

## The Learning Institute™ Presents The 3<sup>rd</sup> Annual Symposium *Ethical Issues from Diagnosis to Dying*

For Healthcare Professionals and Family Caregivers

Join us **Thursday, June 2, 2005** from **8:00 am to 3:30 pm** at the **RIT Inn and Conference Center** for our 3<sup>rd</sup> Annual Symposium.

**Keynote speaker, Stephen G. Post, Ph.D.**, Professor of Bioethics, Religion, Philosophy and Family Medicine at Case Western Reserve University will present *The Moral Challenge of Alzheimer's Disease: Defining the Task*.

A panel discussion including individuals with early stage Alzheimer's disease and their care partners will explore the *Window Into the World of Persons with Alzheimer's Disease: The Voices of Alzheimer's*.

**Jane Greenlaw, JD**, Co-Director of the Center of Palliative Care and Clinical Ethics at the University of Rochester School of Medicine and Dentistry will present *An Introduction to Consent and Capacity*.

**Keynote speaker Stephen Post** will moderate two panel discussions. The first, *End of Life Decisions in Alzheimer's Disease*, includes **Ms. Greenlaw** (see above) and **Robert McCann, MD, FACP**, Chief of Medicine at Highland Hospital and Professor of Medicine at the University of Rochester School of Medicine and Dentistry.

The second panel discussion moderated by Dr. Post, *Respect for Spirituality and Coping*, includes **Barbara Ann Moore, RSM, D. Min.**, Interfaith Ministry of Preaching and Faculty Associate of the Colgate Rochester Crozer Divinity and **Rabbi Kilimnick**, Bachelor of Talmudic Law, MS Education, SMICHA Ordination from Ner Israel Rabbinical College of Toronto.

The \$45 fee per person includes continental breakfast and lunch. To register, contact Kelly Harris at 585-760-5405 or [kelly.harris@alz.org](mailto:kelly.harris@alz.org). For additional information please visit our website at [www.alz-rochesterny.org](http://www.alz-rochesterny.org).



Stephen G. Post, Ph.D.

## 24-Hour Helpline 800-272-3900

We have joined the National Alzheimer's Association 24/7 Contact Center.

During regular business hours, you can reach our Resource Office using this new toll free 800 number. After-hours or during holidays, your call will be answered by our 24/7 Contact Center staff.

The Contact Center's trained and knowledgeable staff can help you with:

- understanding memory loss, dementia and Alzheimer's
- medications and other treatment options
- general information about aging and brain health to Maintain Your Brain™
- skills to provide quality care and to find the best care from professionals
- strategies to reduce stress and manage lifestyle changes
- legal, financial and living arrangement decisions.

Our Nationwide Contact Center also features:

- confidential care consultation provided by masters' level clinicians who can help with decision-making support, crisis assistance and education on issues families face every day
- help in a caller's preferred language using our translation service that features over 140 languages and dialects
- referrals to local community programs, services and ongoing support.

Please update your records by changing the old toll free number to 800-272-3900 today!

We encourage you to call our new helpline number for assistance any time, day or night, even weekends.

**The Harbor at Greece**  
A Senior Living Community for the Memory Impaired  
1 Treeline Drive • 720-9310



**The Crossings at Greece**  
A Senior Living Community  
3 Treeline Drive • 720-9330



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**WHAT'S NEW IN  
RESEARCH**

By *Pierre Tariot, MD*

*Geriatric Neurology & Psychiatry Clinic,  
University of Rochester Medical Center*

**Alzheimer's Disease  
Neuroimaging Initiative  
(ADNI) Set to Launch**

A major new nationwide initiative, sponsored by the National Institutes of Health in conjunction with the pharmaceutical industry, addresses the expanding role of brain imaging and biomarkers in the early detection of Alzheimer's disease and in novel treatment trials. Here is the rationale in brief. We know that the structure of the brain changes with normal aging and in Alzheimer's; this is visible on magnetic resonance imaging (MRI) scans. In addition, positron emission tomography (PET) scans show reductions in how the brain handles glucose, painting a picture of altered function to accompany the structural picture seen with MRI. In addition, new advances are being made in the use of blood and spinal fluid biomarkers to improve the diagnosis of Alzheimer's disease, and also measure disease progression and treatment response. The purpose of the ADNI is to blend these technologies to better understand how to apply them for drug discovery as well as diagnosis and treatment.

