



Memory Matters

April • May • June 2004

Heart of America Chapter
and the
**Mollie Tivol Alzheimer's
Family Resource Center**

INSIDE FEATURES

Maintain Your Brain™1, 3

Executive Director's View2

Tivol Golf Classic3

Memantine Drug Available4

Memory Walk5

New Website Address.....5

Caregiver Question and Answer6

Caregiver Stress7

Calendar of Events8 - 9

Memory Exhibit10

Safe Return Blitz.....11

Caregiver Conference12

Alzheimer's From a Child's Eyes13

Volunteer Opportunities13

Caregiver Education and
Professional Workshops14

Heroes of the Illness15

Seasons of RemembranceBack Cover

Until Alzheimer's is Just a Memory

So many advances have been made in recent years, we have every reason to be hopeful for an Alzheimer's cure, especially if we work together now. As individuals and a nation, it's time to understand that our future is only as healthy as our brains. We must do everything we can today for a better tomorrow.

The Alzheimer's Association has launched a campaign to make brain health a personal and a national priority. That's what Maintain Your Brain™ is all about.

It is true that we need more research, more funding, new treatments, better drugs, increased compassion and understanding, stronger leadership and improved care. But you can do your part.

- Take part in healthy aging.
- Understand the disease.
- Get more active in the fight to conquer Alzheimer's.

Take steps now to take care of your brain.

- Manage your numbers — blood pressure, cholesterol, blood sugar and body weight — to stay healthy as you age.
- Feed your brain with nutrients. Eat foods high in vitamins E and C. Take a multivitamin that includes folic acid. Include salmon, mackerel or other foods high in omega-3 fatty acids in your diet.



alzheimer's  association™

continued on page 3

Board of Directors

Cathy Tivol Maslan
President

Connie Lindesay
Secretary

Bob Mackey
Treasurer

Ace Rowley
Past President

Debbie Biehl

Don Forsythe

Mark Foster

Patricia Brown Glenn

Janice Mayer

Sue McCord-Belzer

Laura Ozenberger

Connie Wood

Debra R. Leib
Executive Director

Main Office Staff

Michelle Niedens, LSCSW
Education Director

Jeanne Reeder, MSW
Patient & Family Services Specialist

Kim Stein

Memories in the Making® and Volunteer Coordinator

Kelly Loeb

Latino Outreach Coordinator

Juliette B. Bradley
Communications Director

Adam Keener
Development Director

Trisha McClanahan
Special Projects Coordinator

Pat Coleman
Finance Director

Mary Shehan
Office Coordinator

Pat Koenig
Receptionist

Midtown Satellite Office Staff

Clemme Rambo
Outreach Coordinator

Northeast Kansas Regional Office Staff

Jennifer Haller
Program Coordinator

Cindy Miller
Outreach Coordinator

Northwest Missouri Regional Office Staff

Victoria Christgen
Regional Director

Brenda Gregg
Program Coordinator

Cindy White
Outreach Coordinator

Southeast Kansas Regional Office Staff

John von Wedell
Outreach Coordinator

New Logo; Same Mission

by Debra R. Leib, Executive Director

As our loyal supporters, you are among the first to share our pride and excitement in this historic time of growth for the Association: the formal launch of our new Alzheimer's Association brand, represented by this logo, symbol and tagline:

alzheimer's association

the compassion to care, the leadership to conquer

During the Association's 23-year history, we have had five brand logos reflect our evolution as an organization. The current version, adopted in February of this year, is part of a national public awareness campaign to make Alzheimer's a national priority. While we have changed our look over the years, we haven't veered from our vision: **a world without Alzheimer's.**

The new brand creates a positive, clear identity and embodies who we are and what we do. The symbol conveys a strong visual statement of our dual "people and science" mission (see sidebar on page 3). We have entered an era of real hope and promise for conquering Alzheimer's disease. Our new brand is part of an aggressive, coordinated effort to foster greater public awareness and recognition of our Association's programs and services.

We also seek a stronger connection with those who are not yet touched by Alzheimer's or those who do not yet know that we are the world leader in Alzheimer's research and support. To speak to these individuals and inspire them to take action, the Association is launching a multi-year, integrated, broad-based campaign to change the way Americans, specifically baby boomers, think about Alzheimer's disease.

The campaign, built around the theme "Maintain Your Brain," aims to

increase the public's understanding of the disease and research progress, as well as urge everyone to take part in healthy aging and to get active in the fight against this terrible disease.



Each of us can help by renewing our personal commitment to this fight in all that we say and do. Spread the word by telling your family, friends and co-workers: "I am an advocate for the Alzheimer's Association, the world leader in Alzheimer's research and support. We're fighting on your behalf to give everyone a reason to hope."

