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# Memory Matters

January • February • March 2005

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

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## New Groups Empower Those with Alzheimer's

People with Alzheimer's disease may feel isolated, helpless or believe that their days of impacting and changing their communities are over.

That, however, is not true. Thanks to the work of the Heart of America Chapter in collaboration with the Missouri Coalition of Alzheimer's Association Chapters, the Administration on Aging (AoA) has awarded the state of Missouri, working through the Alzheimer's Association, a three-year grant to create and implement "Empowerment Groups" around the state. The AoA Alzheimer's Demonstration program supports the development of innovative programs and services for people with Alzheimer's. The Chapter received a similar grant in 2002 to support the development of Arts and Inspiration Centers in Kansas.

The four Missouri Alzheimer's Association Chapters will begin 16 empowerment groups during the grant period. The first group in the Heart of America territory is in St. Joseph and centers on advocacy efforts. Through advocacy, members feel they can use their experiences with Alzheimer's disease to help improve the lives of others. In the process, members gain a renewed sense of self, purpose and connection. A group centering on volunteerism will begin in Clinton in March.

The groups are geared toward those individuals in the earlier stages of the disease and center around nine possible curriculums, all focusing on continuing capacity and the ongoing ability to make a difference.

### *\*\*Important Dates\*\* on the Horizon*

#### **MARCH 8**

Missouri Memory Day  
Call 913-831-3888 for details

#### **APRIL 16**

Caring for the Caregiver Conference  
Doubletree Hotel, Kansas City, MO  
Call Kelly at 913-831-3888 for details

#### **APRIL 22**

Memories in the Making® Art Auction  
See article on page 5

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## Resolve to Make a Difference

by Debra R. Leib, Executive Director



*"How wonderful it is that nobody need wait a single moment before starting to improve the world."* Anne Frank

"Dear God," my friend Rabbi Vered Harris' writing began, "with the advent of the new secular year,

help me make the time to consider my values and goals. I value most the health and well-being of my family. Because of this, it is critical that I help to create a healthy and whole community in which those I love can flourish."

This is one of the special times of the year when we are blessed with the opportunity to reflect upon our lives. Yet how many times have our new year's resolutions focused on self-improvement? Annually we resolve to lose weight, spend less, read more, exercise often.

Our Maintain Your Brain™ campaign would certainly endorse a personal commitment to living a healthier lifestyle. Our fundraising campaign would encourage you to spend more, not less, in the coming year to support worthy organizations and important causes.

But how often do we reflect upon our lives in order to improve the world? This is the year to resolve, first and foremost, to make a difference in the lives of those we love, in the health of the community, and in the fight to end Alzheimer's.

Now is the time to raise your voice, to speak out for change and for hope, to walk, to volunteer, to advocate, to donate, to do everything we can to stop the devastating impact of this disease.

Not long ago, Alzheimer's disease was widely considered a hopeless condition. Our steadfast resolutions have made possible the dramatic strides in advancing care and research. Help us make 2005 a year of continued progress and hope.

## One Man's Resolution to Make a Difference

In 1996, Paul Shireman decided to participate in Memory Walk to honor his parents who were both suffering from Alzheimer's.

After raising more than \$1,000 that year, Paul made it his personal goal to maximize his fundraising efforts through Memory Walk each year, thereby spreading awareness of Alzheimer's to hundreds of new supporters who have joined the fight to end Alzheimer's.

For eight years in a row, he has not only accomplished his goal, but he has modeled how one person can make a difference in a community. To date Paul has raised almost \$40,000 for the Heart of America Chapter and the programs and services the Chapter provides.

While Paul has chosen to raise funds and awareness, "making a difference" can take many forms, from donating to volunteering to advocating. But it all begins with your wholehearted personal commitment. Resolve to begin it now.

## Memory Matters

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

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Parsons, KS 67357  
620.421.6550 ext. 1794  
FAX 620.421.6550 ext. 1702

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## **Congress Announces \$700 Million in Funding for Alzheimer's Research, Plus \$1.6 Million for Joint Alzheimer's Awareness Program with the CDC**

The federal investment in Alzheimer's disease research will grow to approximately \$700 million next year as a result of legislation adopted by Congress on November 20, 2004. This is an increase of approximately \$20 million over funding for 2004.

Due to the advocacy efforts of the Alzheimer's Association, Congress also appropriated \$1.6 million for a joint public education program on Alzheimer's with the Centers for Disease Control and Prevention (CDC). The goal of the program will be to educate health professionals and the public about healthy lifestyle habits that may reduce risk for Alzheimer's. This marks the first time that the CDC has received federal appropriations for an Alzheimer's program.