Approximately 60 million dollars has been committed to conduct this 5-year study. The goal of the study is to develop new "gold standards" for imaging, both for diagnosis and for refining clinical trials methodology. The imaging and biomarkers data will be validated by correlating them with "standard" neuropsychological and

behavioral test results. This huge database will be made available in real time for investigators as well as institutions developing new forms of treatment. The overall goal is to shorten the time to develop new treatments: biological studies appear to be the most promising way to do this.

We aim to enroll 200 older people who are aging normally, 200 with mild Alzheimer's disease, and 400 with mild cognitive impairment, age 55-90 inclusive. All study participants will have repeated clinical and imaging evaluations at 6 month intervals for 2-3 years. In addition, blood and urine will be collected at the corresponding intervals. Finally, spinal taps to obtain cerebral spinal fluid will be performed in up to one half of study participants at baseline and year one. We anticipate start up of ADNI in June, 2005 in the Rochester area, and at 50 sites around the country.

New treatments in development are increasingly specific to biological pathways affected by Alzheimer's disease. The best way to learn if these treatments will work, and learn quickly, is to study their biological effects in patients with Alzheimer's disease, using imaging, blood studies, and spinal fluid studies. The ultimate aim of this project is to accelerate the pace of drug discovery, and more rapidly identify possible disease modification or prevention therapies so that we can spare a generation while taking the best possible care of our patients currently living with Alzheimer's disease.

If you wish to learn more about this study, please contact Colleen McCallum at [colleen\\_mccallum@urmc.rochester.edu](mailto:colleen_mccallum@urmc.rochester.edu) or 585-760-6547.

*This column has been generously underwritten by Barbara Nassmann in memory of Margaret Graefe Terrill.*

**Two Local Research Studies Seek Volunteer Subjects**

The first study, currently conducted by the University of Rochester and Monroe Community Hospital, involves recording brain activity during a simple computer task. There are no experimental drugs given or blood drawn. The purpose of this study is to evaluate the usefulness of EEG (electroencephalogram) recordings as a diagnostic criterion for Alzheimer's disease. If these recordings prove plausible as a diagnostic tool, people may be able to receive treatment prior to developing the disease or in its early stages. 400 subjects are needed, including patients diagnosed with mild Alzheimer's disease or Mild Cognitive Impairment. Family members can also help. All studies need control subjects, which allow researchers to evaluate the differences between normal aging and Alzheimer's disease. For more information, please contact Maria Guillily at 585-275-8676 or [mguillily@bcs.rochester.edu](mailto:mguillily@bcs.rochester.edu).

The second study, Depression in Alzheimer's disease 2 (DIADS-2), is being conducted by the University of Rochester Memory Disorder Team at Monroe Community Hospital. The study aims to determine whether individuals with depression in the context of Alzheimer's disease respond to antidepressant treatment using the medication sertraline (Zoloft®). DIADS-2 is a collaboration study between research teams at five universities: John Hopkins, the University of Rochester, the University of Southern California, the Medical University of South Carolina, and the University of Pennsylvania. The goal is to recruit 130 outpatients with mild-to-moderate Alzheimer's disease and study the nature and course of the illness as well as the efficacy and safety of antidepressant treatment both in terms of depressive symptoms as well as the outcome of the Alzheimer's disease itself. After a detailed baseline characterization, patients will be randomized to treatment with sertraline or placebo and followed for up to 24 weeks. All patients and caregivers will receive psychosocial intervention for Alzheimer's disease and depression. For more information, please contact Colleen McCallum, MSW at 585-760-6547 or [colleen\\_mccallum@urmc.rochester.edu](mailto:colleen_mccallum@urmc.rochester.edu).



**Debbie Houck**  
Senior Resource Specialist

## “Dear Debbie”

**Q:** My husband always gives me a hard time when I ask him to take a shower. What can I do to make this easier?

**A:** The phrase, “take a shower” may not have meaning to your husband anymore. Since this task involves many steps, it may be an overwhelming request. You might need to cue or assist him through the various steps, while allowing him to do as much as he is able to without getting frustrated.

