



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

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ONLINE NEWSLETTER

This newsletter is also available online. You can access this issue or past newsletter issues by logging on to www.alz-heartofamerica.org and clicking on the link in the red box on the home page.

Or, if you prefer the newsletter in print and are not currently a subscriber, fill out the form online or call 913-831-3888.

Memory Matters

August • September • October

**Alzheimer's Disease and Research:
A National Priority**

Ninety percent of everything we know about Alzheimer's disease has been discovered in the last 15 years. That is significant considering the disease was discovered by Alois Alzheimer's in 1906. This disease needs to be an urgent national research priority as with our aging population the magnitude of Alzheimer's disease is steadily increasing. It is projected that by 2050 16 million Americans will have this disease if we don't discover a way to prevent or cure it.

Generally, Alzheimer's disease research is divided into three categories:

1. **Prevention:** what are the causes and risk factors?
2. **Cure:** How can we earlier and better diagnose this disease? What kind of treatment will effectively treat the symptoms and slow its progression?
3. **Coping:** how can we better support the individual with the disease and their caregivers?

With research comes hope and scientists say they are on the edge of finding treatments to slow or stop Alzheimer's disease.

Through clinical trials scientists compare a potential new treatment with a placebo or a standard treatment. This is the only way to determine if a new drug is effective. This process is complex, expensive and involves thousands of people. On average it takes about 12 years for a medication to successfully go through the clinical trials from test tube to receiving final approval from the Federal Drug Administration and on to your local pharmacist. With this lengthy process one can see it is imperative that there are multiple clinical trials.

The large number of clinical trials now under way demonstrates the vigor of the field and the strength of our research infrastructure.

The Alzheimer's Association is excited at the research progression that is being made. The following information describes some of the drugs

See *Alzheimer's Disease and Research* on page 2

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Alzheimer's Disease and Research

continued from Front Cover

which show great possibility and are in Phase III clinical development, the last required clinical trial prior to being submitted to the Federal Drug Administration for final approval.

Flurizan: This agent selectively lowers the production of toxic amyloid. The toxic amyloid creates the plaque formation and neuron degeneration which are the hallmarks of the disease. In the mouse models it reduced the amyloid in the brain which led to improvements in learning and memory. It was well tolerated in patients in Phase II Clinical Trials.

Alzhemed: This drug is designed to act on two levels. First, to prevent and stop the amyloid formation and deposition in the brain; and second, to inhibit the inflammatory response associated with amyloid build-up in the disease.

Evistal: This medication is currently approved to treat osteoporosis in postmenopausal women. This study was designed to see whether treatment with this drug will lower the risk of developing Alzheimer's disease and any cognitive impairment.

Avandia: Epidemiologic studies indicate that people with insulin resistance are at increased risk for both Mild Cognitive Impairment and Alzheimer's disease. This clinical trial will test whether this drug, that has anti-inflammatory properties, can improve memory in people who have Mild Cognitive Impairment.

Zocor: This is a commonly prescribed cholesterol-lowering drug. It is being tested to determine if it can safely and effectively slow the rate of disease progression in people with mild to moderate Alzheimer's disease.

Currently, there are hundreds of various experimental research projects and clinical trials, all at different phases and all needing adequate research funding. Online resources with information include

the Alzheimer's Disease Clinical Trials Database (www.alzheimers.org/trials). This site provides information about Alzheimer's clinical trials, explanations of the Food and Drug Administration approval process and an e-mail announcement service regarding new trials.

These trials are the final proving ground for new treatments under investigation. Every trial represents the end result of years of creative scientific thinking, careful observation, laboratory study and data analysis. The large number of trials now under way demonstrates the vigor of the field and the strength of our research infrastructure.

Since 1982, the Alzheimer's Association has awarded more than \$185 million to scientists investigating the causes, treatment and prevention of Alzheimer's disease. Years later, the commitment is still the same, only the future in research and finding a cure is so much brighter.

Memory Matters

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

**24-hour Information & Support Line
800.272.3900**

www.alz-heartofamerica.org

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816.364.4467 FAX 816.364.2553

Southeast Kansas Office

UCDD Building, 2601 Gabriel
Parsons, KS 67357
620.421.6550 ext. 1794
FAX 620.421.0671

Tournament Tees Off With Success

Thank you to the sponsors, in-kind donors, golfers and volunteers who made the Tivol Classic another success on July 10 at the Nicklaus Course at LionsGate. Your continued support of the Alzheimer's Association is appreciated.

