

## Annual Meeting Highlights

The Alzheimer's Association held its 23rd annual meeting on November 16, 2004, at Oak Hill Country Club. Among the more than 150 guests were New York State Senator Joseph Robach; Joan Harrison, District Representative of New York State Senator Dale Volker; and Michelle Marini, Chief of Staff of New York State Assemblyman Bill Reilich.

Sheldon Goldberg, President and CEO of the National Alzheimer's Association, gave the keynote address. Mr. Goldberg spoke of the Association's leadership role in Alzheimer's disease research, advocacy and support.

At the meeting, Jim Ruppert was awarded the first Celebrating the Spirit Award, established by the Alzheimer's Association in Jim Ruppert's name in recognition of his unselfish efforts on behalf of persons with dementia. In the future, the award will be presented to a person who, like the honoree, exemplifies the spirit of leadership, the spirit of advocacy and the spirit of sharing their story.

The Alzheimer's Association also awarded the 6th Annual Quality of Life Awards. This year, the Fairport Baptist Home's first floor staff received the Quality of Life Award for Outstanding Provider. The award winner for Outstanding Individual was Nancy O'Hara Kraft.

During the event, key community members were recognized for their exceptional contribution in support of the Alzheimer's Association's Memory Walk. The recipients of this year's Memory Walk Leadership Awards were: Steve Dawe, Promotion Director and Christine Webb, Anchor and Health Correspondent for WHAM TV 13; Mary Bennett, Linda Burnett, Beverly Wheaton and Pam Schilstra for the "Shirls' Girls," a Memory Walk Family and Friend Team; and Thompson Health of Canandaigua, Linda Janczak, President/CEO, Thompson Health, Sharon Pepper, President/CEO, Thompson Health M.M. Ewing Continuing Care Center, and Barbara McNabb-Sperling, Recreation Therapy Coordinator, M.M. Ewing Continuing Care Center.

## Research Roundtable



Preceding the Annual Meeting, the Alzheimer's Association hosted a Research Roundtable. Among the invited attendees and guest speakers were renowned local researchers and physicians, and faculty of the Alzheimer's Association Learning Institute™. *From the left, Alzheimer's Association Board Member Margaret M. Bills, T. Franklin Williams, M.D., Alzheimer's Association President/CEO Sheldon Goldberg, and Charles Duffy, M.D., Ph.D.*

## 3<sup>rd</sup> Annual Symposium

*"Ethical Issues from Diagnosis to Dying"*



Presenter:

Dr. Stephen G. Post

Thursday, June 2, 2005  
RIT Inn & Conference Center

Both family caregivers and professionals are encouraged to attend this year's Symposium

Watch our website at [www.alz-rochesterny.org](http://www.alz-rochesterny.org), for a brochure in early May or contact Kelly Harris at 585-760-5405 for further information.

## Ribbon Cutting Ceremony at the Alzheimer's Support Ministry

On Sunday, October 17th, the Alzheimer's Association and Mt. Olivet Baptist Church announced the grand opening of the **Alzheimer's Support Ministry** at the Mt. Olivet Baptist Church. Members of the congregation and the Rochester community joined together in support of this unique faith based program serving the Corn Hill district. The ministry offers a wealth of resources for those affected by Alzheimer's and hosts support groups and caregiver educational seminars on site. For more information on the ministry please call 585-454-0280.



*Pictured left to right: Reverend Dr. Dwight Cook, Loren Ranaletta, Ralph Richards, Teresa Stewart, Mollie Richards, Senator Joe Robach.*

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**WHAT'S NEW IN  
RESEARCH**

By *Pierre Tariot, MD*  
*Geriatric Neurology & Psychiatry Clinic,  
University of Rochester Medical Center*

**My Opinion About the  
Vitamin E Brouhaha!**

A recent study (Ann Intern Med 2004; 142:1-10) looked at deaths in 136,000 subjects who were treated with vitamin E or combinations of vitamin E and other vitamins or minerals, relative to placebo, in a number of controlled trials. Most of the people in these studies had coronary artery disease. None of the individual studies showed an increased risk of death for subjects receiving vitamin E. However, when the studies were arranged by dose of vitamin E, it appeared that those treated with low to moderate doses of vitamin E had a very slight protection against death while those on high dose vitamin E were at a very slightly higher risk of death. The majority of the deaths occurred in individuals who had known coronary artery disease.

A study has been completed looking at the effects of high dose vitamin E in patients with Alzheimer's disease (AD). Patients treated with high dose vitamin E (2,000 IU/day) for up to 24 months reached functional milestones more slowly than individuals treated with placebo. There was no increase in the death rate and slightly fewer patients on vitamin E died during the course of the trial compared to patients on placebo. There were more side effects in the people taking the vitamin E than those taking placebo. Some epidemiological studies have made the observation that people who eat diets rich in vitamin E and other antioxidants, and possibly those who take supplemental vitamin E, have a decreased risk of developing Alzheimer's disease. Doses of vitamin E supplements varied

quite markedly. There are several ongoing clinical trials looking at whether vitamin E supplements reduce the risk of cognitive decline or dementia. This kind of evidence usually does not influence practice very much.