"In a time when our country is at war and our government is operating at a deficit, we are grateful to Congress for the additional funding for Alzheimer's research and related programs," says Sheldon Goldberg, president/CEO of the Alzheimer's Association.

"We will continue to seek a \$1 billion in federal funding for Alzheimer's research. With a five-year investment in research at the \$1 billion level, we could achieve major breakthroughs in delaying the onset of the disease and slowing its progression. If Congress wants to control healthcare costs, Alzheimer's disease is the place to begin, and the time to begin is now."

Alzheimer's is the public health crisis of the 21st century. Increasing age is the greatest risk factor. As baby boomers enter the age of greatest risk, the number of new cases will increase dramatically. Today, there are 4.5 million people with Alzheimer's. One in ten individuals over age 65 and nearly half over 85 are affected. Unless research leads to prevention or a cure, by 2050, Alzheimer's could affect anywhere from 11.3 million to 16 million people.

Alzheimer's is devastating not only to individuals and families, but to society. Unless we address the Alzheimer's crisis now, it will overwhelm the already stretched healthcare system and bankrupt Medicare and Medicaid. An investment in research that merely slows the

progression of the disease and delays its onset could, within just five years, save \$50 billion in Medicare costs and prevent 1.6 million Americans from the heartache of Alzheimer's.

While finding ways to cure or prevent Alzheimer's remains the highest priority, the Alzheimer's Association is pleased to report that our advocacy efforts over the past year have convinced Congress to lend support to families already struggling with the disease by providing:

- the aforementioned \$1.6 million in funding for the "Healthy Aging & Alzheimer's Disease" initiative with the CDC.
- \$11.8 million for the Administration on Aging Alzheimer Demonstration program at the Department of Health and Human Services. This program supports the development of innovative programs and services for people with Alzheimer's, especially those living in underserved minority and rural communities.
- \$1 million to support the Alzheimer's Association's National Contact Center which provides 24 hour, 7 day a week support for individuals with Alzheimer's, their families and caregivers.
- \$883,000 for the Association's Safe Return nationwide program to help locate individuals with Alzheimer's who wander away from home.
- \$157 million for the Family Caregiver Support Program (an increase of \$4.3 million over current funding).

The Association will continue to call upon the federal government to make Alzheimer's a health priority. Concerned citizens can also make their voice heard by writing a letter, calling or emailing their elected officials.

"We need as many voices as possible if we are to influence our political leaders to support and fight for our cause in Congress," says Stephen McConnell, senior vice president of advocacy and public policy, Alzheimer's Association.

## Two Presentations Hosted by Northwest Missouri Regional Chapter Office

**Alzheimer's: A Historical Perspective:** While many people know about Dr. Alois Alzheimer and how he first "discovered" the illness, the disease was present even before Dr. Alzheimer's research.

Alzheimer's Disease: A Historical Perspective will be presented Wednesday, Jan. 19, 2005, at 9 a.m. at the Francis Street United Methodist Church, 12th and Francis Streets, in St. Joseph, MO.

The lecture will focus on the history of the disease, as well as its impact on modern culture and a look into the future of the disease.

The program cost is \$5 per person, which includes breakfast. You can also choose not to join us for the meal and still enjoy the program at no cost. Please call 816-364-4467 for reservations.

If your organization is interested in hosting a seminar like this one, please contact Brenda Gregg at 816-364-4467 or [brenda.gregg@alz.org](mailto:brenda.gregg@alz.org).

**Clergy Conference:** Topics to be discussed are "An Overview of Alzheimer's Disease," "The Significance of Ministering to Those With Alzheimer's Disease and Their Families," and "Strategies For Meaningful Interaction Between Clergy, Those With Alzheimer's Disease, and Their Family." The conference will be held January 26 at St. Francis Methodist Church, 9:00 am – 12:00 pm. The cost is \$10 and will include breakfast. To make reservations, contact Anita Benefiel or Brenda Gregg at 816-364-4467.

## "Better Communication with Medical Professionals," A Caregiver's Workshop

Do you feel intimidated in the hospital setting? Are you confused by medical terms? Are you uncertain of your role as part of the health care team?

The Northeast Kansas Regional office, in partnership with the Jayhawk Area Agency on Aging, is offering a free program for family caregivers. Caregiver Specialist Karel Ramsey of the Jayhawk Area Agency on Aging will be the keynote speaker and trainer.