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Jacqueline Gonzales celebrates her win as the overall female fastest time at the Topeka Memory Walk and 5k Run on June 24 at Hummer Sports Park. She ran in honor of her grandfather, Fletcher Blaylock, with whom she is pictured.

More Memory Walks To Come

Southeast Kansas

Saturday, September 9 in
Pittsburg, KS. Call Lynette at
620-235-0020 or
lynette_emmerson@via-christi.org.

Kansas City

Saturday, October 7 in
Corporate Woods, Overland
Park, KS. Call Trisha at
913-831-3888 or
trisha.mcclanahan@alz.org.

Emporia

Sunday, October 8. Call
Paula at 620-342-9100 or
paulakay46@hotmail.com.

Northwest Missouri

Saturday, October 14 in St.
Joseph, MO. Call Brenda at
816-364-4467 or
brenda.gregg@alz.org.

Love and Art

This is an excerpt from a letter written by Verna Voss

Last spring the Alzheimer's Association called to ask my permission to enter a painting done by my husband in the Memories in the Making[®] program into the 2006 Art Auction. Permission was granted.

My husband Bill was not an artist but he loved the Memories in the Making[®] program. It was a way to express himself. He was a very precise, symmetrical person in life. Everything was symmetrical — bushes, plantings, clothes, and even the food on his plate! So when I saw the painting selected, it came as no surprise that it too was symmetrical. My first thought was that it would never sell at the auction and I would buy it back. And, in my mind, I settled on a figure.



Verna Voss stands proudly next to the painting her husband, Bill, painted for the Memories in the Making[®] Art Auction.

When I saw the painting at the auction I was amazed at how lovely it looked with a beautiful frame. I suggested to my daughter-in-law that we should sign up at the starting bid (\$50), so that it didn't look lonely. To my surprise, someone had already bid on it, so I increased the bid. In just a few minutes the bid was up to \$170. Wow!

People gathered, as it was time to close the auction. A woman asked me if I knew Bill. "Yes, he was my husband," I replied. "I'd love to have that painting," she said. "In reading the biography, there were so many things that Bill enjoyed that I also enjoy." Then she asked if Bill were there and I told her that he'd passed away in December.

I walked away for a while and when I returned, the woman had signed her name, *Kathy*, as the final bidder on the auction sheet. \$190 was the final bid. She turned to me and said, "It's yours!"

Tears followed, from both of us. My husband's last gift to me now hangs in a dedicated place above the desk in my apartment. And, I have a new, special friend and reinforcement of the fact there are beautiful people in this world.

Early Stage Alzheimer's Disease – To Hide or Seek

Yes, there is an early stage of Alzheimer's Disease. And no, it is not always evident to the casual eye. Individuals in the early stage often continue their lives with few people realizing the accommodations necessary to replicate the life that came with ease before.

The changes are subtle and typically slow. Unfortunately, denial and false shame sometimes forces those in early stage Alzheimer's onto a passive, difficult path.

However, there currently is a movement across the country to increase the number of programs and services directed at early stage individuals.

For many years the Heart of America Chapter has had an early stage group which meets at the main Chapter office. The Chapter also has a longstanding early stage group that is redeveloping in the Topeka area. In the last two years, thanks to an Administration on Aging Alzheimer's Demonstration Grant, four other early stage groups have been started across the Missouri territory. Each of those four, unlike the general support groups in Prairie Village and Topeka, has a specific focus area, each allowing for expression of concerns, questions and feelings around the memory loss, but channeling through various curriculum that remind both the participant and others that, indeed, there is life after diagnosis.

In Clinton, the focus is on the Memories in the Making® program, which centers on watercolor painting. Although there are 23 Memories in the Making® programs operating in the Heart of America service area, the Clinton group is the only one directed at those in the

early stage of the illness. In St. Joseph, the Advocacy Empowerment group discusses issues they are facing and develops reaction plans including inviting legislators to visit, letters to the editor of the newspaper and talks to the community.

In Warrensburg, the Collage Empowerment group share information about themselves and their opinions, thoughts and beliefs through the creation of collage art that is discussed, and at times shared, in the community.

The newest group is in Raymore. The Time Slips Empowerment group centers around story creation. Its purpose is to support ongoing imagination, focused thought and creativity as well as allowing issues and feelings to be shared through the stories.