Our mission is the same. Our work will intensify. Our public awareness will increase. Continue to partner with us to achieve a world without Alzheimer's.

Memory Matters

is a quarterly publication of the
**Alzheimer's Association –
Heart of America Chapter**

24-hour Information & Support Line
800.733.1981
www.alz-heartofamerica.org

Main Office
3846 W. 75th Street
Prairie Village, KS 66208
913.831.3888 FAX 913.831.1916

Midtown Satellite Office
2525 East Meyer Boulevard
Kansas City, MO 64132
816.361.6604 FAX 816.361.6627

Northeast Kansas Regional Office
515 South Kansas Avenue
Suite B-2
Topeka, KS 66603
785.234.2523 FAX 785.234.0919

Northwest Missouri Regional Office
801 Faraon Street
St. Joseph, MO 64501
816.364.4467 FAX 816.271.7068

Southeast Kansas Office
UCDD Building, 2601 Gabriel
Parsons, KS 67357
620.421.6550 ext. 1794
FAX 620.421.6550 ext. 1702

Maintain Your Brain™

continued from page 1

- Exercise both your body and brain. Work out, take a class, converse with others, read, play cards or work on crossword or jigsaw puzzles.

Know that a world without Alzheimer's disease can be a reality.

- 95 percent of what we know about Alzheimer's we have learned in the past 15 years. Scientists are making great strides in better treatments and preventions that may one day lead to a cure.
- The joint efforts of government agencies, research centers and pharmaceutical companies have uncovered many secrets of Alzheimer's disease.
- Today, Alzheimer's disease can be diagnosed with 90 percent accuracy.

Volunteer, advocate and donate.

- Join an Alzheimer's Association Memory Walk™ team or spend a few hours at the local Chapter office volunteering your time.
- Lobby your legislators to increase federal funding for Alzheimer's to \$1 billion each year. Talk to them about supporting local Alzheimer's initiatives.
- Give to the Alzheimer's Association and make Alzheimer's part of our past, not our future.

alzheimer's association™

The new logo conveys our dual mission of support and research as represented by people and science.



The symbol is derived from the abstracted forms of a human head in profile and a scientific beaker.


Play Like a Champion at the



The Nicklaus Golf Club at LionsGate will again host the Tivol Classic on June 14th. This tournament is your opportunity to play on the only Jack Nicklaus course in Kansas City and be a champion for the Alzheimer's Association.

This year, participants can choose either to play a "scramble" format in the morning or a "shamble" format in the afternoon. Restaurants and vendors will again be offering food and beverage tasting holes to golfers along the course.

All sponsorships and individual entries include the following for each registered golfer:

- Tournament day lunch provided by 
- Hole-in-one prizes including a 2004 Fat Boy motorcycle from Gail's Harley-Davidson.
- Distinctive Tee Package with memorable gifts.
- Green fees and golf cart (2 golfers per cart).
- Pre-tournament private party invitation for silent/live auction and dinner Sunday evening, June 13th at Union Station.

For sponsorship or registration information, please call Debra Leib, executive director, at 913-831-3888 or log on to our website, www.alz-heartofamerica.org.



Double Eagle Sponsor

Going Once, Going Twice, SOLD!

Even if you don't play golf, you can still participate in this fundraiser. The live and silent auction held the night before the golf tournament features a vast array of items from "fun" to "priceless" including everything from romantic get-aways to a private dinner on a train.

If you have an item or a service you would like to donate, please call Juliette Bradley at 913-345-0494.

If you are not a golfer, or a guest of a golfer, but would like to attend the dinner/auction, we welcome you to do so for \$30 per person. Please call 913-831-3888 for more information.

Treatment For Moderate to Severe Alzheimer's Disease Now Available

Memantine is a drug that was approved in October 2003 by the U.S. Food and Drug Administration (FDA) for treatment of moderate to severe Alzheimer's disease. Forest Laboratories Inc., Memantine's U.S. developer, announced Memantine's availability in January 2004 and markets the drug under the trade name Namenda®.

Memantine is classified as an uncompetitive low-to-moderate affinity N-methyl-D-aspartate (NMDA) receptor antagonist, the first Alzheimer's drug of this type approved in the United States. It appears to work by regulating the activity of glutamate, one of the brain's specialized messenger chemicals involved in information processing, storage, and retrieval. Glutamate plays an essential role in learning and memory by triggering NMDA receptors to allow a controlled amount of calcium to flow into a nerve cell, creating the chemical environment required for information storage.

Excess glutamate, on the other hand, overstimulates NMDA receptors to allow too much calcium into nerve cells, leading to disruption and death of cells. Memantine may protect cells against excess glutamate by partially blocking NMDA receptors.

After reviewing the results of two U.S. studies of individuals with moderate to severe Alzheimer's disease, the FDA's advisory committee agreed that the data submitted in the new drug application support the safety and effectiveness of memantine in treating moderate to severe Alzheimer's disease.