Before approaching the idea of taking a shower, have the bathroom ready – light on, toiletries and towel ready, and be sure to know his preference for a shower vs. a bath keeping in mind that his preference may have changed. You might start by saying, “It’s time to take a shower, let’s go into the bathroom,” then support him as needed through each step. Once the task is complete, you could do something special that he enjoys such as offering him after-shave or cologne. Of course, it is not always this easy. If your husband still refuses, try to be flexible. You might suggest a shower at a different time of day, only do part of the task, or save it for a different day. Sometimes a person needs to connect taking a bath or a shower with getting ready for something; this may be another approach to try if he still resists the idea.

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

### Help Me to Heal: A Practical Guidebook for Patients, Visitors and Caregivers: Essential Tools, Strategies and Resources for Healthy Hospitalizations and Home Convalescence

By Bernie Siegel

This inspirational book encourages the reader to tap into natural healing abilities by becoming empowered and participating in the care they receive. It also provides guidelines for visiting and offers suggestions to visitors and care partners for being an advocate and helping in the healing process. Some of the key messages of the book include: understanding the difference between healing and curing, not allowing illness to define who you are or become your life, learning what’s involved on a healing path, and creating “vital signs” or time outs for yourself. The book also includes information on how to have a successful hospital stay and how to turn your environment into a healing space.

## Voices

**This issue’s question:** “*What are your feelings about driving with dementia?*”

The panel members have discussed at length safety concerns, ethical issues and the struggle between “what I want to do” vs. “what I should do”. Most members continue to drive and feel comfortable doing so. However, many of them now limit their driving to daytime hours only.

Several members admit that although they have occasionally become lost while driving, they will trust and listen to their families when the time comes to stop driving. Those members who no longer drive admit they knew when it was time to give it up. Because there are other reliable transportation options available, these individuals did not feel like the choice to stop driving was the “end of the world”.

*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

## 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.

**NEW FEATURE: Message Boards and Chat Rooms enhance the local support group experience. Check it out today!**

[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.aarp.org/health/comparedrugs](http://www.aarp.org/health/comparedrugs)

This section of the AARP website lists some of the most commonly prescribed medications, information about them – including effectiveness, side effects, and generic vs. brand names, concerns about safety, and a cost comparison chart for other medications in the same category. For each medication, there are also related links to information and articles about the specific health conditions for which the drug is prescribed.

## Video Corner

### The Family Guide to Alzheimer’s Disease

This five video set is designed for families to understand the challenges and rewards of caring for a person with Alzheimer’s throughout the disease process.

*Understanding Alzheimer’s* explains the stages of the disease, typical symptoms and treatment.

*Behavior Issues* deals with agitation, hallucinations and incontinence.

*Daily Life* addresses communication and gives suggestions for creating a safe environment.

*Family Caregiving* shows how daily care activities can become opportunities for nurturing and bonding.

*Transitions* helps caregivers with three challenges: adapting social activities to accommodate their loved one, recognizing when residential care may be needed, and grieving the loss of a loved one.

**To borrow these videos or for a listing of other videos available through our resource library, contact our Resource Office at 585-760-5400 or 800-272-3900. A \$20 refundable deposit is required for all videos borrowed.**

## VOLUNTEER CORNER

### Call for Volunteers

Thanks to all of you who answered our last call for volunteers! We had a phenomenal response. We continue to need volunteers to help in the following areas:

**Community Ambassador**- distribute physician packets in all nine counties. Must be available during business hours. Time commitment is flexible.

**Memories In The Making**<sup>®</sup>- participate in an existing program using art as a means to enhance communication, increase self esteem, and preserve memories of people with Alzheimer's disease or related dementia.

**Support Group Facilitators**- facilitate a support group meeting. Greatest needs are in Chemung, Schuyler, and Wayne counties.

**Gardeners for the Memory Gardens** - help maintain the Alzheimer's Association Memory Gardens on the grounds of Monroe Community Hospital, by volunteering on Tuesday and/or Thursday mornings. A minimum commitment of 2 times per month is required.

**Friendly Connections**- provide telephone support service follow-up to resource contacts.

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

### June is National Safety Month

#### Sign Up for the Safe Return Program

It is common for a person with Alzheimer's disease to wander. In fact, six in ten people with Alzheimer's disease will wander at some point. This behavior can be dangerous, even life threatening to individuals and stressful to families and caregivers.