With few exceptions, these groups are small and require energy to grow. Sometimes, care partners do not see the significance of their loved one participating in early stage programs. The impairments are not significant enough yet, at this stage, to require the level of respite needed at more advanced stages. Despite surveys from individuals who participate in the groups and the feedback from their families that clearly indicate improved emotional states for all, the understanding that early stage programs can positively impact the course of how the disease is managed stands unknown or minimized.

Family support of the person with the disease attending early stage programs is an important factor. Research shows there are direct implications in the affective state of the individual with the illness and the care partner. When depression and grief reactions are faced in the

person with the disease, they are also faced in the care partner.

Early stage programs give individuals a chance to learn and become empowered. Most importantly they give people the chance to see living hope through the eyes of others that continue to enjoy life despite the illness.

There is a message board for individuals in the early stages through the Alzheimer's Association's national website, www.alz.org, as well as a phone support program utilizing volunteers in the early stage to call others who have the illness, geared especially for those who are in areas not geographically accessible to the early stage groups.

The message is this. If you are in the early stages of a dementia, *come out of the shadows*. Face this, get on medication that can slow the progress and know that even more aggressive medications may be closer to market than we think. Attend an early stage group. Continue to attend even if you meet someone that is more progressed than you. By doing these things, you are supporting an honest, alive spirit that has a purpose despite a diagnosis. Talk with your family and be prepared for a variety of reactions. If you are the care partner of someone in the early stage, contact the Alzheimer's Association – Heart of America Chapter. Ask for a family meeting and allow the honest discussion of this illness while there is opportunity to have those discussions. Encourage the attendance at one of the early stage groups and assist in the logistics to make this possible. The old football adage is "the best offense is a good defense" but, in this case, it might better be said that the best defense is a good offense.

Seasons of Remembrance

The following individuals were honored in the Seasons of Remembrance Contribution Program:

Rosa Barber	Joe Chasnoff	Louise Kenney	Lois Sladkey
Evelyn Barlow	Joseph Csom	Helen M. Lenge	Mildred C. Stainbrook
Myra Bradley	Mildred K. Dellere	Lillian V. McField	Ethel Stolz
Garrison "Gary" A Britain Jr.	Gerald W. Deloach	Harland & Thelma Mohler	Rose M. Sullivan
Shirley Boyce	Eleanor Greenshields	Ben Moranville	Virginia Tappen
Nina Mae Bozarth	Dora Gould	Betty W. Nichols	Karin Ulrich
Goloa Cathell	Jack Himmelstein	Jean Shaw	Carolyn J. Warren
	Peter Jimenez		Maurine Wilson

Project Lifesaver Materializes in Kansas City Area

Safe Return is a valuable and successful program, assisting in the expedient recovery of wandering individuals. Approximately 750 people in the metropolitan area are enrolled in *Safe Return*. However, *Safe Return* is not always enough to address the safety needs of the 60 percent of individuals with Alzheimer’s disease who wander and find themselves in harms way.

This fall, through a Missouri Alzheimer’s Demonstration grant funded through the Administration on Aging, the Alzheimer’s Association – Heart of America Chapter and the Raytown Police Department will partner to bring tracking technology to the metropolitan area.

Project Lifesaver is a tracking system that includes law enforcement based receivers with individuals wearing a transmitter. Although there are range limitations, police can utilize the receivers on ground

or in air to increase the chances of finding a lost individual. The initial cost of each transmitter is \$250.00. The transmitters require batteries that are changed monthly and will cost participants \$7.60 a month. The Alzheimer’s Association – Heart of America Chapter is providing limited funds for transmitters for those Missouri residents who can not afford the \$250.00 charge. While the scholarship transmitters are only available to Missouri residents, all metropolitan residents are able to purchase transmitters and benefit from this program.

Program transmitters should be available to individuals by this October. Volunteers will be needed to help change batteries for those involved in the program. If you are interested in this program, either enrolling your loved one in the service or as a volunteer, please contact Michelle Niedens, at 913-831-3888 or michelle.niedens@alz.org for more information.

Who is at risk of wandering?

Those who:

- return later than expected from walks or drives;
- talk about fulfilling former obligations (i.e. going back to work);
- talk about going home even when they are at home;
- are restless and pace;
- have difficulty locating familiar places like the bathroom;
- check the whereabouts of familiar people;
- act as if doing a hobby or chore, but nothing gets done;
- appear lost in a new or changed environment;
- show signs of paranoia and other manifestations of psychosis.

If you are seeing any of these signs in your loved one, safety measures need to be in place. Consider enrolling in *Safe Return* or *Project Lifesaver*.