At this 3-hour interactive workshop you will receive information on how to better navigate the health care system. You will also learn communication skills that will help you make sure your loved one gets the care and attention they deserve. You will have an opportunity to practice new skills, share with others and receive a valuable free workbook that will be yours to keep.

### Date and location of the workshop is:

Thursday, February 17, 2005

1:00 p.m. – 4:00 p.m.

Alzheimer's Association – Heart of America Chapter, Northeast Kansas Regional Office  
515 S. Kansas Ave., Suite B2  
Topeka, Kansas

Pre-registration is requested. Call Cindy at 785.234.2523 or email [cindy.miller@alz.org](mailto:cindy.miller@alz.org).

## Northwest Missouri Regional Office Has Moved

The Northwest Missouri Regional Office in St. Joseph has officially moved into a new location. The office is now located in the First Christian Church at 10th and Faraon. The office is on the second floor in rooms 5 and 6. Office hours will remain the same, but if you prefer to

stop by after 4:00 pm, please call to make an appointment. The phone number also remains the same, but our fax number has changed. The new fax number is 816-364-2553. Please stop by to visit and see our new space.

## Evidence Mounts — Healthy Lifestyle May Protect Your Brain

Need another reason to lose weight, stop smoking, eat your broccoli and get off the couch? Research suggests that weight, blood pressure, cholesterol level, lung function, leisure activity and a diet rich in vegetables are all linked to the risk of getting Alzheimer's disease.

“Although Alzheimer's is a complex disease with complex causes, studies bolster evidence that we may be able to influence at least some factors in the mix,” said William H. Thies, Ph.D., Alzheimer's Association vice president, medical and scientific affairs.

A decade-long study under way at Stockholm's Karolinska Institute shows that individuals who were obese in middle age are twice as likely to develop dementia later. For those who also had high mid-life cholesterol and blood pressure, dementia risk was six times higher. Another Karolinska study found women who scored in the lowest fifth on lung function stood twice the risk of developing dementia as women with the healthiest lungs. Yet another Karolinska project suggests that leisure pursuits involving mental, social or physical activity all seem to offer some protection against dementia. The greatest benefit came from complex pursuits combining two or three types of activity.

A healthy lifestyle includes mental challenges. To keep your brain healthy, keep it active through a steady diet of mental gymnastics. These exercises at the right are perfect for a quick pick-me-up of your brain. Work on them on your own or make it a challenge for you and a friend.



### Challenge Yourself!

#### EXERCISE #1

Rearrange these letters to find the name of a famous artist and inventor.

**N C D E O L V O D N A I R I A**

#### EXERCISE #2

Change the top word into the bottom word by changing only one letter each time. You must form a new word with each move.

JOUST
PAINS

Challenge yourself with exercises like these whenever you get a chance. Whether you love crossword puzzles, TV game shows, or the daily newspaper word search, participate as much as you can...it's brain food!

#### ANSWERS

Exercise #1 Answer  
Leonardo de Vinci

Exercise #2 Answer  
Joust  
Joist  
Joint  
Point  
Paint  
Pains

## Memories in the Making® — An Art Auction to Remember

Please mark your calendar for the 2nd Annual Memories in the Making® Art Auction to benefit the Alzheimer's Association – Heart of America Chapter.

**Friday, April 22, 2005**

**Baron BMW**

Event Chairpersons

*Stacy and Mark Parkinson*

*Shirley Allenbrand and Jeff Cleveland*

Honorary Chairpersons

*Irene and Chris Cumming*

For information please contact Debra Leib at the Alzheimer's Association, 913-831-3888



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## Heart of America Chapter Calendar of Events

January • February • March 2005

### THE FAMILY SERIES

This six part series addresses many of the common concerns caregivers have regarding Alzheimer's disease. RSVP by calling 913-831-3888. All sessions will be held at Temple Heights, Arts and Crafts Room, 5440 Blue Ridge Cutoff, Raytown, MO from Noon to 1:00 p.m. Call Donna Masters at 816.358.9533 for directions.

#### February 3 – Part One: “What Can I Expect?”

*Overview of the disease, including diagnosis, stages & family experiences.*

#### February 10 – Part Two: “I Don't Need Any Help”

*A discussion of managing activities of daily living including breakdown, provision of care and other issues associated with bathing, toileting, dressing, taking medication and feeding.*

#### February 17 – Part Three: “He Just Sits Around All Day”

*Explores the role of activities and structure for the person with Alzheimer's disease. Suggestions on activities and options to maximize strengths.*

#### February 24 – Part Four: “Is She On Too Many Medications?”

*The concerns and appropriate benefits of commonly prescribed medications in the care of the person with Alzheimer's.*

#### March 3 – Part Five: “I Can't Do This Anymore”

*The dilemma around the placement decision. Covers options, resources and the decision making process.*

#### March 10 – Part Six: “I Should, I Ought, I Have To”

*A discussion of the guilt that typically goes along with the role of caregiver.*

### BREAKFAST CLUBS

*A hometown support experience where people gather in a safe environment and where support is provided in a round table way.*

#### Chanute, Kansas

The first Wednesday of every month  
Holiday Park Restaurant, 9:00 a.m. – 10:30 a.m.

