36 Cameron Avenue, Cambridge, MA 02140 or send your comments from our web site: www.alzmass.org, or e-mail Rachel.Hawk@alz.org

1. Have you visited our web site? _____ How frequently? _____
2. How would you rate the overall quality of our web site? Excellent Good Fair Poor
3. What suggestions do you have for us for improving the web site?
 - a. _____
 - b. _____
 - c. _____

Thank you for taking the time to let us know your thoughts! Your feedback helps improve the quality of our work.

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If in doubt, call our
. Visit www.alzmass.org
te listing.

Education



Panel moderator Elaine Silverio

"Thank you ! You have helped validate, taught me new management skills, and given me new areas in which to concentrate my new skills—hopefully with better results."



Panelist Renee Ciarletta

Sberyl Clarke

Early-Stage People Lead Participants through the Maze Annual Professionals Conference Inspires, Educates

Our annual conference for professionals, **A Map through the Maze**, drew a record-breaking 650 participants from across the state at the Royal Plaza Hotel in Marlboro May 8. The conference featured 39 excellent workshops, 44 exhibit tables, and 24 poster displays.

The high point of the day, for many, was the keynote presentation, "We Are Still Here", a panel of people with early-stage dementia moderated by Elaine Silverio.

We are grateful to Pfizer/Eisai for their continuing commitment and educational grant, and to each and every speaker for contributing their knowledge and skill. Some quotes from participants capture the flavor of the experience:

"The panel was wonderful. Very nice to put faces and real life stories to this disease."

"This (panel) was the most memorable part of the conference for me. Thank you so much for having people with dementia share their lives with us."

"Powerful presentations—thank you so much!"

"Profound—thanks—it took great courage to present..."

"Thank you for having this presentation. It was very informative and I appreciate being able to hear someone like Dr. Selkoe as a presenter!"

"Dr. Raia's parables put a human dimension to his expertise. A lot of good ideas."

"Thank you ! You have helped validate, taught me new management skills, and given me new areas in which to concentrate my new skills—hopefully with better results."



Janet Lawrence, M.D.

"Excellent—thank you for your thorough explanation and review of behaviors and interventions—a reminder of the role of emotions."

"Absolutely excellent throughout—very informative and effective. Compassionate speakers!"

"Absolutely excellent throughout—very informative and effective. Compassionate speakers!"

Antonia Coppin, M.D.



Gwen Kopka



Judy Antonangeli



Feeling the groove: keynote panel members dancing.

Professionals Conference photos by Kathryn Hedgepeth

Newly Funded Research

No private organization provides more money than the Alzheimer's Association for research into the causes, treatments, prevention, and cure of Alzheimer's disease. Parts I and II in this series featured the work of six scientists who received Association funding in 2001.

Ashley I. Bush, M.D., Ph.D. Part III concludes here with the work of Dr. Ashley I. Bush of Massachusetts General Hospital in Boston, who received funding for his study: *Therapeutic Interdiction of Brain Hydrogen Peroxide in Alzheimer's Disease.*

Dr. Bush and his research team are testing the therapeutic possibilities of decreasing hydrogen peroxide levels in the brains of mice that have been genetically altered to produce beta-amyloid (Ab) deposits. Ab is an abnormal protein fragment found in the neuritic plaques closely associated with Alzheimer's disease.

The basic idea, according to Dr. Bush, is that when Ab binds to copper (which increases in the brain with aging), it turns into an abnormal protein which can convert the plentiful oxygen in the brain into hydrogen peroxide, which is a bleach. Bleaches, by definition, are chemical oxidizing agents, and the

Caregivers in Cyberspace: Pioneers of the Internet

By Jeanette Rosa-Brady

Alzheimer caregivers have entered a new frontier! HealthVision, a health communications research company, has just wrapped up the Alzheimer's Caregiver Internet Support System (ACISS) Research Project.



ACISS was a pilot project hosted by and housed at the Alzheimer's Association, MA Chapter. The goal of ACISS was to determine whether Alzheimer caregivers could receive the services they needed—support groups, counseling, case management, nursing and physician consultations, education programs, and peer support—via the Internet.