One of the studies was a 24-week U.S. study enrolling 404 individuals with moderate to severe Alzheimer's disease with initial Mini-Mental State Examination (MMSE) scores from 5 – 14 who had been taking donepezil (Aricept) for at least six months, with a stable dose for at least three months. Donepezil is in another class of Alzheimer's drugs currently approved for mild to moderate symptoms. In this double-blind study, participants were randomly assigned to receive either 10 mg of memantine twice a day or a placebo in addition to their donepezil. Those receiving memantine showed a statistically significant benefit in performing daily activities and on the Severe

Impairment Battery, a test designed to measure cognition in profoundly incapacitated individuals, while participants taking donepezil plus placebo continued to decline.

Because this trial was for only 24 weeks, the study does not provide data on the effects of long-term use of memantine when it is added to donepezil. Investigations of longer-term use are ongoing.

Another study, called the M-BEST study, investigated the clinical efficacy and tolerability of memantine in care-dependent severely demented inpatients. Due to the elderly and fragile population, the study period was 3 months, and the trial medication 10 mg per day. Patients with Alzheimer's disease, vascular dementia or mixed forms were included. Investigational focus was on functional disability status and care dependence. This study included 166 patients with moderate to severe dementia. After just 12 weeks of therapy, memantine was shown to improved patients' cognitive performance, their ability to cope with everyday tasks, and the overall clinical picture. There was an improvement in patients' activities of daily living such as getting up, washing themselves, getting dressed, and going to the toilet, and a clinically relevant and significant decrease in dependency on nursing staff.

Although both memantine and drugs that support acetylcholine temporarily delay worsening of Alzheimer's symptoms through different mechanisms, neither class of drugs is known to stop the underlying progression of the disease. Though the benefit of the memantine/donepezil combination was statistically significant in treating moderate to severe symptoms according to the detailed assessments of function used in this study, the effect may be modest in terms of everyday situations and will vary from person to person.

As with all the current medications for Alzheimer's, ethical issues need to be considered with use in late stages of the disease. Please consult your physician for more information and recommendations. Forest Laboratories is providing information about Memantine at www.namenda.com.

Redesign of Chapter Website Enhances Accessibility

The next time you log on to the Heart of America Chapter's website, you will no doubt notice some changes. In addition to the new look, significant enhancements have been implemented.

The site is now easier to navigate and is full of information that those with Alzheimer's, their family members and caregivers will appreciate having at their fingertips. The old website address, kcalz.org, will be redirected to the new website address for a few months, but please make note of the new address:

www.alz-heartofamerica.org



alzheimers association

memory walk'04™

Taking steps to end Alzheimer's

a new logo...an even better event!

Saturday, October 2nd

For more information call 913-831-3888 or log on to www.alz-heartofamerica.org

Memory Walks Begin in June

The Northwest Missouri Regional Office of the Heart of America Chapter will be holding its 3rd Annual Memory Walk in Cameron, Missouri, on Saturday, June 12th.

Registration for the walk will begin at 8:30 a.m., and the walk will begin at 9:30 a.m. at the Pavilion in the Park, located at 221 Seminary.

For more information, please call Barbara York, Chairperson, at 816-632-4800 or Cindy White at the Alzheimer's Association Northwest MO office at 816-364-4467.

New Kansas City Location

The Kansas City Memory Walk will be held in a new location on October 2, 2004.

CORPORATE WOODS IN OVERLAND PARK

Tree-lined roadways through the picturesque business park of Corporate Woods will be the site of this year's Kansas City Memory Walk. Event registration will be held in the parking lot of Building #40 at 9:00 a.m. with the walk beginning at 10:00 a.m.

Glad You Asked

This column features a question or concern from a caregiver, family member or patient who is searching for ideas or suggestions. You can submit a question to Jeanne Reeder, LMSW, Patient and Family Services Specialist, at the Heart of America Chapter office, 913-831-3888, or e-mail jeanne.reeder@alz.org.

Jim hung his head and whispered, “I don’t go see Dad anymore because he doesn’t talk, and I really miss him.”

Jim recently came by the Chapter office with questions on how to communicate with his Dad. It is hard to imagine not being able to communicate with someone you love. Communication is that basic and uniquely human experience that involves both talking and listening; it is verbal as well as nonverbal and allows us to develop relationships. Communication is more than mere words. It is touch, it is one’s approach to another: the tone of voice we adopt, our facial expressions, body language, how we stand — even our sighs and seemingly meaningless sounds.