#### Fort Scott, Kansas

The third Wednesday of every month  
Mercy Hospital, The Xavier room, 9:00 a.m. – 10:30 a.m.

#### Parsons, Kansas

The first Thursday of every month  
Cronies Hotel Parsonian, 9:00 a.m. – 10:30 a.m.

#### Pittsburg, Kansas

The third Thursday of every month  
Mount Carmel Hospital — The Sheridan Room, 9:00 a.m. – 10:30 a.m.

#### Kansas City, Missouri

The second Saturday of every month  
St. Louis Center, 5930 Swope Parkway, 9:30 a.m. – 11:30 a.m.

#### St. Joseph, Missouri

The third Wednesday of every month  
36th Street Restaurant, 501 North Belt, 9:00 a.m. – 10:30 a.m. \$5 Fee

#### Trenton, Missouri

The first Wednesday of every month  
Lakeview restaurant, 9:00 a.m. – 10:30 a.m.

**PLEASE NOTE –** All meetings/classes are free of charge unless otherwise noted. All regional offices of the Heart of America Chapter host meetings and classes. Please note if the meeting/class you are interested in is held in Kansas City, Topeka, or St. Joe. The Alzheimer's Association Heart of America Chapter main office is located at:

3846 W. 75th Street, Prairie Village, KS  
The office sits behind the Reece & Nichols real estate building on the Northeast corner of 75th Street and Mission Road.

Registration for all meetings/classes is highly recommended and sometimes required if noted. Unless otherwise noted, call 913-831-3888 to register. Meeting times and locations are subject to change.

### JANUARY

#### January 19 – Building Creative Dementia Caregivers: A Train the Trainer Approach

*Training for the education staff of long-term care and other health-related agencies on the needs and management of people with dementia.*

Northeast Kansas Regional Office, 515 S. Kansas, #B2, Topeka, KS 9:00 a.m. – 3:00 p.m., Cost \$65.00, \$40 for each additional person from the same facility, includes breakfast, lunch and materials

#### January 26 – Reaching the Spirit Clergy Conference

St. Francis Street Methodist Church, 9:00 a.m. – 12:00 p.m.

#### January 28 – On Being a Caregiver

Golden Valley Memorial Hospital – Clinton, MO  
9:00 a.m. – 12:00 p.m. \$10 per person, includes lunch  
Call to register, 913-831-3888

### FEBRUARY

#### February 3, 10, 17, 24 – Let Me Call You Sweetheart

*This 4-part workshop is especially designed for men caring for women with Alzheimer's disease.*

Main Chapter Office, 9:00 a.m. – 12:00 Noon

**February 3 – Session I – Around the House:** learn how to keep your house in tip-top shape.

**February 10 – Session II – Beautiful in My Eyes:** learn how to style her hair, put on her best face and make her eyes sparkle.

**February 17 – Session III – Food for Body and Soul:** learn how to prepare a nutritious meal for your lady.

**February 24 – Session IV – Heart to Heart:** learn how to talk openly and honestly with the one you love.

#### February 4 – Legal Issues

*An attorney will speak on legal issues facing people with Alzheimer's disease and other dementia.*

Douglas County Senior Center, Lawrence, KS, 10:00 a.m. – 12:00 p.m.

#### February 8 – Reaching the Spirit

Prairie Baptist Church, 75th & Roe, Prairie Village, KS, 9:00 a.m. – 3:00 p.m.

#### February 17 – Better Communication with Medical

**Professionals — A Caregiver's Workshop**

Northeast Kansas Regional Office, 1:00 – 4:00 p.m.

#### February 22 – Building Effective Skills Training (B.E.S.T.)

*Designed specifically for nursing assistants, recreational and activity aides in extended care and community settings. Participants will receive certificates of attendance.*

Main Chapter Office 8:30 a.m. – 3:30 p.m. Fee \$25

### MARCH

#### March 8 – Missouri Memory Day

Call 913-831-3888 for details. Bus transportation available. \$10

#### March 14, 21, 28 – ABC's of Alzheimer's

*A free educational course for family members, caregivers and friends of persons with Alzheimer's disease or a related disorder.*

**March 14 – Session I – Overview of Alzheimer's**

**March 21 – Session II – Care and Consideration of the Patient**

**March 28 – Session III – Dementia-specific Resources for Caregivers**

Topeka Public Library, 5:30 – 8:00 p.m.