Fifty Massachusetts caregivers, half of them new computer users, were given free computers and computer training last year. They completed the project this past spring. The caregivers ranged widely in their ages, in relationship to the person for whom they were caring, and in the disease stage with which they were coping.

The project tested the use of several different cutting-edge types of Internet communication by caregivers who otherwise had a difficult time accessing services due to scheduling problems, being homebound, difficulty receiving respite services, or because they were too far away from services to receive them on a regular basis. Over several months, caregivers sampled the different services to see which worked best for them.

Innovative mix. Some of the services were familiar to those who were already seasoned computer users, such as on-line chat rooms for support groups and an on-line Alzheimer Information Library. Others, such as computer video phone

neuropsychology and education consults, and streaming-audio Alzheimer activities, were new and exciting.

Caregivers filled out monthly questionnaires and feedback forms to let researchers know what they liked best and what didn't work so well regarding their own situations and preferences. A surprising early finding in the study was that several caregivers reported the early stage patients they were caring for liked and used the system as well.

Universal appeal. When asked why she used and liked parts of the Internet site, one early stage patient said, "I think this is even better for patients than for caregivers. I can't drive any more and need these services, too. In my own home is the best place to get them. It's me that this (disease) is happening to."

The project investigators are now compiling all the data collected and will publish the results next year. Hopefully, the results will allow Alzheimer professionals to understand how to best provide service to caregivers who are time-crunched because of their responsibilities, homebound, or simply prefer to access services from the comfort of their own home.

New moon. One participant commented, "I always wanted to know how to use a computer. I love it now and can't imagine doing without it. It was a great experience for me, and I hope it helps others, too."

"You know, I remember the moon landing. Three men changed the whole world's idea of what you could do in outer space. Maybe someday, the other four dozen people in this study and I will be viewed as the people who helped change ideas about what you can do in cyberspace." ❏

Part III: Investigation of Hydrogen Peroxide, Metals Adds Another Piece to the Alzheimer Puzzle

brain in Alzheimer's disease looks like it is being attacked by hydrogen peroxide. Essentially it is being bleached.

CQ treatment. Although antioxidants can fight off some of this attack, Dr. Bush compares their effect to throwing a fire blanket on a chemical fire. He and his research team are operating on the principle that it is far better to turn off the source of the combustion, which is the copper itself.

This is best done by making drugs that specifically bind to copper when it is abnormally reacting with Ab—rather than to normal copper (i.e., not bound to Ab), which is otherwise an essential mineral. Dr. Bush will use the drug clioquinol (CQ) to achieve this effect. CQ acts as a chelator, or chemical binding agent, targeting and attaching itself to the copper bound to Ab while leaving normal copper alone.

Favorable findings in his effort to decrease hydrogen peroxide levels in the brains of transgenic mice, using CQ and other medications, could rapidly be translated into clinical trials.

Editor's notes: The clinical trial of CQ has been completed. That trial was a separate Alzheimer's Association-funded research project for which Dr. Bush, in 2000, received the

Association's prestigious Hatfield Award. The manuscript on the results was recently submitted for publication. Dr. Colin Masters, the principal clinical investigator on the trial, announced encouraging interim results at the 8th International Conference on Alzheimer's Disease and Related Disorders, held in Stockholm in July.



Ashley I. Bush, M.D., Ph.D.

Earlier this summer, our national Association announced an unprecedented 14 new grants for Massachusetts scientists. In the coming months, we look forward to keeping our readers up-to-date about the types of scientific investigations we support by publishing highlights of this exciting new research, as well. ❏

Gerald Flaherty and Catherine Votaw contributed to this article.

Education

A surprising early finding in the study was that several caregivers reported the early stage patients they were caring for liked and used the system as well.

Medicine and Science

Development

5th Annual *Make the Link*

Golf Classic Raises More than \$90,000 for Massachusetts Chapter

By Sandra Gavin

In remarks at the July 22 dinner reception for the Alzheimer's Association's 5th Annual *Make the Link* Golf Tournament at the Andover Country Club, former Boston Bruin Steve Leach said he's looking toward the day "our little ones won't have to deal with this thing called Alzheimer's."