As Alzheimer’s and other dementias progress, problems with communication increase. There are a variety of communication problems from “word salad,” which is a conversation that makes no sense, to jumbled words, to no verbal expression. At times the problem is cognitive: Dad does not understand what you are saying so he does not respond. Sometimes Dad may understand but remains silent because he is afraid of making a mistake. Common language difficulties that may arise:

- Abulia: the person can no longer hold a thought long enough to complete attempted conversation and so gives up trying to communicate.
- Anomia: the inability to recall the correct word or phrase to identify an object.
- Aphasia: the loss of ability to express oneself by speech or writing or to read or understand the speech of others.

When you communicate with a person with Alzheimer’s disease, it may feel like the communication is no longer a 50-50 proposition, but the person is still communicating with us. We have to be attuned to the nonverbal. Remember, when you sit sharing smiles you are communicating. Effective communication is worth the work, for it keeps your loved one connected,

maintains his or her dignity, and protects for both of you the intimacy of your relationship.

Tips for Effective Communication with People Who Have Dementia:

- Be patient — take time and give them plenty of time to respond.
- Approach the person from the front, with friendly expressions.
- Always identify yourself, though you may be familiar to them.
- Pay attention to the communication that is not spoken, the feelings expressed.
- Listen, no matter how many times you have heard a story.
- Be clear — keep conversation simple and direct.
- Affirm their conversation, for example, “I can tell you enjoyed fishing.”
- Invite conversation, “How big was that fish you caught?”

Tools to Encourage Communication:

- Use a variety of objects to boost conversation: a piece of material, soft or rough, a special rock, a greeting card, or flowers.
- Use “remember when” — a haircut was 50 cents, the one room school house, a favorite vacation, their best birthday, the first day of school.
- Give a hand massage or shoulder massage. Talk about the feel or the smell of the lotion or the feel of the massage.
- Read a brief one page story and discuss it or using a picture write a brief story about the picture.
- Listen to old time radio tapes — talk about their favorite show, or what it was like when TV replaced the radio.
- Watch music videos of their favorite music.
- Share photos from their childhood and have them tell you the story behind the picture.
- Take a pet to visit.
- Share a favorite food.

No matter how much or how little your loved ones are capable of communicating, always remember that they still need your love and affection. Your words and gestures are their hope, joy, and comfort for the journey.

Alzheimer's Disease Caregiver Stress

Warning Signs and Ways to Cope

CHICAGO — Alzheimer's disease relentlessly destroys the minds and memories of millions of Americans and has a traumatic and devastating impact on their nearly 20 million family members and caregivers.

Seven of every 10 people with Alzheimer's live at home with family and friends providing almost 75 percent of their home care. Caregivers spend an estimated 69 to 100 hours a week – as much as two full-time jobs – caring for someone with Alzheimer's disease.

Alzheimer's places incredible physical, emotional, and financial stress on caregivers as they face the dramatic changes in the person's personality and abilities. "Coping with the slow, but progressive loss of a loved one's ability to remember, think and reason right before your eyes certainly is overwhelming, exhausting, and stressful," said Kathy O'Brien, senior vice president, program and community services at the Alzheimer's Association. "It's no wonder that more than 80 percent of Alzheimer's caregivers report frequent, high levels of stress, and nearly half say they suffer from depression."

Too much stress can be damaging to caregivers and the people in their care, yet too often Alzheimer's caregivers don't recognize their own needs, fail to do anything about them, or don't know where to turn for help. The Alzheimer's Association urges caregivers to learn to recognize and take steps to reduce stress.

Warning Signs of Caregiver Stress:

- Denial about Alzheimer's and its effect on the person diagnosed;
- Anger that no cure or effective treatments exist;
- Anger toward the person with Alzheimer's or others;
- Social withdrawal from friends or activities that once brought pleasure;
- Anxiety about facing another day and what the future holds;
- Depression that affects your ability to cope;
- Exhaustion that interferes with completing necessary daily tasks;
- Sleeplessness caused by a never-ending list of concerns;
- Irritability that leads to moodiness and triggers negative responses and reactions;

- Lack of concentration that makes it difficult to perform familiar tasks;
- Health problems that begin to take their toll, mentally and physically.

Caring for someone who has Alzheimer's disease is an undeniably stressful responsibility, but there are ways to manage this stress to remain physically and mentally healthy. However, caregivers experiencing several of these stress symptoms on a regular basis should consult a physician.

Coping With Stress:

- Get a diagnosis for your loved one as early as possible. Take the person to a physician when Alzheimer's warning signs are present;
- Know what resources are available in your community — contact the Heart of America Chapter for programs and services that will assist your daily caregiving needs;
- Learn about the different stages of Alzheimer's and the appropriate care giving techniques and strategies;
- Accept help and support from family and friends;
- Take care of yourself. Watch your diet, exercise, get plenty of rest, and take time off and do something for yourself;
- Manage your level of stress. Use relaxation techniques, note your symptoms, and talk with your physician;
- Accept changes as they occur and prepare for the inherent changes associated with Alzheimer's;
- Do legal and financial planning to prepare for future needs;
- Be realistic – about what you can and cannot do and accept your limitations;
- Give yourself credit for your accomplishments and try not to feel guilty for lost patience, mistakes or being unable to do everything on your own.

