

New Hampshire Newsletter

The Alzheimer's Association serves the entire state from Seacoast to Monadnock to the White Mountains

Fall 2008

www.alz.org/NH
24/7 Helpline: 1.800.272.3900

Advocates MOVE the Cause

By Jennifer Carter

Manager of Advocacy & Community Relations

Advocacy today includes traditional grassroots campaigns as well as cyber-advocacy on the internet. In all forms, advocacy is a major component of the Alzheimer's Association's mission. The Association's advocacy corps includes people with Alzheimer's and related disorders, caregivers, health care professionals, friends and families whose voices come together as a powerful tool for change and hope of a future without Alzheimer's.

Alzheimer advocates are calling for advancements in research and enhanced care and support at the federal, state and local levels. Nationally, results have included protecting federal research funding. In New Hampshire, advocates are leading the fight for a statewide Alzheimer's plan.

Advocates can take on many different tasks. They can help increase public awareness and promoting state and federal issues by sending e-mails, phoning senators and representatives, and attending the three-day public policy forum held each year in Washington D.C. Advocates can find their niche, can make a difference. This year, advocates brought Alzheimer issues to the presidential primaries across the state. The Association's e-newsletter, e-action alerts and this newsletter are all ways to keep up-to-date on Alzheimer's issues.

State and Federal Legislators Listen

Letters and e-mails are frontline tools to alert legislators to Alzheimer's issues. The volume of letters and e-mails a public official receives on an issue can affect the way he/she votes. One letter can make the difference. Officials also appreciate office visits or scheduled meetings with the public. Person-to-person visits are the most effective way of letting a public official know about the issues that matter to their constituents.

Phone calls are extremely effective in advocacy. Elected officials and other government decision-makers pay atten-

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Mark Your Calendars Now

Memory Walk – Saturday, September 20, Concord, Keene, Manchester & Portsmouth
See page 5

World Alzheimer's Day, Sunday, September 21

Candlelight Vigil, Thursday, November 13, Concord, State House Plaza

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SAVE THE DATE

**Candlelight Vigil
In honor of National
Alzheimer's Disease Month**

Thursday, November 13,
State House Plaza, Concord
6:00pm – 7:00pm

**Please RSVP
by calling 603.606.6590**

Light Refreshments Provided

Sign-up Today NH Alzheimer's Association Events & E-News

Quick & Easy updates.
Delivered directly to your mailbox.
E-mail to sign up:
communications@alzmass.org
Or call 603.606.6590

Alzheimer's Association New Hampshire Office

One Bedford Farms Drive – Suite 105
Bedford, New Hampshire 03110

www.alz.org/NH
24/7 Helpline
800.272.3900

President and Chief Executive Officer

James Wessler, MBA

Staff

Susan Antkowiak, *Manager of Programs*
Linda Wright, *Coordinator, Administrative Services*
Cynthia Rybczyk, *Development Officer*
Liz McConnell, *Manager, Advocacy &
Community Relations*

Newsletter

Betsy Fitzgerald Percoski, *Editor*
Ginger LaBella Productions, LLC, *Design Consultant*
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From the President

“We’re being too nice.”

These were the words of Mary Pacella, chair of our Chapter’s Public Policy Committee, upon her return from the Public Policy Forum in Washington D.C. As you will read in this newsletter, Mary had joined up with hundreds of advocates from around the nation who traveled to the Capital, trying to convince our national leadership to focus on the growing epidemic of Alzheimer’s.

The Centers for Disease Control (CDC) recently announced that Alzheimer’s has now replaced diabetes as the 6th leading cause of death among Americans.

As we tackle these issues, we are grateful for the leaders who have guided us over the past years, and those taking up the challenge. We want to acknowledge a few retiring and departing leaders.

Thank you to Ann Hurley, Pam Kunkemueller, Ben Liptzin, and Tim Morrison for their dedication and hard work as members of our Board of Directors. And, a very special thank-

you to Mary Ann Marino for her leadership as the Chair of our Board of Directors.



Welcome to six new Board members: Ken Anding, Mary Card, Anne Cayer, Jo Ann Jordan, Suzanne Lissy, and Arlene Lowney. And, congratulations to our new officers: Board Chair, Jeffrey Berry; Vice Chair, John Yahres; Treasurer, Paul Stuka; and Clerk, Paul Donovan.

Mary Pacella is correct, we are being too nice. Whether it is advocating for more funding for research or for basic consumer protections in nursing homes with Alzheimer’s special care units, we need to be more assertive. So join up with Mary and become an advocate today and help us build a promising future.

—James Wessler, President and CEO

Volunteer!