Leach, a Lexington native, movingly recounted how his father had developed the disease when Leach was in high school.

Progress.

Leach said that today he is encouraged by the way the disease has broken out of the shadows and is part of the public's current lexicon. He said that while great progress has been made, everyone's individual help is still necessary as "we still have a way to go."

For the third consecutive year, *Make the Link* was sponsored by Verizon Wireless and presented by Praecis Pharmaceuticals, Inc., both steadfast Association supporters. Other corporate support came from Tufts Secure Horizons, the event's luncheon sponsor; and Motorola, the golfer gift sponsor. The all-day event raised more than \$90,000 in support of our programs and services.

Golfers, more than 140 in all, came from far and wide for the challenging day on the links. Dedicated Golf Committee member **Jenifer Weinstock Fritz** traveled from San Jose, CA to join the 40 golfers she enlisted to attend the event in honor of her father, Arthur "Whitey" Weinstock.

The winning foursome came from Genesis ElderCare: Edward Blake, Jim Noddin, Arthur O'Leary, and Craig Rowley each went home with a Swiss-made Festina watch, graciously donated by DeScenza Jewelers and Festina Watches.

Auction. The successful day's events culminated with an evening silent and live auction with auctioneer Barton Hyte, and a delicious sit-down dinner. More than 100 items were donated.

Event Chair **Bob Cipriani** was delighted with the outcome, which will allow our Association to assist even more people across Massachusetts, and noted that credit is due the scores of supporters, participants, and volunteers. **7**

A foursome enjoying the course (L to R): David Thomson, Dick Fleiss, Hugh MacIsaac, and Honorary Chair, former Boston Bruin Steve Leach.

Photo by Heidi E. Ganss



We are especially grateful to the *Make the Link* Golf Committee:

Bob Cipriani, Chairman
Dick Fleiss
Jenifer Weinstock Fritz
Skip Jenkins
Elisabeth Lang
Steve Leach, Honorary Chair
Jay McMahon
Nancy Mills
Brian O'Hearne
Joe Paresky
Jeff Robinson
Loren Shapiro
Stanley Solomont
Peter Stoner
David Thomson

Special thanks are also extended to the hole sponsors and auction donors:

A Cambridge House Bed & Breakfast Inn
Andover Country Club
B. Yaffe & Sons, Inc.
The Baby Place

Baiting Brook Meadow Farm, Framingham
Bernie Mendelsohn Corp.
The Boston Bruins
Boston Duck Tours
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Greater Boston Media Group
The Green Bay Packers
Guinness and Jennifer Cipriani Curran
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Stanley Solomont
Sonoma Mission Inn & Spa
Staples, Cambridge
David Thomson
Ultima Hair Design, Somerville
We Get Rid of It, Littleton
WEEL-AM
The Wellfleet Beachcomber

3rd Annual Night at the Pops

Taking Patrons to a New Galaxy

By Sheila Watnick

The drum roll prelude exploded into an exciting evening May 29 as Maestro John Williams took the stand to conduct the grand theme song from *Star Wars*, his own original composition! Those few moments set the tone for a spectacular evening of food and music for the 400 Alzheimer's Association supporters gathered at Boston Symphony Hall for our 3rd Annual *Night at the Pops*.

The event raised a record \$100,000 for our programs and services, thanks to presenting sponsor **Praecis Pharmaceuticals, Inc.** and our other sponsors, including Benefactor Cambridgeport Bank; Patrons Beverly Healthcare, Fidelity Investments and Genesis ElderCare; Beverage Sponsor Shirley Spero; and Friends Bingham Dana LLP and Mr. and Mrs. Joseph Gann.

We are also deeply grateful to WGBH's *Classics in the Morning* host **Ron Della Chiesa**, who served as Honorary Chair. And for the third year in a row, we extend kudos to Committee Chair and Board Member **Stanley Solomont**. As a surprise for Stanley, his daughter, Edie Wolf, traveled from Annapolis, M.D. with her husband and children, and introduced her father:

"This special man has inspired me my entire life," she told guests, "and I know he continues to inspire, motivate, and teach others through his efforts with the Alzheimer's Association."