If you are a caregiver of someone with dementia, please turn to page 12 to learn about the 4th Annual CARING FOR THE CAREGIVER CONFERENCE.

Important Dates on the Horizon

APRIL 24
Caring for the Caregiver

MAY 1
Safe Return Mayday

JUNE 13 – 14
Tivol Golf Classic

Local Kansas City Artist Selected for *Memory* Exhibit Chooses to Benefit Alzheimer's Association With His Sculpture

The Salina Art Center is featuring an exhibit called *Memory* — a jurored exhibition of artists investigating the role of memory in personal identity, and the tensions among memory, truth, and loss.

Saralyn Reece Hardy, director of the Art Center and curator for *Memory* said, “We invited artists to expand and deepen understandings of the power of art and the fragile nature of memory. Rewarded by 155 proposals, challenges and meditations on the concept of memory, the project became much larger than we expected. In the end, we stopped at nineteen artists.”

The artists hail from all over the United States as well as three foreign countries. The exhibition *Memory* is part of The Memory Project, a group of exhibitions, seminars, and films, sponsored by the Salina Art Center.

It has been an honor for the Alzheimer's Association to be part of a unique work of art by one of the selected *Memory* artists, Kansas City artist, Matthew Dehaemers. His multi-media interactive sculpture, entitled, “The Significance of the Moment,” is a 4 foot layered wooden “head” with a 7 in. LCD screen in the forehead sharing memories of individuals who live, cope and smile despite the diagnosis of some form of dementia. A 10 ft. long card catalog cantilevers from the back of the head and holds 1500 envelopes, each containing a small piece of paper. Viewers have the opportunity to

make a small donation, then select an envelope out of the drawer and write an important memory or story from their life. They refile it back in the drawer and the next viewer can read what others have shared. All donations will go directly to fund Alzheimer's research.



Dehaemers said the drawer in the back is so long because he wanted to draw an obvious comparison between the smallness of our own physical head and the vast store house of our mind. He posed these questions, “If we had to fill a drawer with all the memories from our very own life...how long would that be? Would it be infinite?”

Dehaemers said “This sculpture is meant to look at a small but powerfully positive spot, despite the disease of dementia and specifically its derivative of Alzheimer's disease — that despite the disease that erodes the mind and brain, there are certain memories that even those individuals manage to hold on to and recount for a long time because for one reason or another they are that powerful of moments no matter how big or how small.”

Dehaemers said that his multi-media sculpture was inspired by his grandmother who passed away over two years ago, but had dementia the last few years of her life. “I remember times I spent with her in those last few years when she would recount these very precise and particular memories the two of us had together.” Dehaemers said.

The Salina Arts Center *Memory* exhibit runs until May 16th. It is anticipated that Dehaemer's sculpture will be shown at some point in Kansas City and

around the country with opportunity to raise more funds for Alzheimer's research.

On behalf of the Alzheimer's Association, we thank Matthew for his amazing creative talent and his desire to generate awareness about Alzheimer's disease, and help fund disease research.



Mayday! Mayday! Enroll Your Loved One in Safe Return for FREE on May 1, 2004

The Alzheimer's Association – Heart of America Chapter is planning a Safe Return enrollment blitz on Saturday, May 1. The goal is to enroll as many dementia patients as possible during this event to promote the safe return of individuals with Alzheimer's or a related dementia who may wander and become lost.

Wandering is a common behavior among people with a dementia illness, especially Alzheimer's disease, and this behavior can quickly lead to dangerous circumstances. Wanderers seldom seek help, do not usually respond to shouts, and leave few physical clues to their whereabouts. If a wanderer is not located within the first 24-hours, the risk of death due to exposure and dehydration increases dramatically.

Safe Return is a nationwide identification, support, and registration program that works at the community level. Assistance is available 24 hours, every day, whenever a person is lost or found. When missing, Safe Return faxes the registrant's information and photo to local law enforcement. When found, a citizen or law official calls the 800 number and Safe Return notifies listed contacts. Local Alzheimer's Association Chapter offices provide support.

The enrollment fee for Safe Return is \$40 (caregiver identification is an additional \$5) but, on May 1, the enrollment fee, including the charge for caregiver ID, will be waived for individuals residing in the Alzheimer's Association – Heart of America 66-county service area. Within 4 to 6 weeks of submitting the completed enrollment, participants will receive an engraved identification bracelet or necklace, iron-on clothing labels, key chain, lapel pin, refrigerator magnet, stickers, wallet cards and a caregiver checklist.