There is help! The Alzheimer's Association Safe Return™ program assists in the safe return of individuals with Alzheimer's disease or related dementia who wander and become lost. It is important to enroll in the program before wandering or getting lost becomes an issue.

In recognition of National Safety Month, the Alzheimer's Association is offering a free copy of the book, *The 36 Hour Day*, to anyone who registers at one of the locations listed in the column to the right during the month of June only. This special offer is *not* available when registering online.

Help ensure peace of mind and enroll today! Please contact Deanna Mascari at 585-760-5403 or [deanna.mascari@alz.org](mailto:deanna.mascari@alz.org) to learn more or to receive an enrollment brochure.



### Save the Date

#### CANANDAIGUA

Thompson Health  
**Saturday, September 17, 2005**  
Registration 9:00 AM • Walk 10:00 AM

#### CORNING

Centerway Square on Market Street  
**Saturday, September 17, 2005**  
Registration 9:00 AM • Walk 10:00 AM

#### ROCHESTER

Monroe Community Hospital  
**Saturday, September 24, 2005**  
Registration 9:00 AM • Walk 10:00 AM

#### GENESEO

Village Park  
**Saturday, September 24, 2005**  
Registration 9:00 AM • Walk 10:00 AM

#### WATERLOO

Huntington Living Center  
**Saturday, September 24, 2005**  
Registration 9:00 AM • Walk 10:00 AM



#### 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 register your loved one in the Safe Return Program, **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, 315-539-1765



## 2005 LEARNING INSTITUTE™ NEWS

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

Learning Institute™ Director

The Learning Institute™ provides dementia specific, culturally appropriate educational programs and consultative services for professional and non-professional caregivers and seminars for businesses and the community at large.

#### On-Site Education Programs

Organizations and facilities that have provided Alzheimer's Association Learning Institute™ dementia specific education for staff during this quarter include:

Hornell Gardens  
 The Shore Winds  
 Newark Manor Nursing Home  
 Penfield Place  
 Wedgewood Nursing Home  
 Seneca Nursing and Rehabilitation Center  
 Woodside Manor Nursing Home  
 Elm Manor Nursing Home  
 Avon Nursing Home  
 The Wesley Community  
 Elcor Health Services  
 The Harbor at Greece  
 The Highlands at Pittsford Laurelwood  
 Alterra Clare Bridge Perinton  
 Finger Lakes DDSO  
 Heritage Christian Homes  
 ARC of Monroe County  
 Seneca-Cayuga ARC  
 Continuing Developmental Services  
 Ontario ARC  
 Wayne ARC

#### PROFESSIONAL ON SITE EDUCATION PROGRAMS AVAILABLE

Families want educated professional staff to care for their loved ones with Alzheimer's disease and related dementias. The Alzheimer's Association can help local organizations and facilities meet this need through The Learning Institute's™ Professional On Site Education Program.

##### Who these programs serve:

All staff in a facility but primarily CNAs, nurses, those involved in care of those with dementia as well as families.

##### Three different approaches:

Each approach will be scheduled at the facility on mutually agreeable dates and times. Facility determines number of attendees.

##### Approach One: Cost \$675.00

- On site visit to facility to conduct focus group to assess needs
- One two-hour program on the overview of the disease
- Three one-hour programs designed to meet specific needs identified by focus group.
- Letter of participation for facility

##### Approach Two: Cost \$1,250.00

- On site visit to facility to conduct focus group to assess needs
- One two-hour program on the overview of the disease
- Six one-hour programs determined by the assessment
- Two one-hour family education programs
- Letter of participation for facility

##### Approach Three: Cost \$3,000.00

- One full Train the Trainer Series for facility representative (7 courses and 27 clock hours of instruction with materials that can be used by the facility for ongoing education)
- On site visit to facility to assess needs
- Two-hour program on the overview of the disease
- Ten one-hour programs determined by the assessment
- Development of competencies for staff based on programs presented
- Three one-hour family education meetings
- One one-hour follow up program at six months
- Certificate for facility to display publicly

#### Dementia Specific Caregiving Train the Trainer® Course Highlights for May and June 2005

A Train the Trainer option is also available – Dementia Specific Caregiving Train the Trainer® – opportunity to train a representative from an organization is available. The courses include training materials, interactive applications, powerpoint, handouts- all the material necessary to provide on going education.