Based on the pooled data in the recent vitamin E paper, I am forced to admit that it is difficult to draw firm conclusions or make recommendations. The benefits of vitamin E supplements for AD prevention are unproven, although there is little harm in a high antioxidant diet. A cautious interpretation of the risk reported in the new study would be that normal individuals should limit their intake of vitamin E to no more than 400 IU per day. For individuals with AD, the results are less clear. High dose vitamin E was beneficial and in this population the risk of death was not increased. Since the Alzheimer's trial was much smaller than the published cardiovascular trials, it is possible that a small degree of increased risk could not be detected. It is unclear whether the risk-benefit ratio warrants use of 2000 IU of vitamin E or whether a lower dose should be recommended, although in practice I see lower side effect rates at doses at or below 800-1,000 IU/day, and have typically recommended this dose range. An additional caution is that the protective effects of statins on cardiovascular disease can be attenuated by the addition of anti-oxidants, suggesting that individuals with coronary artery disease who are on statins should not take high doses of vitamin E. My opinion, and that is all it is, is that it remains reasonable to maintain patients with Alzheimer's disease on high doses of vitamin E unless coronary artery disease is present, in which case a reduction in dose to 400 IU per day might be considered. There will undoubtedly be new information forthcoming. We will try to keep you posted.

*This column has been supported as a tribute to the life of Florence Wethey by her family.*

**Voices**

**This issue's question:** What were your feelings at the time you were diagnosed?

**The panel's responses:**

"I couldn't believe it."

"Relief, although it confirmed what I feared."

"Doubt at first. Then I wanted to die because I knew what [another] family member had gone through."

"Fear for the future."

"There must have been a mistake. I thought I would overcome it. But I'm in tough shape now and my spouse has to carry the load."

"Surprised, but I knew my faith in God would help me weather this. If He allowed this to happen then He will give me the grace to handle it."

*Voices is a new feature of the newsletter that poses questions to a panel of people with dementia. If you have a question for the panel or would like to know more about joining, please contact Debbie Houck at 585-760-5411.*

Current panel members: B., Bill, Carl, Frank, Harry, Jim, Lee, Norma

**Don't forget to  
Designate #130  
on your United  
Way donation  
form this  
Spring!**

**If you need help  
filling out the  
forms, let us know  
by calling**

**585-760-5418.**





**Debbie Houck**  
Senior Resource Specialist

## “Dear Debbie”

**Q:** My daughters keep telling me that I should go to a support group but I don't want to sit around and listen to a bunch of people complaining—I have enough of my own problems. How can I get my daughters to understand this?

**A:** I'm sure that your family is trying to be helpful and recognizes the benefit that a support group could provide to you. For instance, in a support group you can be open and honest about your feelings and the problems you are encountering. It's a place where you can talk freely about your caregiving role, your family, day-to-day issues, your feelings and even coping strategies such as humor. Other attendees truly understand how you feel. In addition, you may learn how others handle specific situations because people in the group may have had similar experiences. You are not alone in this and finding support can be very beneficial. We often suggest trying a couple of different groups until you find one that meets your needs and makes you feel comfortable. Of course, the group experience is not for everyone, so if you'd like to know about other options for support you can contact our Resource Office at 585-760-5411 or 800-724-0587.

## What's New in the Marie C. & Joseph C. Wilson Library

### Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease

By Joanne Koenig Coste

Developed for use at home with her husband, and easily adaptable for others, the author has identified the tools that allow a person with Alzheimer's to function at their optimal ability. By adopting the five principles explained in depth, care partners will learn to focus on the person's feelings, choices and strengths. There are many examples and practical tips for dealing with a variety of situations, along with suggestions for obtaining support and taking care of the care partner.

### The Best Friends Book of Alzheimer's Activities

By Bell, Troxel, Cox and Hamon

This easy to use book has over 100 activities that incorporate the “best friends” model of care\*. By using “the knack”, everyday activities and interactions become more meaningful for both the person with dementia and their care partner, whether in a facility or at home. Fifteen activity-specific guidelines are offered. In addition, there is an easy-reference grid that may help with choosing activities at a glance.

\*Companion books using the best friends model include: *The Best Friends Approach to Alzheimer's Care*, *The Best Friends Staff*, and *A Dignified Life - which is specifically for family caregivers*.

### Mental Aerobics: 75 Ways to Keep Your Brain Fit

By Barbara Bruce

The author provides the reader with 75 suggestions for stimulating your brain and maintaining your thought processes. There are a variety of exercises throughout the book called “brain breaks”. Many of these activities are adaptable so that you can use them repeatedly in a variety of ways. Tips for paying attention to attitude, challenging yourself, and enhancing memory are shared, along with recommendations for diet and exercise, and suggestions for life long learning activities.

For further information regarding Alzheimer's resources, please contact our Resource Office at 585-760-5400 or 800-724-0587.