If you attend one of the Safe Return enrollment locations on May 1, please have the following information with you to enroll a loved one in the

program. This information will also be necessary if you choose to enroll online:

- Name of the enrollee as it will appear on the identification products
- Full address and telephone number
- Social Security number
- Date of birth
- Height and weight
- Eye, hair, and skin color
- Race and native language
- Medical conditions
- Critical medications
- Unique characteristics such as a beard, scar, etc.
- An original photo, passport size or larger
- Exact wrist measurement if ordering an ID bracelet

Contact information will also be collected. Up to three contacts may be listed, with the primary caregiver listed as the first contact. Name, full address, work and home phone numbers, plus relationship to the registrant will be provided to Safe Return for their database. In addition, the exact wrist measurement of the primary caregiver must be provided if a caregiver ID bracelet is desired.

A few of the Safe Return enrollment sites scheduled for May 1st are:

Chanute, KS	Osage Village, 301 W Walnut
Garnett, KS	Extension Office, 411 S. Oak St.
Parsons, KS	Fire Station, 1819 Washington
Pittsburg, KS	Fire Station, 205 W 7th.
Topeka, KS	Fairlawn Plaza Shopping Center Hunter's Ridge Shopping Center Fairlawn Plaza Shopping Center
Chillicothe, MO	Livingston County Division of Senior services, 601 W. Mohawk
Princeton, MO	Mercer County Courthouse Public Administrator's Office
St. Joe, MO	East Hills Shopping Center

Other enrollment sites will be available. For more information about the Mayday Safe Return enrollment opportunity in your area, call 1-800-733-1981.

Don't Just Survive, But Thrive Through the Caregiving Experience

Nearly one out of every four households is involved in caregiving to someone aged 50 or over. If your household is the one in four, you know the impact that this new role has on your life. Whether you are in a crisis situation or involved for the long term, taking care of a loved one can be one of the most exhausting, challenging, difficult, yet loving things you will ever do.

That is why the Alzheimer's Association is offering a very special day for any family caregiver of someone with Alzheimer's. If you are a caregiver, you are invited to Caring for the Caregiver, a day for rejuvenation, self care and personal encouragement. This special day will be at The Embassy Suites just north of the Country Club Plaza on Saturday, April 24th and will begin at 9:00 a.m.

Your loved one can be cared for that day with free respite care. And, this day will not cost you anything.

The feature presentation will be *The Balancing Act: How to Stay Healthy, Happy, and Hopeful While Caring for a Loved One*, presented by Karen Rowinski, author and motivational speaker.

This program is a light-hearted look at the impact of caregiving on our lives. We'll laugh as we learn simple strategies and techniques to not only survive but thrive through the caregiving experience.



Karen Rowinski,
featured speaker at the Caring for the
Caregiver Conference on April 24th



Karen takes her first-hand experience in living with adversity and turns it into a message of encouragement and motivation that everyone can take to heart. She blends personal anecdotes, thoroughly researched information, and most importantly, strategies that people can use immediately to embrace the change, chaos and challenges that we all inevitably face.

You will come away from this conference with more resilience to deal with your stress and frustrations, more energy to do what you have to do, more time for yourself and more contentment and joy in spite of the challenges in your life.

Caring for the Caregiver Event Schedule:

- 8:30 a.m. Registration and Continental Breakfast
- 9:30 a.m. Welcome – Lewis Diuguid, Honorary Chair, V.P. Community Resources, The Kansas City Star
- 9:30 a.m. Karen Rowinsky, Author and Motivational Speaker
- 10:40 a.m. Pampering activities (chair massage, manicure, journaling, music therapy)
- 12:30 p.m. Lunch
- 1:30 p.m. The Question Box – A distinctive panel to answer your questions. Panelists include:
Dr. Lynn Lyon, Neurologist, The Memory Clinic, Rehabilitation Institute
David Pyle, Licensed Psychologist
Jill Watsky, Elder & Disability Law Firm

To register for Caring for the Caregiver, please call 913-831-3888 or log on to the Chapter website at:
www.alz-heartofamerica.org

Emporia to Host Alzheimer's Teleconference

Paula Sauder of Emporia has helped arrange a link to the teleconference "Living with Grief: Alzheimer's Disease," sponsored by the Foundation for End of Life Care and Hospice of the Flint Hills. The conference will be held Wednesday, April 28, at Emporia State University, Visser Hall room 330, 12:30 – 3:00 p.m. A 30-minute panel discussion will be presented following the teleconference. Reservations are not needed, but are appreciated by calling 620-340-6177.

Sauder is well known in Emporia and the surrounding communities for her tireless work on behalf of the Alzheimer's Association. In addition to facilitating two support groups, arranging educational conferences, presenting her own informational programs, and developing community resources, she also chairs the local Memory Walk and has raised nearly \$100,000 since she first became involved with the Association.

