

# alzheimer's association™

## *early-onset connections*

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**Oklahoma and Arkansas Chapter**  
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Early-onset Connections program

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### **Tulsa Education Conference sets attendance record**

More than 500 people attended this year's Tulsa Education Conference and "Celebration of Excellence Award" luncheon, setting an attendance record.

"While this number is wonderful in terms of attendance, it tells us how many people need the services and programs we provide. The numbers reinforce the need for this type of conference in northeastern Oklahoma," said Tonda Ames, vice president of Marketing and Programs for the Oklahoma and Arkansas Chapter.

In addition to the entertaining and informative keynote speaker, Dr. David Snowdon, the attendees listened as national Alzheimer's CEO, Harry Johns, spoke during the "Celebration of Excellence Award Luncheon" about the future of the disease and his personal stories about his mother who recently passed away with Alzheimer's disease. Coach Frank Broyles also provided words of wisdom and encouragement to the 500-plus caregivers and professionals in attendance.

During the award luncheon, the Alzheimer's Association Oklahoma and Arkansas Chapter, Tulsa office, recognized the Hille Foundation with the prestigious "Maureen Reagan Award." "Accepting the award were Maggie Hille Yar and Mary Ann Hille. Harry Johns made the presentation.

The Maureen Reagan Memorial Award was established following the 2001 death of Maureen Reagan to honor the

spirit and passion in which she championed the cause on behalf of President Ronald Reagan. Maureen worked diligently for increased Alzheimer's awareness, support, and education on behalf of her father, President Ronald Reagan. This extraordinary recognition is presented for personal affirmation and noble response to the Alzheimer's Mission: to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.



### **Camp Building Bridges: *Support for the Children***

(Editor's Note: as this issue of the newsletter goes to press, the camp is already in session.)

**WHAT: Camp for kids who have a parent with Alzheimer's Disease**

**WHEN: July 6 – 12, 2008**

**WHERE: Camp Classen, Davis, Oklahoma**

*Written by Tracy Mobley*

My name is Tracy Mobley and many of you may already know my story but for those of you that don't, I was diagnosed with EOAD in 2002 at only 38 years old. This disease is a very cruel disease but the cruelest aspect of all was that our little boy was only 7 years old at the time.

How do you explain to a 7 year old that mommy's memory is fading day by day? How do you explain that when she appears to be upset or angry and takes it out on him that it is the disease not mommy? How do you explain that forgotten promises are just that, forgotten? How do you tell your child not to be afraid that mom is going to be okay, at least for the moment? All of these questions and more are questions that became a part of our life through our son. As he has grown, and I have slowly progressed, we have tried to be up front and honest with him as much as possible to his ability of understanding.

It is because of our son Austin, who is now 13 years

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**From JoAnn's Desk**

**Early-onset voices speak out:**  
*advocating increased funding for research, services for young families, better and earlier diagnosis in 2008*

In mid-April, three families joined JoAnn Webster, early-onset coordinator of the Oklahoma and Arkansas Chapter, at the Springdale, Ark., Education Symposium “Early-onset: The New Face of Alzheimer’s” to tell participants of the challenges faced by their loved one.

Ann Bowers and Terry Lang, care partners for their spouses, talked of the lengthy diagnosis process and the frustrations of going from doctor to doctor to get an accurate diagnosis. The spoke of the stress on their marriages that eventually led to divorce in one case. Ann told of the stress on her two young daughters, Tori and Cat, as they began to be caregivers for their Dad. Cat told the audience “no one told me that my Dad would eventually forget my name.” They urged physicians and other professionals in the audience to go ahead and tell patients the diagnosis was Alzheimer’s, so that they could then know what “their adversary was,” accept it and move on! Pat Chernicky-Prater, a person with dementia, encouraged families to learn as much as possible about the disease, and to get their legal and financial affairs in order. She encouraged them to plan for the future as soon as possible after the diagnosis, while the person with the disease is able to have input into the plans.