## Log On

[www.alz-rochesterny.org](http://www.alz-rochesterny.org)

What's going on in our nine county Finger Lakes region for people affected by Alzheimer's disease? You'll find out here at our agency website with information on programs, services and events. There's also a “Contact Us” option if you would like to request specific information from one of our staff.

[www.alz.org](http://www.alz.org)

The National Alzheimer's Association website offers information for persons with dementia, their professional and family caregivers and advocates. Get connected to advocacy efforts, research programs and a variety of appropriate links and area chapters.

[www.memoryhelp.us](http://www.memoryhelp.us)

A program of the University of Rochester to provide care, research and treatment services for families affected by dementia and related memory disorders. There is information about clinical trials and studies that are currently enrolling participants, including the newest study evaluating an investigational medication to see if it alleviates the symptoms of Alzheimer's disease.

[www.alznys.org](http://www.alznys.org)

The New York State Coalition of Alzheimer's Association Chapters is working diligently to assure that every voice is heard in the effort to help people with Alzheimer's disease, their caregivers and families. Find out about advocacy efforts including upcoming events, what's happening at state and national levels and how to lend your voice in this critical campaign.

[www.howsyourhealth.org](http://www.howsyourhealth.org)

A consumer-focused initiative coordinated by the Rochester Health Commission to encourage individuals to log on to this free, noncommercial, anonymous website and complete a user-friendly survey developed by a geriatrician from Dartmouth. Once the survey is completed, individuals are provided with a one or two page summary to take to their doctor, an education packet of information unique to their needs and other forms to help them manage their health.

## Video Corner

### Alzheimer's Disease: Natural Feeding Techniques

This video features techniques for feeding individuals in the late stage of Alzheimer's disease. It follows three families and their choices to feed their loved ones orally versus tube feeding. The video shows the viewer that providing opportunities for oral feeding can continue throughout the disease and is the preferred technique. It also demonstrates that oral feeding can decrease infection, increase comfort and enhance the individual's quality of life.

**To borrow this video or for a listing of other videos available through our resource library, contact our Resource Office at 585-760-5400 or 800-724-0587. A \$20 refundable deposit is required for all videos borrowed.**



## 2005 LEARNING INSTITUTE™ NEWS

### Message from Kathleen Powers, Ed.D., R.N.

*Learning Institute™ Director*

#### Professional In-Service On Site Education

Families want educated professional staff to care for their loved ones. The Alzheimer's Association will provide on-site education at the providers' location for CNA's, nurses and all those involved directly in patient care, as well as family members and other staff members the provider deems appropriate.

Three different approaches will meet the needs of most facilities. These approaches range in cost from \$675 and up. Visit us online at [www.alz-rochesterny.org](http://www.alz-rochesterny.org) for details.

#### Dementia Specific Caregiving Train the Trainer® Course Schedule

Dementia Specific Caregiving Train the Trainer® is designed to provide staff educators, as well as other professional caregivers, with specialized training in dementia care in order to improve the quality of life for those with Alzheimer's disease and related dementias. Teaching materials, including interactive applications, and materials for overheads and handouts are provided. Individuals working in residential long term care facilities, group homes, assisted living communities, adult day programs and home healthcare agencies are encouraged to attend. Anyone completing all seven of the **core** courses qualifies for the annual graduation ceremony.

**3-Hour Core Courses** include: 1) Nuts & Bolts of Dementia Care, 2) Effective Communication in Dementia Care, 3) Sexuality and Intimacy, 4) Spirituality, 5) Meaningful Activities for Dementia Specific Care. **Cost: \$90.00 each**

**6-Hour Core Courses** include: 1) Problem Solving & Managing Behavioral Issues in Dementia Care, 2) End of Life. **Cost: \$180.00 each**

**3-Hour Elective Courses** include: 1) Strategies for Creating Better Care, 2) Music and Dementia – Making a Connection, 3) Dementia, Art and Quality of Life, 4) How to Work with Families. **Cost: \$90.00 each**

Continuing Education credits are available.

For more information regarding Train the Trainer® Course Schedule or Professional In-Service On-Site Education opportunities contact: Kathleen A. Powers, Ed.D., R.N., Learning Institute™ Director 585-760-5426 or [kathleen.powers@alz.org](mailto:kathleen.powers@alz.org).

#### The Quality Care Initiative Update

The following area providers have sent staff to dementia-specific education through the Learning Institute™. This includes those that attended programs from September 2004 – November 2004 at the Alzheimer's Association as well as programs presented by the Alzheimer's Association in facilities and organizations:

Avon Nursing Home • Canandaigua VAMC • CDS • Clark Manor House  
Clifton Springs Hospital • Comfort Keepers  
Conesus Lake Nursing Home • E. John Gavras Center  
Elm Manor Nursing Home • Fairport Baptist Home • FLDDSO  
Friendly Home • Heritage Christian Home  
Hornell Gardens • Lifespan • Lifetime Assistance  
Livingston-Wyoming ARC • Monroe Community Hospital  
Monroe County ARC • Monroe County Ombudsman Program  
Newark Manor Nursing Home • Ontario ARC  
Penfield Place • Quail Summit • Seneca Cayuga ARC  
Seneca Lake Terrace • Seneca Nursing and Rehabilitation Center  
The Brightonian Nursing Home • The Harbor at Greece  
The Hurlbut • The Shore Winds • Thompson Health  
Traditions in Caring • Unity Health System • ViaHealth  
Wedgewood Nursing Home • Wesley Community  
Woodside Manor Nursing Home • Yates ARC

#### Learning Institute™ Celebrates Third Graduation

On November 23, 2004 the Alzheimer's Association celebrated the graduation of 13 people from the Learning Institute's Dementia Specific Caregiving Train the Trainer® program. All graduates completed the seven core courses.