VOLUNTEER OPPORTUNITIES

There are many ways to volunteer to help the Alzheimer's Association – Heart of America Chapter. If one of the opportunities listed interests you, please call the number shown below.

Tivol Classic Dinner/Auction

This fundraising event includes a silent and live auction. If you can assist with, or provide a contact for, a donated item, please call Juliette Bradley at 913-345-0494.

Memories in the Making[®]

Volunteer artists needed. Call Kim Stein at 913-831-3888.

Main Office

General office volunteers are always needed. Contact Kim Stein at 913-831-3888.

Seeing Alzheimer's From a Child's Eyes

The experience of Alzheimer's disease is not isolated to the individual with the illness. Nor does it only touch a spouse or an adult child. The experience of Alzheimer's disease, like all of the challenges that life presents, affects all our support systems...families, friends and neighbors. But the role children assume in that process is often unrecognized.

Children are impacted by parents caring for their parents. They struggle with unanswered questions about the disease and they are affected by the manner in which the disease is discussed and addressed.

The Alzheimer's Association joined with Kansas City Public Television (KCPT) and other community agencies to work on several projects in follow up to the documentary, "The Forgetting". One such project was the "I'm a Helping Hand" day, a day of fun and celebration for the contributions children make as caregivers. They

were celebrated for the songs they sing to individuals with Alzheimer's disease, for holding hands and giving hugs, for sharing their parent's time, for seeing a person for who they are, not who they are not, and for the hundreds of small ways they participate in loving care. They were led in singing, creating stories and art work that tell the stories of their thoughts and feelings around caregiving. Pizza, ice cream and a tour of KCPT were part of their celebration.

Twenty-one children from around the metropolitan area joined in. Each child was given a gift bag that included the book, "Wilfrid Gordon McDonald Partridge". Special appreciation goes to KCPT for making all this possible, as well as partners Strokes for Support, Catholic Community Services and Midwest Bioethics. Extra special appreciation goes to every child who finds room in their heart to see beyond an illness.

Recharge Your Batteries Caregiver Education Workshop

Springtime is finally here, and it's time for caregivers to "recharge their batteries" by empowering themselves with education. The Northwest Missouri Regional Office has scheduled a rural caregiver education workshop from 9 a.m. – 3 p.m., May 12, 2004, at the Moila Shrine Temple, 701 North Noyes, St. Joseph, Mo.

The workshop is intended for family members, CNAs, personal care attendants, LPN students and other health-related caregivers who wish to gain a greater understanding of caring for a person with Alzheimer's disease or related dementia.

A group of specialists will discuss the history of Alzheimer's disease, medication advances, nutrition concerns and how to introduce fun into caregiving.

The "Recharge Your Batteries" caregiver workshop is part of an ongoing series of education events designed to increase awareness, education and services utilization among Alzheimer's families and caregivers in rural areas of Northwest Missouri.

The cost of the program is \$10 per person, which includes lunch and materials. Please call the Northwest Missouri Regional Office at 816-364-4467 for more information or to register. Registration deadline is May 5, 2004.

Northeast Kansas Regional Office Offers Professional Workshop

On Wednesday, April 28, the Northeast Kansas Regional Office will host a workshop for health care professionals titled "Current Interventions for the Treatment of Alzheimer's Disease."

The keynote speaker will be Cornelia Beck, RN, PhD, FAAN. Dr. Beck currently serves as the director of the Alzheimer's Disease Center at the University of Arkansas for Medical Sciences in Little Rock, Arkansas. She is a published author and researcher with a passion for implementing effective behavior milieu in long term care settings for people with Alzheimer's disease.

In this presentation, Dr. Beck will review studies on behavioral interventions to increase cognitive and functional performance and decrease behavioral symptoms in persons with dementia. The review will highlight recent innovative research that has been proven effective for this population.

Also on the program will be the medical director of the Senior Diagnostic Unit at Stormont Vail Regional HealthCare. Psychiatrist Brady J. Schroer, DO, will address the subject of recent developments in drug therapy for persons with Alzheimer's disease.

Co-sponsors of the workshop are Stormont-Vail Regional Medical Center and Forest Pharmaceuticals, Inc.

The workshop will be from 9:00 a.m.-12:00 noon in the Pozez Education Center Auditorium at 1515 SW 8th St., Topeka. Continuing education credits will be awarded. Cost to attend is \$24 which includes light refreshments. Pre-registration is requested. A brochure can be obtained by contacting the Northeast Kansas Regional office in Topeka at 785-234-2523 or 800-733-1981.

Northeast Kansas Regional Office Gets Long Deserved Facelift

The Northeast Kansas Regional office invites you to stop by and see their recently updated office including a family reception area and a library of books addressing dementia topics.