#### March 22 – Building Effective Skills Training (B.E.S.T.) – in Spanish

*Geared for individuals for whom Spanish is their primary language. Designed specifically for nursing assistants, recreational and activity aides in extended care and community settings. Participants will receive certificates of attendance.*

Roeland Park Community Center, 8:30 a.m. – 3:30 p.m. Fee \$25

#### March 24 – Generating Smiles

Village Shalom, 9:00 a.m. – 3:00 p.m. Fee \$25

## Virginia and Preston Lynch Still Enjoy The Moment Despite Alzheimer's

Scott Peck once said, “true love is not a feeling by which we are overwhelmed. It is a committed, thoughtful decision.” That, indeed, is what one sees when watching relationships survive and thrive through difficult times.

It is no accident that Preston and Virginia Lynch have remained together for the past 61 years. And, it is no accident that Virginia and Preston face Alzheimer's with the same commitment to each other and to life as they have the many other transitions that have marked their time together.

Preston was diagnosed with Alzheimer's disease four years ago. He is described as a loving man who chooses to participate in many wonderful experiences in life. He has spent many years working the good earth on a farm northwest of Trenton, Missouri. Music has been a friend to him through playing the french harp, the guitar and the piano. He continues to use his gift of music, playing for nursing homes and for church specials.

### Heroes of the illness

#### Virginia and Preston Lynch



*Virginia and Preston Lynch share a love for one another and for life that even Alzheimer's can not change. In fact, their love has strengthened since Preston was diagnosed and their lives have been enriched by the support of family and friends.*

The Lynchs have spent happy moments traveling together, socializing with friends, playing Pitch, and attending church. While some of their leisure activities have had to evolve due to the illness, they continue to search for and find joyful moments in watching videos of their travels, participating in the Senior Center, participating in the Trenton Breakfast Club and using their continuing capacity to help others.

Preston and Virginia are not remarkable because they face this illness. They are remarkable because they continue to make the committed, thoughtful decision to stay connected

to one another, to prioritize joyful moments, and to continue to show their love despite the illness. They are remarkable because they do not allow what isn't to hinder what is.

That kind of true love is heroic.

### Habla Español?

Those serving Spanish-speaking persons with Alzheimer's disease and their families have a place to turn for communication assistance.

The Alzheimer's Association – Heart of America Chapter has a full time Latino Outreach Coordinator, Kelly G. Loeb, on staff.

Kelly provides bilingual information about Alzheimer's disease to facilities and/or directly to family members of those with Alzheimer's. She is available to visit sites, meet with families, and help facility staff communicate with patients and families. Contact Kelly at 913-831-3888 or [kelly.loeb@alz.org](mailto:kelly.loeb@alz.org). The Chapter's website, [www.alz-heartofamerica.org](http://www.alz-heartofamerica.org), also has helpful Spanish-language information about Alzheimer's.

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

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**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.*

**GENERAL CONTRIBUTION FORM**

**YES! I want to help the thousands of area families affected by Alzheimer's Disease!**

Enclosed is my **tax-deductible** contribution of \$ \_\_\_\_\_.

Check Enclosed (payable to Alzheimer's Association)  Visa  MasterCard Card # \_\_\_\_\_ Exp Date \_\_\_\_\_

Card Holder's Name \_\_\_\_\_ Signature \_\_\_\_\_

Please print, and include salutation (Mr. & Mrs., Dr., Mr., Mrs., Ms.) Donor Name \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ ZIP \_\_\_\_\_

Home Phone \_\_\_\_\_ Work Phone \_\_\_\_\_

My gift is given:  In Memory of \_\_\_\_\_  In Honor of \_\_\_\_\_

Special Occasion \_\_\_\_\_ (birthday, anniversary, congratulations, etc.)

Please notify: Name \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ ZIP \_\_\_\_\_

Please send me information about:  Volunteering  Providing for the Alzheimer's Association in my will

I have made a gift to the Alzheimer's Association in my will  My employer has a matching gift program, form enclosed

**Please return to: Heart of America Chapter • 3846 W. 75th Street • Prairie Village, KS 66208**  
**For more information call the Chapter office: 913-831-3888 or 888-293-8636**