The celebration, held at Locust Hill Country Club, began with a reception for the graduates, their family members, friends and colleagues. Each graduate was recognized with a Certificate of Completion, a "Dementia Caregiving Training Graduate" pin and a CD with the core seven courses in PowerPoint.

##### Congratulations to:

**Alisa M. Briggs**, Quail Summit  
**Dayna Cohen**, Livingston-Wyoming ARC  
**Grace L. Coley**, Heather Heights of Pittsford  
**Richard K. Davis**, Canandaigua VA  
**Kathleen H. Dever**, Traditions in Caring  
**Christie A. Engelfried**  
**Amy L. Hay**, Comfort Keepers  
**Raquel Makitra**, FF Thompson Senior Community  
**Tracey Mayen**, Conesus Lake Nursing Home  
**Christine C. McCracken**, Monroe Community Hospital  
**Roger L. Miller**, Caregivers  
**Emily B. Scheil**, The Harbor at Greece  
**Jeanne Shanley**, Unity Health System



*Learning Institute™ graduates*

# VOLUNTEER CORNER

## Call for Volunteers

Volunteers are needed for the following positions:

**Support Group Facilitators** ~ Facilitators that reside in or are willing to travel to Wayne County (Newark, Ontario, Wolcott), Schuyler County, and Chemung County, Livingston County (Avon). Groups meet once each month and training is provided.

**Online Support Group Development** ~ Assist in developing and facilitating an online support group.

**Memories In The Making® Volunteers** ~ Work with individuals with dementia in existing Memories In The Making® program sites in our area. Memories In The Making® uses art as a means to enhance communication, increase self-esteem, and preserve memories of people with dementia.

**Friendly Connections** ~ Assist the Resource Office by offering telephone support.

**Librarian** ~ Organize our books, track books and videos, etc. one time per week.

**Training is provided for all positions. For more information, please contact Deanna Mascari at 585-760-5403 or [deanna.mascari@alz.org](mailto:deanna.mascari@alz.org).**

## Caleb Ministries Pilot Program Comes To An End

Caleb Ministries, a program offering an opportunity for people with early stage dementia to participate in purposeful volunteer work in a structured, social environment, has ended a successful pilot period. The program was facilitated in partnership with Browncroft Community Church using volunteers from the church to work along-side the participants to complete a variety of tasks to benefit Browncroft's ministries. Over the next month we will be evaluating the program's success and planning for the future.

**If you have an interest in participating in Caleb Ministries or becoming a volunteer facilitator, please contact Deanna Mascari at 585-760-5403 or [deanna.mascari@alz.org](mailto:deanna.mascari@alz.org).**

## Memories In The Making® A Success At Valley Manor

The Memories In The Making® program has been a welcomed success at the Seniorsfirst Day Program at Valley Manor. Jeanne Mulley, program manager and Alzheimer's Association volunteer, has been working with program participants nurturing their creative abilities and opening the lines of communication among artists. "We have seen program participants open up and express their frustrations and joys," says Mulley. She adds, "We have given them something to look forward to each week. Memories In The Making® has been great for our program."

**The Alzheimer's Association will be offering a volunteer training for Memories In The Making® in February. If you are interested in learning more about the program or becoming a volunteer at an established site or in creating a Memories In The Making® site at your program or facility, please contact Deanna Mascari at 585-760-5403 or [deanna.mascari@alz.org](mailto:deanna.mascari@alz.org).**

## RESEARCH STUDIES

### Do You Know Someone 60 Years or Older Who Suffers from Dementia with Agitation?

If so, they may qualify for a research study being conducted to test the effectiveness of an investigational medication to decrease agitation in dementia. Qualified participants will receive study related physical assessments by a physician, laboratory testing and study medication at no cost.

### Do You Know Someone 60 Years or Older Who Suffers from Dementia with Agitation and Lives with Their Caregiver?

If so, they may qualify for a research study to determine if some symptoms of Alzheimer's disease can be evaluated using new technologies like electronic monitoring. Participants must live with one caregiver who is also willing to participate in the study.

*Both research studies are being conducted by Dr. Adrian Leibovici at the University of Rochester Medical Center.*

**To learn more call: 585-275-4809, Carol Basener, RN, Study Coordinator**

safe  
return  
alzheimer's association

### Safe Return Registration Now Online

Safe Return is a program to help identify, locate and return individuals who are memory impaired. Research shows that almost half of the people who wander may die of dehydration or hypothermia unless found in the first 24 hours. Those registered in Safe Return are located nearly 100% of the time.