Teamwork. Joining Stanley were tireless committee members Mark Ailinger, Amy Beck, Francesca Correia, Dick Doucette, Judy Green, Joan Johnson, Irene Kaplan, Joan Linsky, Nancy Fernandez Mills, Deb Morrison, Debbie Mozes, David O'Hearne, Pat O'Hearne, Joe Paresky, Katherine Prins, Marc Romvos, Marcia Simons, Shirley Spero, Kathy Stafford, Lisa Marie Stout, Lyn Trojanowski, and Joe Walsh.

Special thanks are extended to pianist Stanley Macht; Joan Johnson for the cocktail floral centerpieces; Edible



The Alzheimer's Association can always count on the support of Marcia Simons, who treated 40 of her friends to a delightful evening. Shown with Mrs. Simons (front, center) are Association President Jim Wessler and Night at the Pops Beverage Sponsor Shirley Spero, one of Mrs. Simons' closest friends and a longtime supporter of the Association.



Night at the Pops Founder and Chair Stanley Solomont (C) with his daughter, Dr. Edith Wolf, and her husband Ron, legendary football great and former manager of the Green Bay Packers.



Honorary Night at the Pops Chair Ron Della Chiesa (R) met with volunteer Greg Dwyer (L) of Cambridge. Greg completed the Boston Marathon in April and raised over \$10,000 for the Association in honor of his father, who has Alzheimer's.

Arrangements for the buffet centerpiece; Kinko's of Framingham for our signs; and freelance producer Bob Comiskey and Leona McCarthy of WCVB-TV Channel 5 for their help with television promotion.

We are extremely grateful to the following people and organizations for their donations of fabulous prize drawing items: Mark Ailinger, Alyce's Fine Jewelry, Ardan Spa Salon, AzuR, The Baby Place, Bakers' Best, Betsy's, The Big Dipper, Bloomingdale's, Boston Symphony Orchestra, Building #19 Foundation, Cambridgeport Bank, Francesca and Manuel Correia, Debsan's Paint & Wallpaper, DeScenza Diamonds, Essentia, Figs, Folklorica, FoodLogic LLC, Globaltex, Green Mountain Coffee, Grettacole, Head Games, Lumiere, Marco

Polo, Marquis Jewelers, Nancy Fernandez Mills, Deb Morrison, Debbie and Jack Mozes, Pat and David O'Hearne, Judith Rhodes, The Ritz-Carlton Hotels of Boston, Yoga Shapes, and Zoots Dry Cleaning.

With the increasing popularity of this event, planners feel that it's just a matter of time before *Night at the Pops* enthusiasts will totally fill Symphony Hall! 🎵



Night at the Pops Committee member Joe Walsh of Lexington attended the event with his family and friends in honor of his wife, Joan.

Development

Third Annual Memory Run

A heartfelt thanks to **JoAnn Tupper** for organizing the 3rd Annual *Memory Run*, a motorcycle race from Framingham to Oxford, MA, held July 14. This one-of-a-kind event raised over \$3,500 for the Alzheimer's Association. Participants enjoyed lunch and a raffle, in addition to a beautiful ride. Many thanks, also, to corporate sponsors and donors Wal-Mart, All Time Tree Care, Dancers Workshop, and Waverly Tool Rental. 🎵

More Newlyweds Make Pledge

Thank you to newlyweds **Antonio Eires** and

Christy Marques of New Bedford, who made a generous gift to the Chapter in loving memory of Christy's grandmother and in lieu of wedding favors. For information on making a gift in conjunction with a milestone event such as a wedding, birthday, anniversary, or retirement, please call our Development Office at (617) 868-6718. 🎵

A Special Thanks! Helen Driscoll Road Race

Thank you to **Ed Nolan** and **Grace Driscoll**, organizers of the Helen Driscoll Road Race, which was held May 11 in Medford and hosted by Medford Mayor Michael McGlynn. Over 500 people participated in this annual event, which raised over \$21,500 for our programs and services. In the past six years, this event has grossed almost \$100,000. Congratulations to **Kevin Hynes** of Medford, the male winner, finishing in 21:49; and to **Laura O'Donnell** of Boston, the female winner, finishing in 25:22.