##### Course Five: Sexuality and Intimacy

May 3<sup>rd</sup> 9:00 am – 12:00 pm \$90.00 (3-hour course)

##### Course Six: Spirituality

May 3<sup>rd</sup> 1:00 pm – 4:00 pm \$90.00 (3-hour course)

##### Course Seven – Meaningful Activities for Dementia Specific Care

May 16<sup>th</sup> 9:00 am – 12:00 pm \$90.00 (3-hour course)

##### Course Four: End of Life

May 24<sup>th</sup> 9:00 am – 4:00 pm \$180.00 (6-hour course)

##### Course Eight: Strategies for Creating Better Care Environments (Elective Course)

June 9<sup>th</sup> 1:00 pm – 4:00pm \$90.00 (3-hour course)

##### Course Ten: Dementia, Art and the Quality of Life (Elective Course)

June 9<sup>th</sup> 9:00 am – 12:00 pm \$90.00 (3-hour course)

##### Course Nine: Music and Dementia – Making a Connection (Elective Course)

June 28<sup>th</sup> 1:00 pm – 4:00 pm \$90.00 (3-hour course)

##### Course Eleven: How to Work With Families (Elective Course)

June 28<sup>th</sup> 9:00 am – 12:00 pm \$90.00 (3-hour course)

Continuing education units are available.

For the full course catalog: call 585-760-5400 or visit our website at [www.alz.rochesterny.org](http://www.alz.rochesterny.org).

#### Contact Information:

Kathleen A. Powers, Ed.D., R.N.

Learning Institute Director

Alzheimer's Association

585-760-5400 phone • 585-760-5401 facsimile

[kathleen.powers@alz.org](mailto:kathleen.powers@alz.org) email

# Coping Through Ed

## **MAY 2005**

### **Thursday, May 5, 2005**

Time: 2:00-4:00 P.M.  
Place: Corning Senior Center, 1 Park Lane, Corning  
Topic: "Seminar for Understanding Alzheimer's Disease"\*

### **Monday, May 9, 2005**

Time: 6:00-8:00 P.M.  
Place: Wayland Library, 101 W. Naples St., Wayland  
Topic: "Caregiver Efficacy: Coping and Empowerment" ; "Taking Care of Yourself"

### **Wednesday, May 11, 2005**

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

### **Monday, May 16, 2005**

Time: 6:30-8:30 P.M.  
Place: Mt. Olivet Baptist Church, 141 Adams St., Rochester  
Topic: "Seminar For Understanding Alzheimer's Disease"\*

### **Wednesday, May 18, 2005**

Time: 6:00-8:00 P.M.  
Place: Seneca County Office for the Aging, 1 DiPronio Dr., Waterloo  
Topic: "Seminar for Understanding Alzheimer's Disease"\*

Time: 6:30-8:30 P.M.  
Place: Monroe Community Hospital, 435 E. Henrietta Rd., Rochester  
Topic: "Steps to Understanding Legal and Financial Issues"

### **Thursday, May 19, 2005**

Time: 6:30-8:30 P.M.  
Place: Monroe Community Hospital, 435 E. Henrietta Rd., Rochester  
Topic: "How to Talk to your Doctor" ; "Newest Treatment Modalities"

### **Monday, May 23, 2005**

Time: 7:00-8:00 P.M.  
Place: Atria Greece, 150 Towngate Dr., Rochester  
Topic: "Effective Communication"

Time: 7:00-8:00 P.M.  
Place: Heather Heights, 160 W. Jefferson Rd., Rochester  
Topic: "Dementia vs. Normal Aging"

### **Wednesday, May 25, 2005**

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

## **JUNE 2005**

### **Wednesday, June 1, 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, June 8, 2005**

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

### **Thursday, June 9, 2005**

Time: 3:00-5:00 P.M.  
Place: Pro-Action Yates County Office for the Aging, 417 Liberty St., Conference Room 1037, Penn Yan  
Topic: "Seminar for Understanding Alzheimer's Disease"\*

Time: 6:00-8:00 P.M.