The Alzheimer's Association counts on thousands of volunteers. Please join us. Visit our website at www.alz.org/NH for upcoming volunteer opportunities.

Our mission is to eliminate Alzheimer's disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's.

helpline corner

By Lindsay Brennan, Manager, Helpline Services

Q: My wife is in the late stages of Alzheimer's disease and lives in a nursing home; she can't get out of bed, can hardly move or speak. I visit her every day and found myself becoming very depressed because I had no way of connecting with her. Then one day I had an idea and I got permission from the nurse – I took off my shoes and climbed into bed with my wife, cuddling close, hugging and kissing her. I told my wife that I loved her and then I asked her if she loved me, but there was no answer. I told her again that I loved her and asked the question again and told her to say "yes" or "no" – all of a sudden she said "yes." I was ecstatic, it was the first word she had spoken in months – I had never been so happy in my life. Now when I visit, I get in bed with her for about an hour and I finally feel like I am connecting with her again. I am now a happy man, I am much less depressed. Do you think that this is okay to do? –S. Rogers, Newton, MA

A: Thank you so much for sharing your personal story with us so that we are able to share it with so many others who might benefit from it. Yes. What you are doing is okay; in fact it is perfect late stage care. You have found a way to meet your wife in the moment and emotionally connect with her through physical contact. Even in the very advanced stages of this disease we believe that people are able to feel and react to emotions. I applaud your achievement – you have found a way to connect with your lifelong partner despite the effects of Alzheimer's disease. I guess love does conquer all.

Stage Play Highlights Health Fair

The UpperValley Memory Center, the Centers for Health and Aging and the New Hampshire Office of the Alzheimer's Association, MA/NH Chapter will present a performance of the play, "Norman and Beatrice." This one act play, written by Barbara Hammond, is about a man with Alzheimer's disease and his wife who cares for him despite his sometimes erratic and unpredictable behavior. Ms Hammond is an accomplished and well-recognized playwright, currently living in New York City.

Following this entertaining and very moving production, audience members will be encouraged to participate in a discussion about their experiences with Alzheimer's disease and care giving.

This production is part of the Sixth Annual Autumn Community Health Fair and UpperValley Memory Fair at Dartmouth Hitchcock Medical Center in Lebanon, Sunday November 2, 2008, 8 a.m.–1:00 p.m. The play and discussion will be presented in Auditorium E and F from 10:00 a.m.–11:30 am.

updates

Will Reiter Named Director of Education



Will Reiter has joined the Alzheimer's Association, MA/NH Chapter as Director of Education. Will follows in the formidable footsteps of Rachel Hawk who retired in June after 21 years with the Association. He will oversee educational programs for families and people with Alzheimer's, along with an array of professionals' trainings including the annual A Map Through the Maze conference.

Will comes to the Association with more than 20 years of experience working with and coordinating programs assisting individuals, families and professionals responding to the challenges of dementia and other chronic health concerns. Initially trained as a music therapist, he developed and managed a unique adult day program in Philadelphia, serving older adults with developmental disabilities or with cognitive impairments. As Education Coordinator at Family Caregiver Alliance in San Francisco, he directed an educational program for families and professionals, including a pilot program using conference call technology, enabling easier access from the convenience of home. Most recently, Will worked as Assistant Director of Community Programs at Elder Services in Lawrence, Massachusetts.

Go Purple — World Alzheimer's Day is Sunday, September 21. Show your support for the millions worldwide with Alzheimer's. "Go Purple" for the day!

Use a purple font in e-mails, or dress in purple or best yet, tie purple ribbons in your community.

For your free purple ribbons, e-mail Linda.Wright@alz.org.

support

Tips for Late Stage Care: Oral Hygiene

With so many things to do when caring for a person in the later stages of a dementing illness, it is easy to forget about what's happening inside the mouth. Providing meticulous oral hygiene for a person who is unable to perform this task presents a considerable challenge, particularly when cooperation is an issue. However, good oral hygiene will lead to better eating and drinking and prevent the pain of sores or deteriorating teeth.

- The need for carefully vigorous twice daily brushing with a child sized brush and a safe-to-swallow toothpaste cannot be overemphasized. For those without teeth, use a very soft toothbrush or gauze moistened with saliva substitute. Remain attentive to good care of dentures.
- A dry mouth is not healthy. Mouth breathing, medications and the person's own inattention to the situation make it worse. Swabbing the entire inside of the mouth several times a day will help to maintain or

add moisture. Use gauze with a saliva substitute or buy prepared swabs at the pharmacy. If drinking doesn't cause choking, offer sugarless fluids frequently.