After the Race, participants enjoyed a lively BBQ and party at the VFW Post 1012, featuring music of Reuben the DJ. Thanks to the following businesses: Marty's Caterers, Domino's Pizza, Pizza Hut, Coach's Pizza, Kayem Hot Dogs, Hood Ice Cream, Medford Police Dept., Medford DPW, and Middlesex County Sheriff's Dept.

Race sponsors include Mass. Electric, Mt. Auburn Hospital, White's Auto Body, Marty's Caterers, Collins Overhead Door, Cataldo Ambulance, Arthur's Pastry, Atlas Liquors, Cross Country Automotive Services, Donahue's Bar and Grille, Cheetah Learning, Eliminator Pest Control, and Adidas Printers. Special thanks to the Dente, Driscoll, Leary, and Lawless families for their tireless support. **7**

Families Celebrate Loved Ones at *Spirit of Remembrance* Dedication

More than 60 family members and friends gathered at the Association's Cambridge Office for a heartwarming, memorable evening May 14 for the 2001 *Spirit of Remembrance* dedication. Each had an opportunity to speak individually about the special people being honored.

Spirit of Remembrance is a multi-paneled acrylic etching featuring a reproduction of *Taking Leave*, a woodblock print by artist Eleanor Rubin, whose mother died of Alzheimer's disease. Four gift categories, ranging from \$250 to \$2,000 and above, entitle donors to memorialize or honor their loved ones. For information on including a name on our 2002 *Spirit of Remembrance* display, please call our Development Office at (617) 868-6718. **7**



Board member Nancy Mills (R) and her daughter, Lauren (L), attended in memory of Nancy's mother Ruth Ferguson, who died on Christmas Eve, 2001.



Dedication Photos by Heidi Ganss

Sisters Frayda Brenner (L) and Donna Dorfman (R), with husbands Barry Brenner and Martin Dorfman, attended in memory of their mother, Charlotte Weiner. Their nephew and Charlotte's grandson, Lee Millstein of Tokyo, also generously supports our Association each year in her memory.



The Peacock family attended the dedication in honor of Jeffrey Peacock, shown at left in photo.

Partners in Progress Kickoff Breakfast

The Alzheimer's Association relies on the generous support of the corporate community to continue our work. On June 11, Board member **Dennis Selkoe, M.D.** of Brigham & Women's Hospital and Harvard Medical School, provided a research update to more than 100 business leaders and supporters at our 1st Annual Partners in Progress Breakfast, hosted by **Pracis Pharmaceuticals, Inc.** at their attractive corporate headquarters in Waltham.

Dr. Selkoe has received our Association's prestigious Pioneer Award for his cutting-edge research into the role of beta-amyloid in Alzheimer's disease.

Thanks, also, to the Association's Development Committee for organizing the event: Kate Salmon-Robinson, Joe Paresky, Stanley Solomont, Bob Margil, Peter Stoner, Elisabeth Lang, Mary Ann Marino, and Joe Walsh. **7**



The Alzheimer's Association is fortunate to have a cadre of committed and dedicated volunteer leaders such as Development Committee members Mary Ann Marino and Joe Paresky, who both attended the Partners in Progress breakfast.



Breakfast Photos by Brenda Vitale

Dr. Malcolm Gefter (L), Founder and CEO of Pracis Pharmaceuticals, hosted our Partners in Progress Breakfast. He is shown here with Dr. Dennis Selkoe (R) of Brigham & Women's Hospital, who gave the research update.

Bernard Reisman, Ph.D., Founding Director of the Hornstein Program in Jewish Communal Service and Professor Emeritus at



Brandeis University, introduced Dennis Selkoe, M.D. Dr. Reisman has articulately and passionately spoken of his own Alzheimer's disease on behalf of our Association and of others with the disease.



Photo by Ed Nolan

Runners in the Helen Driscoll Road Race.