Place: MM Ewing Continuing Care Center, 350 Parrish St., Canandaigua  
Topic: "Steps to Understanding Legal and Financial Issues"

### **Tuesday, June 14, 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"\*



### **Thursday, June 16, 2005**

Time: 10:00 A.M. – 12:00 P.M.  
Place: Williamson Library, 6380 Rt. 21, Suite 1, Williamson  
Topic: "Dealing with Denial - How To Tell Other Individuals" ; "Family Dynamics and Conflicts"

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

Place: Monroe Community Hospital, 435 E. Henrietta Rd., Rochester  
Topic: "Dealing with Denial - How To Tell Other Individuals" ; "Managing Grief and Guilt"

### **Monday, June 20, 2005**

Time: 6:30-8:30 P.M.  
Place: Mt. Olivet Baptist Church, 141 Adams St., Rochester  
Topic: "Effective Communication" ; "Meaningful Activities"

Time: 7:00-8:00 P.M.

Place: Atria Greece, 150 Towngate Dr., Rochester  
Topic: "Managing Challenging Behaviors"

# Education & Support

## Tuesday, June 21, 2005

Time: 1:00-2:00 P.M.  
Place: Wayland Library, 101 West Naples St., Wayland  
Topic: "Driving and Dementia"

## Wednesday, June 22, 2005

Time: 6:00-8:00 P.M.  
Place: Chemung County Office for the Aging, 425 Pennsylvania Ave., Elmira  
Topic: "Driving and Dementia" ; "Safety Concerns"

## Monday, June 27, 2005

Time: 7:00-8:00 P.M.  
Place: Heather Heights, 160 W. Jefferson Rd., Rochester  
Topic: "Meaningful Activities"

## JULY 2005

### Tuesday, July 12, 2005

Time: 6:00-8:00 P.M.  
Place: Dormann Library, 101 W. Morris St., Bath  
Topic: "Seminar for Understanding Alzheimer's Disease"\*

### Wednesday, July 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"\*

### Monday, July 18, 2005

Time: 6:30-8:30 P.M.  
Place: Mt. Olivet Baptist Church, 141 Adams St., Rochester  
Topic: "Managing Challenging Behaviors" ; "Taking Care of Yourself"

### Thursday, July 21, 2005

Time: 6:30-8:30 P.M.  
Place: Monroe Community Hospital, 435 E. Henrietta Rd., Rochester  
Topic: "Family Dynamics and Conflicts" ; "Long Distance Caregiving"

## Thumbs Up

...to **Terri Celona** whose birthday party fundraiser, in honor of her parents Joseph and Marie Juliette Fichette, raised \$680 in support of Alzheimer's disease research.

*Terri Celona and Sharon Boyd*



...to **Baywinde** for their Bistro Night which raised \$125 for the Alzheimer's Association.

*Laura Hollenbeck, Baywinde, Director of Memory Care, presents a check to Sharon Boyd*



...to **Watson's Chocolates** for their Valentine Day promotion which raised \$200 in support of the Alzheimer's Association programs and services.

## Monday, July 25, 2005

Time: 7:00-8:00 P.M.  
Place: Heather Heights, 160 W. Jefferson Rd., Rochester  
Topic: "Nutrition and Dementia"

## AUGUST 2005

### Wednesday, August 10, 2005

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

### Monday, August 22, 2005

Time: 7:00-8:00 P.M.  
Place: Heather Heights, 160 W. Jefferson Rd., Rochester  
Topic: "Role Changes and Transitions"

## SEPTEMBER 2005

### Monday, September 26, 2005

Time: 7:00-8:00 P.M.  
Place: Heather Heights, 160 W. Jefferson Rd., Rochester  
Topic: "Communication Through the Stages"

\*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 800-272-3900.**

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

## Professional Network

**Next Meeting: Wednesday, June 8th 2005 8:30 AM – 10:00 AM**

Since its inception in 2003 the network has reached over 25 agencies throughout our 9 county region and served an average of 15 providers at each meeting. The network was designed for professionals working in dementia care to share their expertise with others, familiarize them with the Alzheimer's Association's programs and services, introduce them to other community resources available, and inform them of educational opportunities, advances in research and public policy issues that affect those with dementia.