It's easy to place your loved one in the Safe Return program by registering online. Just go to our website at [www.alz-rochesterny.org](http://www.alz-rochesterny.org), click on Programs & Services, then go to the Safe Return description and follow the directions. Registration is only \$40 and you may use your VISA, MasterCard or American Express to register.

If online registration is not an option for you, register by visiting or calling any of our Safe Return registration sites listed below.

- **Monroe County:** Alzheimer's Association, 585-760-5400
- **Bath:** Steuben County Office for the Aging, 607-776-7813
- **Canandaigua:** Ontario County Office for the Aging, 585-396-4040
- **Dansville:** Noyes Memorial Hospital, 585-335-4355
- **Elmira:** Chemung County Office for the Aging, 607-737-5520
- **Geneva:** Adult Day Health Care, 315-787-4713
- **Lyons:** Wayne County Department of Aging and Youth, 315-946-5624
- **Montour Falls:** Schuyler County Office for the Aging, 607-535-7108
- **Mt. Morris:** Livingston County Office for the Aging, 585-243-7520
- **Penn Yan:** ProAction Yates Office for the Aging, 315-536-5515
- **Waterloo:** Seneca County Office for the Aging, 315-539-5655

# Coping Through Ed

## **FEBRUARY 2005**

### **Tuesday, February 1, 2005**

Time: 6:30-8:30 P.M.  
Place: Monroe Community Hospital, 435 E. Henrietta Rd., Rochester  
Topic: "Medicaid Planning"

### **Tuesday, February 8, 2005**

Time: 6:30-8:30 P.M.  
Place: Monroe Community Hospital, 435 E. Henrietta Rd., Rochester  
Topic: "How To Utilize Home Care"; "How To Evaluate Health Care Providers"

### **Wednesday, February 9, 2005**

Time: 10:00 A.M.- 12:00 P.M.  
Place: Wayland Library, 101 W. Naples St., Wayland  
Topic: "Seminar for Understanding Alzheimer's Disease"\*

Time: 7:00 - 9:00 P.M.  
Place: Monroe Community Hospital, 435 E. Henrietta Rd., Rochester  
Topic: "Seminar for Understanding Alzheimer's Disease"\*

### **Wednesday, February 16, 2005**

Time: 10:00 A.M.-12:00 P.M.  
Place: Wayne County Department of Aging and Youth, 1519 Nye Rd., Lyons  
Topic: "Seminar for Understanding Alzheimer's Disease"\*

### **Thursday, February 17, 2005**

Time: 6:30-8:30 P.M.  
Place: Monroe Community Hospital, 435 E. Henrietta Rd., Rochester  
Topic: "Managing Challenging Behaviors"; "Communication Through the Stages"

## **MARCH 2005**

### **Wednesday, March 2, 2005**

Time: 6:00-8:00 P.M.  
Place: Seneca County Office For The Aging, 1 DiPronio Dr., Waterloo  
Topic: "Safe Proofing Your Home"; "What is Happening in Research"

### **Wednesday, March 9, 2005**

Time: 7:00-9:00 P.M.  
Place: Monroe Community Hospital, 435 E. Henrietta Rd., Rochester  
Topic: "Seminar for Understanding Alzheimer's Disease"\*

### **Tuesday, March 15, 2005**

Time: 10:00 A.M.-12:00 P.M.  
Place: Monroe Community Hospital, 435 E. Henrietta Rd., Rochester  
Topic: "Seminar for Understanding Alzheimer's Disease"\*

### **Monday, March 21, 2005**

Time: 7:00-8:00 P.M.  
Place: Atria Greece, 150 Towngate Dr., Rochester  
Topic: "Discussing Treatments with Your Doctor"

### **Thursday, March 17, 2005**

Time: 1:00-3:00 P.M.  
Place: Schuyler County Office for the Aging, 336 W. Main St., Montour Falls  
Topic: "Seminar for Understanding Alzheimer's Disease"\*

Time: 6:30-8:30 P.M.  
Place: Monroe Community Hospital, 435 E. Henrietta Rd., Rochester  
Topic: "Techniques for Families Giving Daily Care"; "Taking Care of Yourself"

### **Wednesday, March 30, 2005**

Time: 6:00-8:00 P.M.  
Place: Noyes Memorial Hospital, 111 Clara Barton St., Dansville  
Topic: "Managing Challenging Behaviors"; "Effective Communication"



## **APRIL 2005**

### **Wednesday, April 6, 2005**

Time: 2:00-4:00 P.M.  
Place: Ontario County Office for the Aging, Human Services Building Conference Room 8, 3010 County Complex Dr., Canandaigua  
Topic: "Seminar for Understanding Alzheimer's Disease"\*

### **Tuesday, April 12, 2005**

Time: 6:00-8:00 P.M.  
Place: Wayne County Department of Aging and Youth, 1519 Nye Rd., Lyons  
Topic: "Nutrition and Dementia"; "Memory Loss: Is it Always Alzheimer's Disease?"