Support Group listing continued from back cover

Mansfield: Christine Filocco or Deborah Supernant	508-261-1333	Westfield: Ellen Nepomuceno	413-781-5070
Marlboro: Bonnie Plankey or Jessica Sorgi Joyce Henderson	508-481-9898 508-485-4040	Weston: Shirley Earle	781-893-0154
Medford: Douglas Lloyd or Sheila Witkus	781-324-5759 781-395-5542	Westport: Susan Oliveira	508-636-1026
Mendon: Marlene Fregeau or MaryPat McDavitt	508-473-0862	Westwood: Peter Byron	781-326-5652
Merrimac: Patricia Lavoie	978-803-3296	Weymouth: Barbara Orlandi Denise Moore or Julie Barcelo	781-337-3121 781-340-9100
Methuen: Donna Koski	978-682-3582	Wilbraham: Beth Vettori	413-596-0006
Middleboro: Robella Coates Carol Ann Landreville	508-946-2490 508-947-4774	Williamstown: Fredrica Sloan	413-458-8127
Milford: Marlene Fregeau	508-473-0862	Winchester: Valerie Gramolini	978-897-7455
Millbury: Michelle Stevens	508-793-0088	Woburn: Jennifer Jaroch	781-932-0350
Nahant: Rev. David Dodge	781-581-1202	Worcester: Faith Bandama Laurie Googins or Ann Fitman	508-791-5543 508-753-4791
Nantucket: Pam Meriam	508-325-5360	Allison Leger	508-752-2546
Natick: Judy Sabol Lois Pecora	508-650-9003 508-655-5000 x3988	Debbie DeRossier	508-754-3800 x126
New Bedford: Jenny Nelia	508-998-7807	Worthington/Cummington: Sandra Epperly or Lucille Temple	413-238-5584
Newburyport: Patricia Lavoie	978-777-2700		
Newton: Mara Klein Emily Saffer or Carol Westheimer	617-928-0007 617-558-6443 781-455-8588		
North Adams: Beth Hinkley	413-664-4536		
Norwood: Mary Beth Whitefield	781-769-4495		
Peabody: Linda Smith	978-531-2254 x137		
Pittsfield: Louise Posnick Robert Hamilton Beth Hinkley	413-445-2300 413-499-0524 413-499-1992		
Plymouth: Deborah Feurtado	508-746-7016		
Quincy: Kathy Prince Beverly Moore	617-471-5712 617-233-1145		
Reading: Marie Ammer	781-942-9059		
Rockland: Laurene Walsh	978-878-0099		
Roxbury: Ilene Marsh or Michael Kincade	617-361-7486 617-868-6718		
Saugus: Debbie Bennett	781-233-8123		
Sharon: Mary Fegan or Christine Lewis Dushku	781-784-6718		
Somerset: John Rogers	508-679-2240		
South Hadley: Gerri Bennett	413-532-8098		
Southbridge: Roger LaMontagne Susan Klezcka	508-765-9771 508-248-7344		
Springfield: Ellen Nepomuceno	413-781-5070		
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Wayland: Candace Steingisser	508-358-3000		
Wellesley: Amy Beck Peggy Mullen	781-237-6400 508-533-7020		
West Springfield: Lois Goralski	413-781-1282		
Westboro: Aimee Rizzo	508-836-4354 x3706		