Recently, a few changes have been implemented. Professional Network now meets quarterly (March, June, September & December) from 8:30 AM – 10:00 AM. We also have a new meeting location: the Alzheimer's Association Education Center, located on the third floor at Monroe Community Hospital, 435 East Henrietta Road, Rochester.

At our next meeting, Deanna Mascari, Program Coordinator of the Alzheimer's Association and Jeanne Mulley, former Program Manager from Seniorsfirst Day Program at Valley Manor will provide a presentation on Memories in the Making®. Learn what Memories in the Making® is, how it has benefited those with dementia and how you can implement it within your program, residential setting, or agency.

To register call us at 585-760-5400 or check us out on the web at [www.alz-rochesterny.org](http://www.alz-rochesterny.org).

## PUBLIC POLICY 2005

### FEDERAL UPDATE

#### Medicare Prescription Drugs

Medicare activity at the federal level continues to focus on implementation of the new Medicare prescription drug benefit. The Association is playing a lead role in the Access to Benefits Coalition for Prescription Drugs (ABC) and submitted comments on the proposed rules concerning the administration of the new drug benefit. In addition, the Association has participated in numerous meetings with CMS officials, including Administrator Mark McClellan, to discuss implementation, education and outreach efforts regarding the Medicare drug benefit and concerns about implementation of the Medicare prescription drug benefit for long-term care residents and beneficiaries with Alzheimer's disease.

In other Medicare news, on January 24th Senator Blanche Lincoln (D-AK) introduced S 40, the *Geriatric and Chronic Care Management Act of 2005*. S 40 is similar to a bill introduced by Senator Lincoln last year and would improve quality of care for people with Alzheimer's and other chronic conditions by extending Medicare coverage to geriatric assessment and care coordination. The legislation authorizes Medicare to cover the cost of essential chronic care services by paying physicians to manage medications effectively, work with other health care providers as a team, and provide necessary support for caregivers. The Alzheimer's Association supports S 40.

#### Ronald Reagan Alzheimer's Breakthrough Act of 2005

As we reported at the end of 2004, Congress did not pass the *Ronald Reagan Alzheimer's Breakthrough Act* that was introduced after President Reagan died in June. The bill would increase the authorization level for Alzheimer research at NIH to \$1.4 billion and expand services for caregivers by increasing funding for the National Family Caregiver Support Program and the Alzheimer's Disease Demonstration Grant Program and authorizing a family caregiver tax credit, as well as an above-the-line tax deduction for long term care insurance premiums. The legislation would also authorize a public education campaign to inform individuals about prevention techniques that can maintain their brain as they age.

Senators Barbara Mikulski (D-MD) and Christopher Bond (R-MO) are expected to re-introduce the *Ronald Reagan Alzheimer's Breakthrough Act*. The new Senate bill will contain the same language as the bill that was introduced last year (S 2533/ HR 4595). In the House, Representatives Christopher Smith (R-NJ), Michael Burgess (R-TX) and Edward Markey (D-MA) are planning to re-introduce a similar version of the Ronald Reagan bill. However, the House bill will not incorporate the caregiver tax credit and above-the-line tax deduction for long term care insurance included in the Senate bill. The Alzheimer's Association will support the re-introduced Senate and House bills. Bill numbers and legislative language will be available from [www.thomas.loc.gov](http://www.thomas.loc.gov) after the bills are introduced.

#### Medicaid

The Alzheimer's Association has joined with other organizations urging Congress to avoid Medicaid cuts and to work with us and

other organizations to solve the Medicaid issue. Our message is to preserve the value of the Medicaid benefit to low income people with long term care needs and protect Medicaid expenditures from budget cuts or caps.

The Alzheimer's Association has produced a brochure "The Threat to Medicaid", that helps individuals get the facts and take action. If you would like a brochure, call the Rochester office at 585-760-5400 or 800-272-3900.

### STATE PRIORITIES

#### Medicaid

The NYS Coalition of Alzheimer's Chapters supports maintenance of Medicaid funding for long-term care services in the home and community and residential settings. We oppose any state attempt to restrict or eliminate the right of spousal refusal; we oppose any attempt by the state to extend the look back period; and we oppose any attempt to initiate or extend a look back period for Medicaid home care.