In May, the last Early Stage Town Hall meeting was held in Washington, D.C., prior to the national Public Policy Forum. Ann and her daughters again traveled to Washington to lobby with numerous others for increased funding for Alzheimer’s research and services for young families faced with the diagnosis. Justice Sandra Day O’Conner, Newt Gingrich and several others testified before a Senate hearing to push for Alzheimer’s research.

Chuck Jackson made his third trip to D.C. and pleaded for funding for a cure so his daughter would not have to take up the cause next year.

The Tulsa Office had another successful and large turnout for it’s annual education conference. The highlight of the June 5 conference for early-onset families was the face- to-face discussion for early-onset and early-stage persons and their families. Several recently diagnosed families were able to talk with “veteran” families and learn from them. We will report some of these discussions in future newsletters. One suggestion was to push to have more frequent half day or full day seminars or workshops that would facilitate such discussions. We are giving serious thought to trying to do this here in the Oklahoma and Arkansas Chapter. Email the EO coordinator at [joann.webster@alz.org](mailto:joann.webster@alz.org) if you would be interested in attending such a workshop or conference of your peers.

**Cat Sweatman, Terry Lang, Ann Bowers, and JoAnn Webster are all smiles after their plenary session at the Springdale conference and the wonderful reception they received.**



**“Camp”**

old, that I felt a strong desire to find a program to help children understand and at the same time, for just a brief period, take them out of the world of Alzheimer's disease/dementia. Through our own travels and struggles as advocates for Alzheimer's disease, we have seen first-hand that there is NO form of support for children. We have many conferences, seminars, workshops, support groups, etc., for adults, but our children are left to figure this out on their own.

This year for the first time, with the award of a very generous grant and donations from families from around the world, we have the pleasure of introducing Camp Building Bridges. This camp will give young teens ages 12-16, a six

day break from their home atmosphere and allow them to connect with others facing a similar situation. It will allow them to reconnect with themselves and form a support network of their own. For just a brief period they can just be kids and hopefully put Alzheimer's disease in the back of their minds.

To make this camp possible (because of the financial hardship that this disease causes) scholarships are available. Please visit our website for Camp Building Bridges [www.freewebs.com/younghope2007/](http://www.freewebs.com/younghope2007/)

Plans are being made for a similar camp in 2009. If you are interested, please contact Tracy or Allen Mobley at 417-933-5520.

## New Early-stage, Early-onset Support Group schedules Meetings for second and fourth Mondays of the month

Coping with Alzheimer's is difficult for anyone, but when it strikes people in their 30's, 40's, 50's and early 60's, they often deal with very different challenges than they would if diagnosed later in life.

Are you under age 65 and living with the early stages of Alzheimer's or related dementia? Do you have a loved one who is? Then this support group is for you. The group meets from 6:30—8 p.m., the second and fourth Mondays at Southern Hills United Methodist Church, 6160 South Lewis, Tulsa, Okla. This support group is for people with early stage, early-onset Alzheimer's and related dementias and their care partners.

Benefits of a support group include receiving encouragement and moral support; discovering that you are not

alone; learning ways to cope; sharing experiences; getting tips from others experiencing similar situations; learning about resources; and hearing from expert speakers.

Individuals with dementia and care partners meet together for a brief time then divide into two concurrent groups. Individuals with dementia must know of their diagnosis and be willing and able to talk about their feelings and participate in the group. ***Both they and their care partners must meet with the Early-onset coordinator prior to attending the group.***

If interested, please call or email: **JoAnn Webster, Early-onset Coordinator, 918-481-7746 or email [joann.webster@alz.org](mailto:joann.webster@alz.org).**

## Scientists Isolate Toxic Key to Alzheimer's Disease

Scientists have long questioned whether the abundant amounts of amyloid plaques found in the brains of patients with Alzheimer's actually caused the neurological disease or were a by-product of its progress. Now, using new research techniques, scientists have shown that a two-molecule aggregate (or dimer) of beta-amyloid protein fragments may play a role in initiating the disease. The study, supported by the National Institutes of Health, suggests a possible new target for developing drug therapies to combat the irreversible and progressive disorder.