- Choose times of relaxing quiet. Don't rush.
- Sometimes occupying the person's hands with an object helps with cooperation.
- Raise the head of the bed, or at least add a thick pillow. Approach from the front and move to the side, sit down if possible so as to be less threatening. Touch the cheek, quietly ask to "open your mouth." Then "I'm cleaning your teeth—doesn't this taste good?"
- It does take some time to become comfortable and adept at cleaning someone else's teeth and mouth.
- Maintain regular visits to the dentist as long as possible and have a conversation with the dentist about what to do next. Some dentists will make home visits.

New Hampshire Alzheimer Support Groups

Berlin: Tiffany Kenison	603.752.3336
Concord: Trudy Bantle	603.228.1108
Jaffrey: Lori Lohrmann	603.532.2428
Keene: Lucy Stonewall	603.355.8281
Lebanon: Robert Santulli	603.650.5804
Manchester: Pam Potter	603.621.3548
Manchester: Nancy Zidle	603.621.3548
Meredith: Frank Vignand	603.279.8111 x123
Nashua: Beverly Remillard	603.888.1573
Nashua: Colleen Wentworth	603.595.3722
Newport: Lorraine Strobble	603.543.6800
Plymouth: Kathy Wieliczko	603.238.2216
Portsmouth: Nancy Lamoureux	603.430.8615
Rochester: Hanna Jacoby	603.335.1770
Wolfeboro: Linda Johnson	603.323.9394 x24

New Hampshire Caregiver Support Groups

Boscawen: Faith Flint	603.796.2165 x202
Colebrook: Tiffany Kenison	603.752.3336
Laconia: Pat Marceau	603.524.8444
Lebanon: Jane Conklin	603.448.1558
Londonderry: Stacy Thrall	603.425.1770
Manchester: Sheryl Brooks	603.624.4717 x12
N. Haverhill: Tony Gahn	603.787.6971 x183

Massachusetts Alzheimer Caregiver Groups Near the New Hampshire Border

Amesbury: Patricia Lavoie	978.290.1797
Andover: Kristine Arakelian	978.623.8321
Athol: Wanda Landry	978.249.3717
Chelmsford: Patty Keane	978.251.8491
Fitchburg: Harriet Klayman	978.343.5216
Fitchburg: Judy Wilson	978.342.9428
Lowell: Maria Maskaluk	978.458.4844
Shelburne Falls: Jackie Stanford	413.625.2502
Turners Falls: Molly Chambers	413.773.5555 x262

Planned Giving

Did you realize that there are ways to support Alzheimer's Association programs and research while...

- Reducing your income or capital gains taxes?
- Receiving a stream of income for your (and your spouse's) lifetime that will be partially tax-free?
- Helping your heirs minimize costly estate taxes?

You and your family could benefit from any number of Planned Gift options, including:

- Charitable Gift Annuity
- Charitable Lead or Remainder Trust
- IRA Rollover
- Gift of Life Insurance, Real Estate, or other non-cash asset
- Gifts of appreciated stock
- Will provision

For more information, contact Laura Ewing-Mahoney at Alzheimer's Association, Northeast Regional Planned Giving Office at 603.362.4687 or at laura.ewing-mahoney@alz.org.

alzheimer's association  **memory walk'08®**

4 Regional Sites in New Hampshire

Saturday, September 20
Registration at 8:30 AM
Walks start at 10:00 AM

Capital Area Walk

State House Lawn
 107 North Main Street, Concord
 Contact Kim Landry at 603.731.5577
 or kimlandry@comcast.net

Monadnock Region Walk



Keene State College
 229 Main Street, Keene
 Contact Bonnie Moore at 603.357.3902 x3023
 or info@memorywalknh.org

Seacoast Area Walk

Pease Tradeport
 2 International Drive, Portsmouth
 Contact Jessica Slattery at 603.772.5251
 or jessica.slattery@sunh.com

Southern New Hampshire Walk

Fisher Cats Stadium
 1 Line Drive, Manchester
 Contact Laurie Mantz at 603.647.9300
 or lmantz@arborsofbedford.com

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Volunteer Patron MORIARTY	In-kind sponsor The Clarks Companies, N.A.  Media partner 

16th Annual Memory Walk
www.memorywalknh.org
603.606.6590

WE'RE ON THE MOVE
TO END ALZHEIMER'S

For a brochure or team tool kit or to find out about sponsorship, exhibitors and ways to volunteer, contact 603.606.6590 or info@memorywalknh.org



PLUS!
 Nine walks
 September 13-28 in
 Massachusetts:
 www.memorywalkma.org

education

Online, by phone Learn About Alzheimer's Education Programs

Living with Alzheimer's disease or providing assistance or care, means that your need for information or education may change over time. For the most up-to-date information about all the Alzheimer's Association's education programs, utilize our easy to use website or call us for more information.