### **Wednesday, April 13, 2005**

Time: 7:00-9:00 P.M.  
Place: Monroe Community Hospital, 435 E. Henrietta Rd., Rochester  
Topic: "Seminar for Understanding Alzheimer's Disease"\*

# Education & Support

## Thursday, April 14, 2005

Time: 3:00-5:00 P.M.

Place: St. Mark's Terrace, 110 Chapel St., Penn Yan

Topic: "Driving and Dementia" ; "Dealing With Denial-How to Tell Other Individuals"

## Thursday, April 21, 2005

Time: 1:00-3:00 P.M.

Place: Schuyler County Office for the Aging, 336 W. Main St., Montour Falls

Topic: "Memory Loss: Is it Always Alzheimer's Disease?" ; "Nutrition and Dementia"

Time: 6:30-8:30 P.M.

Place: Monroe Community Hospital, 435 E. Henrietta Rd., Rochester

Topic: "Driving and Dementia" ; "Safe Proofing Your Home"

\*A two-hour seminar designed for families of persons newly diagnosed with Alzheimer's disease.

**The Alzheimer's Association offers a variety of support groups – both for caregivers and for persons with dementia. For more information, please call Debbie Houck, Senior Resource Specialist, at 585-760-5411 or 800-724-0587.**

*Caregiver education and support partially funded by Title III-E money from the Monroe County Office for the Aging.*

## New Caregiver Support Group at Mt. Olivet Baptist Church

We are pleased to announce that Mt. Olivet Baptist Church is now hosting a caregiver support group the **first Monday of each month from 6:30 – 8:00 PM** to ensure caregivers have the support they need to cope with the challenges of caregiving. If you are interested in learning more about the Alzheimer's Support Ministry and the support and services they offer please call 585-454-0280.

## Individual and Family Counseling Available

The Alzheimer's Association now offers fee based individual and family counseling. Whether you are newly diagnosed or caring for someone with Alzheimer's disease, we can help you deal with all aspects of the disease. If you are struggling or feeling overwhelmed, let's make a plan to get you on the right path to improving your quality of life. Contact Paula Casselman at 585-760-5400 or paula.casselmann@alz.org.

## Agency News

**Kelly Harris**, formerly Office Manager, has been promoted to Director of Administration.

## Professional Network

Please join us for our next Professional Network **Wednesday, March 9th from 8:30-10:00 AM** in our new Education Center at Monroe Community Hospital. The Network was designed for professionals who work in the field of Alzheimer's disease and related dementias.

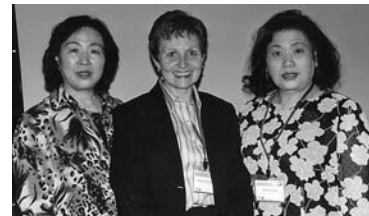
### How can the Professional Network benefit you?

- 1) Provides updates on what is happening at the local chapter.
- 2) Informs participants of local educational programs to expand their knowledge of the disease.
- 3) Offers an opportunity to gain greater insight into advances in research.
- 4) Promotes awareness of public policy issues affecting those with Alzheimer's disease.
- 5) Fosters stronger relationships with agencies/providers who serve those with Alzheimer's disease and related dementias with an emphasis of how we can benefit each other.

**On the 9th we have a special program planned, which will include a grand tour of our new expansion, known as "Hallway of Hope", and a presentation by our partners – Mercy Center with the Aging. Learn about Mercy Center and what it can do for your consumers as the official Caregiver Resource Center for Monroe County.**

For more information about the Professional Network or other offerings for professionals please call the Alzheimer's Association at 585-760-5400 or 800-724-0587 or check us out on the web at [www.alz-rochesterny.org](http://www.alz-rochesterny.org).

## Staff Travels to Japan to Present Memory Gardens and the Learning Institute™ at International Alzheimer's Conference



In October 2004, Bob Wilcox (left photo) and Kathy Powers (with representatives from the Support House Yorokobi – right photo) attended the International Alzheimer's Conference in Kyoto, Japan where photographs and descriptions of our Memory Gardens were on display and Kathy Powers presented the Learning Institute™.

## PUBLIC POLICY 2004

### Attention Advocates

#### Lobby Day in Albany

Tuesday, April 5, 2005

It's a great experience being with other advocates and meeting with our elected officials.

Registration is required.

Questions or to register call 585-760-5400

Thank you to the following New York State Legislators who supported legislative initiatives for the Alzheimer's Association this past year:



James S. Alesi



Joseph A. Errigo



David R. Koon



Joseph E. Robach

Their support enables the Association to continue to provide information, referral, education, care consultation, counseling, support groups, respite and Safe Return for the more than 24,000 persons with dementia and their caregivers within our region.

### FEDERAL UPDATE

In mid-November, Congress returned to Washington to complete work on legislation combining the nine unfinished appropriations bills into an omnibus budget package. On Saturday, November 20th, the House and Senate adopted H.R. 4818, the Consolidated Appropriations Act for Fiscal Year 2005 by a vote of 344-51 in the House of Representatives and 65-30 in the Senate. The 1300-page bill totaled \$388.4 billion and, to avoid a threatened Presidential veto, held overall growth in domestic spending to less than one percent. The bill included funding for Alzheimer research at NIH and other Alzheimer programs. Passage of the omnibus act officially signaled the end of the 108th Congress. President Bush signed the legislation the week of December 3rd. The 109th Congress convened in Washington on January 4, 2005.