Specialized Groups**Adult Child Caregivers**

West Roxbury: Susan O'Connell 617-325-1230
or Margaret Wright

Caregivers of Mentally Retarded Adults with AD

Kevin Leahy 781-324-4303

Families of VA Patients with AD

Bedford: Jennifer Hill 781-687-2701

Interfaith Support Group

Framingham: Malka Young 508-875-3100
Springfield: Marcia McKenzie 413-787-1113

People Under 65 Early Stage & Early Onset**Alzheimer's and their Caregivers**

Cambridge: Elaine Silverio 617-868-6718

People with AD and their Caregivers

Wellesley: Peggy Mullen 508-533-7020

People with Early Stage Alzheimer's and their Caregivers

Acton: Kate Marshall 978-369-4728
or Arlene Parillo 978-897-2569

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

Chicopee: Beth Hewson 413-592-5199

Danvers: Carol Owen 978-774-4400 x4022

Natick: Joanne Koenig-Coste 508-879-5338

or Lois Pecora 508-655-5000

Springfield: Ginny Sinkoski 413-787-1111

Webster: Gary Davis 617-653-7242

Westboro: Rosalie Hentz 508-366-9933 x3797

or Muriel Baum 508-435-0019

Weymouth: Julie Barcelo 781-340-9100

Spanish-language Group/En Español

Boston: Conchita Rodriguez 617-868-8599

Spouses' Group

Brockton: Geralann DiDomenico 508-427-6099

Chelmsford: Susan Antkowiak 978-934-0000

West Roxbury: Susan O'Connell 617-325-1230

or Stephanie Walsh


Younger Adult Caregivers

Cambridge: Erin Whalen 617-868-6718

Support Groups

Our web site support group leader list at www.alzmass.org is also updated more frequently. For more information about support groups, including Cape Cod and the Islands, call our Helpline at 800-548-2111.

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

We need your support!

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

Support Groups

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

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

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Please don't toss this Newsletter!

We encourage you to "recycle" Newsletters to a friend, doctor's office, house of worship, or club—and let us know if you wish to be removed from our mailing list.

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Thank you for your payroll deduction contribution.

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Agawam: Judy Pothul	413-821-9911	East Longmeadow: Ellen Nepomuceno Mary Anne Stout	413-781-5070 413-525-8150
Amherst: Melissa Rohde	413-548-6800	Easthampton: Wendy Perrault	413-527-7737
Andover: Kristine Arakelian	978-623-8321	Fall River: Maureen Hebert Judy Elste	508-679-0011 508-675-2101
Arlington: Laurie August	781-316-3400	or Paulette Masse	800-260-6028 x6293
Athol: Wandra Landry	978-249-3717	Fitchburg: Alice Murphy or Joanne Harris Judy Wilson	978-343-5368 978-632-1230
Attleboro: Mary McCormick or Ginny McDermott	508-222-6655 508-222-0118 x2122	Foxboro: Diane Caldwell	508-337-8419
Sharon Leary	978-226-6150	Framingham: Judy Sabol	508-650-9003
Belmont: Nava Niv-Vogel or Lauren Storck	617-484-5501 617-484-0949	Gardner: Judy Wilson Ray Cormier	978-632-1230 978-632-5477
Boston: Barbara Hawley or Maureen Tardelli	617-724-0055 617-391-7878	Gloucester: Margaret Marasco	978-281-1750
Bourne: Judy Anthony	508-759-0654	Great Barrington: Kelly Thorne	413-528-2650
Braintree: Denise Hughes or Chris Togneri	781-848-2714	Hadley: Linda Wallace or Jennifer Read	413-584-5057
Bridgewater: Kathy Hayes or Sue Daniels	508-697-0929 508-697-4368	Haverhill: John Freeman or Nancy Savarese	978-346-4743 978-683-2771
Brockton: Nancy Bresciani Marie Albert, RN	508-583-2517 508-587-6556	Hingham: Jo Ann Mitchell Eleanor Blair	781-749-5417 781-749-4774
Brookline: Pattie Chase or Howard Block	617-232-8848 617-277-4289	Holden: Naomi Sohlman	508-829-0270
Burlington: Stacey Kohler or Sue Mike Ann Cooper	781-744-8114 781-270-9008 x202	Hyde Park: Wendy Marks	781-449-5368
or Nancy Kinton	781-721-0788	Jamaica Plain: Tara Fleming or Susan Kelley-Grasso	617-983-2300 617-868-6718
Cambridge: Alice McCarter or Mary Costello	617-547-3543 x25	Kingston: Hollie Spooner	781-585-4100
Trudy Bauer or Ruth Gordon	617-491-1815	Lancaster: Christi Mendoza	978-365-4537
Canton: Susan Sheehan	781-828-7450 x307	Lee: Dolores Thimot	413-243-4747
Chelmsford: Pat Keene Susan Antkowiak	978-251-8491 978-934-0000	Leicester: Eva Dawson	508-987-8056
Chicopee: Judy Pothul	413-821-9911	Lexington: Sandy Simon	781-861-2742
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		Lynn: Lisa Mercurio or Mark Hurd	781-596-2992 781-581-7197
		Malden: Mary Darling	781-324-4999 X216

Support Group listing continues on inside cover

CONTACT CENTER/HELPLINE 24/7: (800) 548-2111



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