Most exciting is the artwork on display created by participants in the Memories in the Making® program at the Wayne and Mary Lou Johnson Arts and Inspiration Center of Salina. Stop by anytime 9 a.m. to 4 p.m. Monday through Thursday or call 785-234-2523 for directions.

The “Thief In The Night” Will Never Steal Their Love

Edna Humphreys tells it as she sees it – and that includes talking about caring for her husband, John, who was diagnosed with Alzheimer’s disease three years ago.

It’s been a long, difficult journey for Edna and John, who lived for almost 60 years in Humphreys, a rural community in Northwest Missouri. More than a year ago, John moved into a nursing facility in nearby Trenton, while Edna also left her longtime home to be closer to John.

The couple loved the outdoors and went dancing every Friday and Saturday night. Now, they spend their time together in John’s room or in the activity area of the nursing home.

Edna is open about the hardships of caring for a person with dementia; however she also exhibits the strength of character and heart necessary to love someone with Alzheimer’s disease.

Here is Edna’s story in her own words.

“Alzheimer’s is a ‘thief in the night’ – at least it was for us. Johnnie was postmaster for thirty years and really enjoyed life. These past three years, he became a different person.

Hunting and fishing were his favorite hobbies, but the last year he was home, he never went fishing. I read later that sometimes people with Alzheimer’s can be afraid of water. I believe that.

Having Johnnie change was hard on me, as well as on all his family. For months, I couldn’t talk or associate with anyone without crying. Our children finally told me, ‘Mom, it’s time.’ Sometimes, it’s nice to have decisions taken out of the mate’s hands. I always thought, ‘Maybe he’ll improve.’ But he didn’t.

Heroes of the illness



Edna and John Humphreys

Edna Humphreys is a very accepting woman. She has accepted that her life with her husband John will not ever be the same. Life changes have been made and in general, John may not remember who Edna is on a regular basis. But on a good day, it only takes that one special glance from John when he indeed not only recognizes Edna, but looks at her with a love that not even Alzheimer’s can take away. Edna and John are heroes of the illness, and we honor them.

We put Johnnie in a nice home where he is cared for better than I could. He always liked music and dancing. If there’s music at the home, I’ll go out and we will dance, and the nurses – bless them – will dance with him. When you first move loved ones away from home, you learn not to say words like “going home” or “where you live” because they remember them and want to leave. Sometimes when I see him, for a second, I see some recognition and that makes my day.

Alzheimer’s is a disease, and I’m glad people are out there who will listen and that we have organizations like the Alzheimer’s Association to help people. Alzheimer’s disease isn’t something you put in a closet and shut the door. It’s not going away.

Every family member handles Alzheimer’s disease differently. It isn’t easy, but it gets easier. I know.”

Now that John rarely talks, Edna misses the person who he used to be, but she accepts who he is now. With the help of friends, family and through sharing their story, she and John are courageously walking through the process of Alzheimer’s disease, but not alone...they walk together.

And sometimes, the past doesn’t seem that far away. At the nursing home Valentine’s Day party, piano music started up and John asked Edna to dance. And it was as if things were the way they used to be, for they danced to every song.

Their lives have taken an abrupt turn. The dance has been altered, but they still relish the moments they have together. The “thief” may take Johnnie’s mind, but it will never steal his spirit or his love for Edna.

Heart of America Chapter
3846 W. 75th Street
Prairie Village, KS 66208

NON-PROFIT ORG
US Postage Paid
Jefferson City, MO
PERMIT NO. 210

RETURN SERVICE REQUESTED



Mission Statement:

To provide education and leadership to enhance care and support services for those affected by Alzheimer's disease while supporting efforts to eliminate the disease.

MOTHER'S DAY FATHER'S DAY *Seasons of Remembrance* MEMORIAL DAY BIRTHDAY

There are many days throughout the year that bring opportunities to remember the special people we once shared our lives with, and for whom we miss dearly each day. "Seasons of Remembrance" is a chance to honor them. Simply fill out the form below. Each honored individual will be acknowledged in a special "Seasons of Remembrance" section of the next newsletter.

Enclosed is my gift of: \$25 \$50 \$100 \$250 \$500 Other _____

Please designate my "Seasons of Remembrance" donation: in honor of in memory of

Name of person you wish to honor/remember

This donation is being made in celebration of:

Mother's Day Father's Day Memorial Day Other _____

Donor's Name _____ Address _____

City _____ State _____ ZIP _____

Telephone Number _____

Donations may also be charged to your Visa MasterCard

Credit Card # _____ Exp. Date _____

Credit Card Holder's Signature _____

Mail this completed form and your check to:

The Alzheimer's Association – Heart of America Chapter
3846 W. 75th St., Prairie Village, KS 66208