As Congress turned out the lights on the 2004 session, here is an overview of how Alzheimer programs fared in the omnibus budget bill:

#### Alzheimer's Disease Research Funding

As noted above, broad-based concern about the growing federal deficit provided the overall theme during negotiations on the omnibus bill. With the threat of a Presidential veto on the table, appropriators in both the House and Senate were forced to hold-the-line on spending, resulting in a lower overall number for NIH research funding.

Despite strong opposition to increasing funding for medical research, Senator Arlen Specter (R-PA) led the fight to secure a 2.9% (\$800 million) increase over fiscal year 2004 funding for NIH. It should be noted that the three institutes that conduct the majority of Alzheimer research, the National Institute on Aging (NIA), the National Institute on Neurological Diseases & Stroke (NINDS) and the National Institute of Mental Health (NIMH) received among the highest percentage increases: 3.5%, 3.4% and 3.0% respectively. Funding for Alzheimer research will rise to approximately \$700 million in fiscal year 2005 (a \$20 million increase over current funding).

Although the increase in funding for Alzheimer research is not as significant as we had hoped, the Alzheimer's Association will continue to aggressively advocate for our goal of \$1 billion in federal funding for Alzheimer research. The Alzheimer's Association would like to extend its sincere appreciation to Alzheimer advocates and family caregivers across the country who wrote multiple letters and emails to and called their Senators and Representatives, traveled to Washington in March to attend the Public Policy Forum, visited their members of Congress at home during recess periods and participated in media activities. It is clear that our messages about the need for increased Alzheimer research funding are

getting through to members of Congress even as the overall budget for NIH continues to shrink. The funding increases for NIA and NINDS are a direct result of the dedicated efforts of advocates. In the end, Alzheimer priorities fared reasonably well, especially considering the difficult budget environment.

#### CDC Alzheimer's Initiative

The omnibus budget bill included \$1.6 million for a new Alzheimer initiative at the Centers for Disease Control & Prevention (CDC). The language describing the CDC initiative is as follows:

Healthy Aging and Alzheimer's Disease- Recent preliminary studies suggest that some of the same strategies that preserve overall health may also help prevent or delay Alzheimer's disease and dementia. For example, epidemiological studies have revealed that individuals taking anti-inflammatory drugs to treat conditions such as arthritis appear to have a lower-than-expected occurrence of Alzheimer's disease. Furthermore, a growing body of evidence appears to link known risk factors for diabetes, heart disease, including high blood pressure and high cholesterol, and risk factors for Alzheimer's disease and dementia. Additionally, evidence supports that maintaining intellectual and physical activity and remaining socially connected may also help stave off dementia. In light of this information, the Committee strongly urges the CDC to work with the Alzheimer's Association to design and launch an Alzheimer's-specific segment of the Healthy Aging Program, to aggressively educate the public and health professionals as to ways to reduce the risks of developing Alzheimer's by maintaining a healthy lifestyle. The Committee has provided \$1,600,000 for this initiative. CDC should also coordinate this effort with the National Institute on Aging and the Administration on Aging.

#### AoA Alzheimer Grant Program

The omnibus budget bill also provided \$11.8 million for the Administration on Aging Alzheimer Demonstration Grants to the States Program, the same as current funding. The Alzheimer Demonstration Grants Program supports the development of innovative programs and services for people with Alzheimer's disease, especially those living in underserved minority and rural communities. In 2005, AoA anticipates continuing financial support for ongoing demonstration projects in addition to funding three to five new grants.

#### Family Caregiver Support Program

Strong Congressional backing for the National Family Caregiver Support Program was evident in the omnibus budget bill. The bill included \$157 million for the caregiver program, an increase of \$4.3 million over current funding.

*Continued on opposite page*

**Loren Ranaletta,  
Alzheimer's Association  
Chairman of the Board  
2002 - 2004**



These last two years have passed very quickly. It has been a pleasure to work with so many dedicated volunteers, especially my fellow board members, and a privilege to work with the caring and dedicated staff of the Association. Teresa Stewart and her leadership team are very special people who have guided our chapter's growth with great conviction and strength.

The Rochester Chapter is very strong and professionally respected at both the State and National level. Our pioneering effort in establishing the Learning Institute™ has created a model for other chapters to follow and greatly enriched the skills of the caregivers in the Rochester area. Our support groups are diverse and have reached many caregivers and families. The opening of our most recent outreach center at Mt. Olivet Baptist Church and the continued expansion of our presence in the Southern Tier are most noteworthy. Our advocacy efforts have resulted in close working relationships with our State Senators and Assembly members. The generous member item grants are the latest examples of support for our cause and commitment to the Rochester Chapter. Our collaboration with the University of Rochester and the Mercy Center with the Aging are continuous examples of our agency at work in this community.