Our website provides a current listing of our classes and workshops for individuals with Alzheimer's disease, family members and professionals. Go to our website, at www.alz.org/NH and click on "Education Programs Calendar" at the left side of the page. You can click on each program for more specific details.

The online calendar gives a month-at-a-glance list of the education programs and community events, the city or town where they are being offered and the date. Be sure to check back regularly to see new programs in your area.

We are always happy to talk with you directly about one of our programs and whether it can meet your needs. Call us at 800.272.3900 if you are interested in learning more about a program, and one of our staff members can help you. They can share with you when and where a program is being offered and help you decide if it's right for you.

To learn more,
visit our website at
www.alz.org/NH or
call 1.800.272.3900.

Alzheimer's Education Programs

Programs are FREE (unless otherwise noted), but group size is limited. Registration is required.

PROGRAMS FOR FAMILY CAREGIVERS

The following programs are for family members caring for someone with Alzheimer's disease or a related dementia. We ask that professionals not attend these programs. Professional programs are listed separately.

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

This 2.5 hour comprehensive program is for families just starting to care for someone with Alzheimer's or a related dementia. It focuses on how to get a diagnosis, understanding and addressing behavior and communication problems, how to find and what to expect from local resources.

Alzheimer's Disease Legal and Financial Issues & Answers

Too many families wait until it's too late before learning about legal and financial concerns. This 1.5 hour presentation by an elder law attorney provides information about wills, durable power of attorney, protection of assets, health care proxy, and what Medicare and Medicaid do and do not cover. Regardless of your financial situation, learn how to avoid common problems through adequate planning.

PROGRAMS FOR THE COMMUNITY

Maintain Your Brain: How to Live a Brain-Healthy Lifestyle

Find out what you can do to keep your brain healthy and help reduce the risk of getting Alzheimer's disease. This 1 hour workshop focuses on scientifically-based nutritional and lifestyle advice, and includes interactive exercises and activities. This program is for adults who want to learn more about staying fit from the neck up!

November
is National Alzheimer's
Disease Month. Please check
our website www.alz.org/NH
for special events &
programs.

PROGRAMS FOR PROFESSIONALS

Care for People with Alzheimer's disease: A Train-the-Trainer Program for Professionals

This program provides tools to train staff in the Habilitation model of Alzheimer's care, which emphasizes taking advantage of an individual's potential instead of his or her deficits. It also addresses improving functional independence while reducing the need for psychoactive medications. Participants spend one full day learning the curriculum. Participants receive trainer materials, including the lectures, handouts, tests, discussion questions, and role plays for 12 hours of training to direct care staff. CEU's available for certain disciplines. Registration: \$300 per registrant, \$500 for 2 registrants from the same company.

Activity Based Alzheimer Care: Building a Therapeutic Program

ABAC is a one day, interactive training for activity professionals who already possess a basic understanding of Alzheimer's disease. Energetic and experiential exercises, case studies and discussion help you design and implement a successful and varied activity program. Each participant receives a reference manual. Seven contact hours available for Activity Professionals. Early Bird Registration: \$200, Regular Registration: \$225.

SAVE THE DATE!**2008 Matthew & Marcia Simons Research Symposium:****A New Era in the Understanding and Treatment of Alzheimer's Disease**

The annual Matthew & Marcia Simons Research Symposium on Alzheimer's disease is the centerpiece of the Alzheimer's Association, MA/NH Chapter's yearly scientific presentations. This year's lecture will feature Dale B. Schenk, PhD, Executive Vice President & Chief Scientific Officer for Elan Pharmaceuticals, the Association's Medical & Scientific Advisory Committee announced.

Dr. Schenk has gained national attention as the inventor of an immunotherapy that is currently in clinical trials for treatment of Alzheimer's disease.

Join us Thursday, October 30, 2008 at the Cambridge Marriott Hotel, Kendall Square (50 Broadway), Cambridge. Ample parking will be available onsite. Call 617.868.6718 for early registration information.

Alzheimer's 101

Designed for professionals, such as nurses, social workers, home health aides, or nursing assistants who are new to the field. This program provides current information about Alzheimer's Disease and related disorders, the diagnostic process, the stages of Alzheimer's and current treatments. This half day program is \$40 per registrant.