Alzheimer's disease is marked by the build-up of plaques consisting of beta-amyloid protein fragments, as well as abnormal tangles of tau protein found inside certain brain cells. Early in the disease, Alzheimer's pathology is first observed in the hippocampus, the part of the brain important to memory, and gradually spreads to the cerebral cortex, the outer layer of the brain. In this study, researchers tested cerebral cortex extracts from brains donated for autopsy by people aged 65 and older with

Alzheimer's and other dementias, as well as those without dementia. The extracts contained soluble one-molecule (monomer), two-molecule (dimer), three-molecule (trimer) or larger aggregates of beta-amyloid, as well as insoluble plaque cores. The researchers then injected the extracts into normal rats or added the extracts to slices of normal mouse hippocampus.

Shankar, Selkoe and colleagues discovered that both the soluble monomers and the insoluble plaque cores had no detectable effect on the hippocampal slices. However, the soluble dimers induced certain key characteristics of Alzheimer's in the rats. The dimers impaired memory function, specifically the memories of newly learned behaviors. In the mouse hippocampal slices, the dimers also reduced by 47 percent the density of the dendrite spines that receive messages sent by other brain cells. The dimers seemed to be directly acting on synapses, the connections between neurons that are essential for communication between them.

To confirm this effect, the researchers then injected certain antibodies against beta-amyloid protein fragments. These latched onto and inactivated the dimers, preventing their toxic effects in the animal models. However, much work remains to be

done before inactivation of dimers could move into the clinic.

"Scientists have theorized for many years that soluble beta-amyloid may be critical to the development and progression of this devastating disease. Now these researchers have isolated a candidate causative agent from brains of people with typical Alzheimer's and directly tested it in an animal model," said NIA Director Richard J. Hodes, M.D. "While more research is needed to replicate and extend these findings, this study has put yet one more piece into place in the puzzle that is Alzheimer's."

"These findings may help explain why people with normal cognitive function are sometimes found to have large amounts of amyloid plaques in their brains, which has been a puzzle for some time," said Marcelle Morrison-Bogorad, Ph.D., director of the NIA Division of Neuroscience. "Their findings noted that the brain of an individual who was never clinically diagnosed with dementia was found with abundant insoluble Alzheimer's plaques, but no soluble beta-amyloid."

## Looking for early-onset coordinators and support groups

Does your chapter have an early-onset, early stage support group, and an early(young)-onset coordinator designated to provide information, education, and services to people under age 65 who are diagnosed with Alzheimer's or any of the other dementias? We are looking to compile a directory of such groups across the country, and publish it in our early-onset quarterly newsletter, "early-onset connections" twice a year. If your chapter has such a group, please contact the early-onset coordinator in the OK/AR chapter at 918-481-7741 or [joann.webster@alz.org](mailto:joann.webster@alz.org). Please include the following pertinent information:

Name of group  
 Frequency of meeting, contact person/facilitator, phone, email  
 Chapter affiliation  
 Criteria for joining group  
 Is it an open or closed group (meets for a fixed time period, then is closed and a new group forms)  
 I would like to host a conference call for early (young) onset coordinators in the fall, probably October. Please let me know if you are interested in participating.

## Useful Resources

- National Alzheimer's Association: [www.alz.org](http://www.alz.org); Find your local chapter, the early-onset Message Board and Clinical Trials. Check out the new design and information on this site.
- If you have moved and have a new mailing address, phone number and/or email address, please let JoAnn Webster, Early-onset Coordinator, know of this change. We want to stay connected with you and by providing us up-to-date information we can make sure you have the information you need.  
[joann.webster@alz.org](mailto:joann.webster@alz.org) or 918-481-7746.
- CareFinder: [www.alz.org/carefinder/index.asp](http://www.alz.org/carefinder/index.asp). A new website to assist in finding good care, coordinating care, planning, and resources in the community.
- Nedy Meds: [www.nedymeds.com](http://www.nedymeds.com). A useful website for finding financial assistance for getting prescription medications.