The strength of the Rochester Chapter has also had a positive impact nationally, raising money for research, in advocacy, and with Teresa's participation in developing The Long Range Strategic Plan for our national organization. With the reorganization of the Chapter System, the Branding Initiative and the Healthy Brain promotion, there is a new sense of urgency on eradicating this disease.

I have enjoyed my tenure as Chairman, and working with so many wonderful people. I have learned a great deal about the disease, and have become sensitized to the devastating impact on victims, families and caregivers.

Alzheimer's disease is a formidable challenge. We must continue our work to create a world without Alzheimer's disease. I thank you for the opportunity to lead our Chapter a few steps forward on the pathway to success.

*Federal Update Continued*

**Other AoA News**

The omnibus budget bill also included \$1 million to support the Association's national 24/7 Contact Center. Last year, Congress provided \$993,500 for the Contact Center to link Association chapters to other organizations and groups in the aging services network and expand outreach into multicultural communities.

**Safe Return**

Funding for the Safe Return program is provided in the omnibus budget bill. The bill included \$883,000 for Safe Return, the same level as current funding.

**Ronald Reagan Bill**

Although there was strong momentum around the Ronald Reagan Alzheimer's Breakthrough Act (S 2533/ HR 4595), Congress did not act on the bill this past year. The key House and Senate sponsors of the legislation have already indicated that they will introduce the bill again in 2005.

**14th Annual Chefs' Connection Dinner**

*A Symphony of Flavors*

*with RPO Principal Pops Conductor*

**Jeff Tyzik**

**Sunday, April 3, 2005**

**5:00 PM**

Rochester Riverside Convention Center

For tickets or further information  
please call 585-760-5400

**Rosemary Society Members  
Recognized**



Members of the Rosemary Society, a special group of leadership donors, were recognized at a private reception held at Oak Hill Country Club on November 16, 2004. Members of the Rosemary Society were recognized for their leadership and commitment to creating a world without Alzheimer's.

**2005 Members**

**\$3,000-\$6,999 Silver Level**  
**BARBARA NUSSMANN**

*in memory of Margaret Graefe Terrill*

**THE ROHRER FAMILY**

*in memory of Ellie Rohrer*

**\$1,000-\$2,999 Bronze Level**

**JANE ADAMS**

*in memory of Gerard A. Adams*

**MARGARET BILLS**

*in memory of Mary Bills*

**THE KENNETH BOSS FAMILY**

*in honor of Lillian F. Boss*

**RICHARD & NANCY COLE**

*in memory of Marcia B. Cole*

**JOHN & MARY ANN GUARRE**

*in memory of Lena Beninati*

**DR. LUCILLE HEGGENESS**

**ELISABETH K. KITZING**

**BETTY PADDOCK**

**BILL & CANDACE RYAN**

*in memory of Francis P. & Mary T. Ryan*

**ELSIE WIBERG**

*in memory of John S. Wiberg*

**It's people like you who make our  
community a better place.**

# THANK YOU FOR YOUR SUPPORT

Your gifts to the Alzheimer's Association to honor and remember loved ones help us to continue to provide education and support to those in our nine-county region. We appreciate your generous support. Our sincere apologies for any errors or omissions in this listing. Please call 585-760-5400 with corrections.

## In Memory Of

### ADAMS, GERARD

Judy Speziale

### ADAMS, HARTSON

Jeanne Barry  
Joan Belgiorio  
Rose Bouchard  
Judy Brye  
James Campanella  
Charles & Carolyn Dean  
Steve & Joanne DeLorm  
Marlene Duerr  
Catherine Finocchiaro  
Friends at Bausch & Lomb  
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The family of Ida VanGraafeiland  
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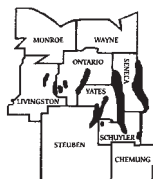
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Alzheimer's Association  
Rochester New York Chapter  
435 East Henrietta Road  
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## Alzheimer's Disease And Related Disorders Association - Rochester NY Chapter

Statement of Activities - Year-ending June 30, 2004

	Total	
REVENUE	2004	2003
Contributions, memorials and bequests	\$212,108	\$243,068
Grants	407,302	232,124
United Way	125,043	142,018
Membership dues	54,131	45,336
Special events	188,606	195,820
Net investment income (loss)	75,038	29,985
Educational fees and product sales	52,296	48,892
Contributed services	85,405	106,695
Total revenue	1,199,929	1,043,938
<b>EXPENSES</b>		
Program services	977,916	799,399
Management and general	133,743	105,473
Fundraising	87,937	141,975
Total expenses	1,199,596	1,046,847
<b>CHANGE IN NET ASSETS</b>	333	-2,909
<b>NET ASSETS - beginning of year</b>	629,471	632,380
<b>NET ASSETS - end of year</b>	\$629,804	\$629,471



**DON'T FORGET** to check off the Alzheimer's Fund when filing your New York State Income Tax Forms.

Because of a recently enacted law all tax payer contributions will be matched by the Legislature, dollar for dollar. Your support will assist us in expanding programs and services to our local communities.