Glad You Asked

by Jeanne Reeder, L.M.S.W., Individual and Family Services Specialist

With tears streaming down her face, Molly, a loving daughter, grieving, though she didn't know it, continued her story: "and the worse part is, I should help more. I need to visit more, but I can't. This woman is not my Mother. We had such a great relationship. We were friends, best friends. Now there is no relationship."



Jeanne Reeder, L.M.S.W.

I hear these words often. It may be a daughter or a spouse today, a son or a sibling tomorrow, and maybe the next day, it is a friend coming into the office or calling on the phone. Each one is struggling to figure out what to do with the grief, the pain, the change in the cherished relationship with someone who has dementia.

When someone we love has Alzheimer's disease or other dementia, it does, indeed, change the relationship. And make no mistake, some of the changes will be painful. You will be saddened and frustrated, and you may find yourself experiencing grief in surprising ways. But these changes can also bring new depth to the relationship, create crystal moments to hold in your heart, and help you experience joy and celebrate your loved one in new and wonderful ways.

In focusing on our relationships with someone with dementia, the operative word is change. Remember, however, that few of our relationships we enter into are static. Relationships generally change over time as we unfold and grow. Think about the parent/child relationship. Or remember when you first fell in love. You were sure your beloved could slay every dragon and solve every problem, but then one day you knew that it would take both of you to slay the dragon and solve all your problems. Acknowledging change normalizes the situation, and helps us meet the challenges of our new situation.

Some of the problematic changes in our relationships are due to role reversal. We no longer share decision making, for example, or an equal division of labor. Communication difficulties and behaviors, such as accusations, wandering, and self-absorption, also tax the relationship. Perhaps worst of all are the changes in understanding and perceiving, the forgetting and confusion. We naturally grieve all these changes, especially when our loved ones do not recognize family members. Each caregiver I talk to has a list of changes that are specific to his or her relationship, and each change affects the relationship.

So how do we maintain our relationships with our loved one? The first step is to focus not on what's been lost, but on what remains – what is. What are the things you loved about your spouse, or your friend or mother that are still here? It might be one's sense of humor, affectionate nature, or an underlying characteristic that remains despite their losses. My friend Ginny had been diagnosed with Alzheimer's at least three years prior to me meeting her, but she was still a gracious hostess, offering me coffee and pie. A year later while visiting Ginny in the nursing home her first response was to offer me her chair and a cookie. The person we love lives on despite the disease. Ginny, even with Alzheimer's, is a gracious hostess.

Go with the flow. If your loved one thinks today is his or her birthday, burst into song, serve the ice cream. Throw away the rules. If he or she plays a five, seven, and nine in gin rummy, laugh and be amazed that he or she has won again. Seize the moment and find the serendipity within. Look beyond the disease to the one you love. While he or she may have difficulty communicating with words, listen and watch for the feelings that replace words. What is the thought, the emotion, the need that he or she is expressing by the inappropriate or confused behavior?

Other things to help you maintain relationship:

- learn all you can about this disease;
- join a support group;
- seek and accept help;
- check out our family resource library for books that can help you deal with relationship changes; and
- take advantage of other groups, like the new "Growing through Grief Group" scheduled to begin in September at the Chapter office (see the educational calendar for details).

That the relationship endures despite the disease is poignantly shared by Deborah Shouse in her book, *Love in the Land of Dementia: Finding Hope in the Caregiver's Journey*. For example, Deborah tells us that she really struggled with whether she should tell her Mom, who was in the late stages of Alzheimer's, that her husband and daily visitor, Deborah's father, had died of a sudden heart attack. After a week, Deborah noticed her mother's sadness and asked, "You miss, Dad, don't you?" "Yes," she said. Deborah then understood that her mother did "deep in her soul" know that her husband was gone. Deborah also knew that her dad had been right: he had always believed that Mom knew a lot. "He believed she was happy to see him. He had intricate conversations with her and believed her responses, whether silence, nods, or the occasional, 'Yes, dear,' meant something." Despite our skepticism and fears, our relationships live.

Heart of America Chapter Calendar of Events

August • September • October

ABC'S OF ALZHEIMER'S SERIES

Trinity Presbyterian Church, 4746 SW 21st, Topeka, KS
5:30 – 8:00 p.m.

September 11: Part I – “Disease Overview”

September 18: Part II – “Legal Issues”

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 – 10:30 a.m.

Fort Scott, Kansas

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

Parsons, Kansas

The first Thursday of every month
The Bake and Bean, 105 S. 18th, 9:00 – 10:30 a.m.