#### Assisted Living Bill Chapter Amendment

We seek an Assisted Living Bill Chapter Amendment to require facilities with residents with dementia or cognitive impairment but do not advertise as specializing in care for the population demonstrate that they can meet the special care needs of these residents. The requirement should not be limited as it is in the bill to facilities advertising/marketing as providing special care for persons with dementia or cognitive impairments. Language should be incorporated strengthening this bill to require that a facility caring for even one resident with dementia or a cognitive impairment demonstrate how they will safely meet their needs as detailed in this provision. We also recommend that as a means of ensuring the character and competence of assisted living providers, they should be subject to review by the Public Health Council – just as other providers of health care services.

#### Family Health Care Decisions Act

The Legislature must address the need for family health care decision legislation. New York is one of two states without a law to enable families to make medical decisions for patients without a health care proxy who lack decision capacity. There is a need for legislative action to pass a Family Health Care Decisions Act to enable families to make medical decisions forgoing life-sustaining treatment in medically and ethically appropriate circumstances. A mechanism for making health care decisions for incapacitated patients who are without family or friends should be included. This legislation has long been of importance to families and friends of persons with Alzheimer's who are without health care proxies.

*For a complete listing of the New York State 2005 Legislative Agenda, call the Alzheimer's Association at 800-272-3900 or 585-760-5400.*

## Remember or Honor Your Loved One In Our Memory Gardens

Purchase a brick, tree or bench to memorialize your loved one. For more information or to receive a brochure, contact us at 585-760-5400 or 800-272-3900.

## Agency News

Alzheimer's Association's Board Member and Treasurer, Stewart Putnam, Executive Vice President and COO, Unity Health, was honored with the 2005 Health Care Achievement Award.



## New Officers of the Board Appointed

**Anna E. Lynch, Esq.** has been elected Chair of the Board. Anna is managing partner at Underberg & Kessler, LLP.



**Margaret M. Bills** has been elected Vice Chair of the Board. Meg is the Executive Administrator at Hill Haven Nursing Home.

**Richard Mueller** has been elected Secretary of the Board. Dick is Administrative Vice President Commercial Real Estate Finance at M&T Bank.



**Stewart C. Putnam** has been elected Treasurer of the Board. Stewart is Executive Vice President of Unity Health System.

## New Board Members Appointed

**Kay Prey**, retired Director of Community and Donor Relations of Genesee Country Village and Museum.



**John Tracy**, Partner of Mohawk Customs & Shipping, LLC.

**Ann McCormick**, General Counsel, Executive Vice President and Secretary of Home Properties.



**Victoria Hines**, President/CEO, Visiting Nurse Service of Rochester and Monroe County.

## Memory Gardens Receive National Award

The Alzheimer's Association Memory Gardens were recognized during an elegant ceremony at Genesee Valley Club on Friday, March 11th. The Memory Gardens were selected as an Honorable Mention award recipient in the 2004 Mutual of America Community Partnership Award competition.

During the luncheon, Thomas Gilliam, Chairman and Chief Executive Officer of the Mutual of America Foundation, Theodore Herman, Vice Chairman of the Mutual of America Foundation and Brian Thomas, Vice President of the Mutual of America Rochester Office recognized the individuals and organizations that played a key role in the success of the Memory Gardens.

Coins were presented to Teresa Stewart, Bob Wilcox and Deanna Mascari of the Alzheimer's Association; Frank Tripodi, President/CEO of The Wartburg Adult Care Community, Mt. Vernon New York; Devvie Schleyer, Board Member and Public Policy Chair of the Alzheimer's Association; Trude Wright of the Rochester Garden Club; Austin Hildebrandt and Tom Hildebrandt of Davenport Hatch Foundation.

New York State Assemblyman Joseph Errigo was among the more than sixty guests who attended the ceremony.

## Rosemary Society

### THANK YOU

to these special Rosemary Society members for their generous contributions that support vital programs and services for people affected by Alzheimer's in our nine-county Finger Lakes region.

### 2005 Members

#### \$3,000-\$6,999 Silver Level

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*in memory of Lena Beninati*

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*in honor of All Who Suffer from This Disease*

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*in memory of Lena Beninati*

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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.

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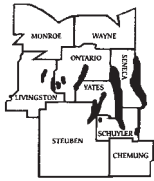
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