Support Group Leader Training

Support groups are a lifeline for people with Alzheimer's and those who love and care for them. Along with this intensive group leader training, we offer ongoing support for group leaders, refresher courses and online resources. Training is \$65 per person and CEU's are offered for Social Workers, Nursing, Activity Professionals and Licensed Mental Health Counselors.

Foundations of Dementia Care

This comprehensive training is based on the Alzheimer's Association Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes. It focuses on person-centered care, teaching direct care providers to make better connections with residents with dementia, resulting in improved quality of life for both residents and staff. Flexible time configurations and onsite training can be arranged. CEU's are available. For pricing information and to learn more about this program, call 617.868.6718. Learning modules include:

- Learning to Lead (for supervisors)
- About Dementia
- Enhancing Mealtimes
- Reducing Pain
- Making Connections
- Falls and Restraints
- Wandering
- End of Life Care

Advocates MOVE *continued from page 1*

tion when citizens take the time to call and express their views on an issue. When time is critical, phone calls are quicker and easier than writing. If an issue is moving fast, a phone call may be the only way to get a message through in time to make an impact. Contact information for state and federal representatives can be found at www.alz.org.

Hearings, town meetings, and forums provide a chance to put issues before policy-makers and fellow townspeople. These kinds of meetings are also a way to learn more about how the policy making process works, and to monitor the work of public agencies and bodies.

Local media affords exposure through opinion forums such as call-in talk radio and letters to the editor. Legislators, government officials, and their key staff follow opinion forums closely. More and more, there are also community discussion groups and bulletin boards that allow for opinions as long as they have an impact on local residents. Making the case for a position on a bill or issue in any of the various media puts pressure on public officials to take action.

Putting a "face" on Alzheimer's is one of the most important ways to advocate. Each person willing to tell his or her story adds to the growing advocacy on behalf of Alzheimer issues. Whether agreeing to be interviewed by the media, or testifying before a panel of policy makers, each advocate has an impact far beyond the reach of a phone call or a letter.

Advocacy is Your Story

The most effective advocates are knowledgeable about the issues, but they also recognize that nothing can substitute for individual experiences with Alzheimer's disease. Personal stories most clearly show elected representatives the human scope and impact of the disease.

The advocacy successes of the Alzheimer's Association are the result of advocate volunteers. From assisted living regulations that set standards for dementia care to funding for research, advocates have played a key role in making things happen. To learn more, contact Liz McConnell at ElizabethMcConnell@alz.com

support



Profile: Tiffany Kenison

Tiffany Kenison is the Program Manager for Tri-County CAP's, Alzheimer's Health Care Services and the Caregiver Specialist for ServiceLink of Coos County. Her role in the North Country includes managing two adult day programs, and facilitating three Alzheimer caregiver support groups. Tiffany has been doing a group in Berlin for two years, a group in Whitefield Support group for almost a year, and just started a new group in Colebrook this past spring.

Why do you feel support groups are so important?

Groups are a safe place where caregivers can express their feelings, not feel alone and receive helpful feedback and information. It's amazing to see how a quickly people relax when they are in a room with others who are experiencing the same hardships. It's also important to give caregivers the opportunity to interact since [studies have shown] that this is key to significantly reducing caregiver burnout.

What do you find are the best moments in your support groups?

Recently in one of my groups one caregiver kept making excuses as to why he couldn't get additional help. He said his wife only wanted his help, etc. Another member stopped him and said, "Nobody can do this alone. Give up some pride and accept that you can't do it all.

Maybe having someone else help isn't your or your wife's first choice but that doesn't matter. If you get sick she will be in a much worse situation. You need help! You can't feel bad about it.

Having help ensures that you'll be able to continue being a good caregiver."

Other members agreed.

The husband left the support group with a new outlook. He felt less guilty, less at fault, and realized asking for help was a positive thing not an admission of defeat. These eye-opener moments are my favorite support group moments.

What is special about support groups? Why do you think they are better than reading a book or information on the internet?

Learning about Alzheimer's any way you can is great! But as a professional I

know I can say the same thing to a caregiver as a group member does, but coming from another caregiver who has experienced or is experiencing a situation, it has much more impact. They live the disease everyday and no books or training will ever give me or anyone else the knowledge they have and share together each meeting.

What do you think caregivers should know about your support groups?

I feel I am there to facilitate and support. The caregivers who attend and share with each other make the group as successful as it is. Anyone attending any group should know that they will immediately realize they are not alone in caring for someone with Alzheimer's, they will reduce their stress level, and that all members will experience eye opening moments and relief. Also, no caregiver should be afraid to go to a group because they think they might be depressing--they're not!

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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.

alzheimer's  association®

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