Pittsburg, Kansas

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

Kansas City, Missouri

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

St. Joseph, Missouri

The third Wednesday of every month
Francis Street United Methodist Church, 12th & Faraon
9:00 – 10:30 a.m. \$5 Fee

Trenton, Missouri

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

GROWING THROUGH GRIEF SERIES

This four part series addresses grief issues of families with a loved one suffering from Alzheimer's disease.

September 12: Part I – “The 5 Tasks of Griefwork?”

September 19: Part II – “The Big Three: Fear, Anger & Guilt”

September 26: Part III – “The Changes & Constancy of Relationships”

October 3: Part IV – “Holding On and Letting Go”

Main Chapter Office, 4:00 – 5:00 p.m.

REDEFINING ME SERIES

A 4-part series for individuals who are new to the diagnosis of Alzheimer's.
Main Chapter Office
11:00 a.m. – 12:00 p.m.

September 12: Part I – “What Alzheimer's Means?”

September 19: Part II – “Taking Control”

September 26: Part III – “Changing Relationships”

October 3: Part IV – “Finding Meaning?”

Main Chapter Office, 11:00 a.m. – 12:00 p.m.

THE FAMILY SERIES

This six part series addresses many of the common concerns caregivers have regarding Alzheimer's disease.

Part I – “What can I expect?”

Part II – “I don't need any help”

Part III – “He just sits around all day”

Part IV – “Is she on too many medications?”

Part V – “I can't do this anymore”

Part VI – “I should, I ought, I have to”

Part II will be August 3 with Parts III – VI continuing August 10, 17, 24 and 31 respectively. The series will begin again October 11 as shown below:

August 3, 10, 17, 24, 31

6:30 – 8:30 p.m., Bickford House, 9110 East 63rd, Raytown, MO

October 11, 18, 25

12:30 – 2:00 p.m., Southview Day Services, 1701 S. 45th, Kansas City, KS

OTHER IMPORTANT DATES

August 3 – “Light Your World” Rally

Join others and show your support against proposed federal budget cuts on Alzheimer's research and support services.

The Pavilion at Loose Park, 51st & Wornall, Kansas City, MO 6:30 p.m.

August 22 – Building Effective Skills Training (BEST)

Specifically for nursing assistants, recreational and activity aides in extended care and community setting. Participants will receive certificates of attendance.

Both sessions are 8:30 a.m. – 3:30 p.m. Fee \$25

Kansas City: Research Medical Center, 2316 E. Meyer Blvd., Kansas City, MO, Level B, Classroom L

Topeka: Northeast Kansas Regional Office, 515 S. Kansas, #B2

September 9– Memory Walk in Pittsburg, KS

9:30 a.m. Registration, 10:00 a.m. 1 and 2-mile Walks start

October 3 – 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.

Main Chapter Office, 9:00 a.m. – 3:00 p.m. Fee \$65 per person, \$40 for each additional person from same facility

October 4 – Eating, Drinking and Alzheimer's

Special considerations around eating and hydration as it relates to Alzheimer's.

5:00 – 6:00 p.m., Clinton Senior Center, 970 East Sedalia, Clinton, MO

For more information, contact Linda 660-885-3482

October 7 – Memory Walk in Corporate Woods, Overland Park, KS

9:00 a.m. Registration, 9:45 a.m. 1 and 3-mile Walks start

October 8 – Memory Walk in Emporia, KS

Call Paula at 620-342-9100 or paulakay46@hotmail.com

October 12 – Building Effective Skills Training (BEST) *In Spanish*

Specifically for nursing assistants, recreational and activity aides in extended care and community setting. Participants will receive certificates of attendance.

8:30 a.m. – 3:30 p.m. Fee \$25

Ruiz Library, 2017 Pennway, Kansas City, MO

October 17 – Alzheimer's Disease 101

An overview of the disease process and how family and caregivers can work with the individual experiencing the disease.

5:30 – 8:00 p.m., Cloud County Community College (Community Education Building – Conference Center), 2221 Campus Drive, Concordia, KS

November 1 – Defining Hope Conference

Keynote speaker: David Troxel, MPH, widely recognized expert on the best practices in Alzheimer's care and author of several books including, “The Best Friends Approach”.

Topeka Historical Museum, 6425 SW Sixth Ave.

\$40 (\$50 for conference and CEUs) RSVP to 785-234-2523

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.

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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!

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Address _____ City _____ State _____ ZIP _____

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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 800-272-3900