

## younger-onset connections

Oklahoma and Arkansas Chapter  
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Connections program

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[www.alz.org/alzokar](http://www.alz.org/alzokar)  
1.800.272.3900

### Adventure Through Alzheimer's

#### *A Male Caregiver's Journey*

College sweethearts Dave and Toni Zucconi shared many memories over the years and when Toni was diagnosed with Younger-onset Alzheimer's - they didn't let it stop their love for adventure.

Married in November 1963, they went to Ecuador for their honeymoon to see if they wanted to live there. However, after the honeymoon they

decided it was a great adventure, but realized they weren't quite as "outdoorsy" as they had thought to live there permanently.

As time went on, the Zucconi family began to grow, first with daughter Tanya and then son David. During which time, the family moved from state to state as Dave served at several city zoos including Milwaukee County Zoo, Director of Tulsa Zoo and El Paso Zoo.

In early 2005, Toni was diagnosed with Younger-onset Alzheimer's disease at the age of 65. It was tough on Dave being a caregiver, but it was balanced by the joy he received in being a caregiver.

After the diagnosis the Zucconi's were able to spend more time together and with their children, grandchildren and friends. Traveling remained prevalent in their lives, taking an extended driving trip to



*Dave and Toni Zucconi didn't let Toni's diagnosis with Alzheimer's stop their love for adventure or for each other and family.*



*Toni Zucconi with daughter, Tanya and son, David.*

Milwaukee, Michigan, Ontario, Boston, New Jersey and New York. Dave and Toni continued to enjoy their favorite hobbies including movies, lectures, plays and book reviews.

Dave facilitates a men's support group that meets once a month and is also a participant of the Asbury Younger-onset support group. Dave has personally found support groups to be "beyond helpful" as they helped boost him mentally and emotionally as a caregiver.

## From Denyce's Desk

### *Younger-onset Memory Walk Teams Challenge*



**J**ust wanted to take this opportunity to remind you that the Tulsa Memory Walk and North Central Arkansas Memory Walk are coming early this year!

At a recent event, several individuals shared why they walk:

- For people who no longer have a voice
- To raise money to aid in research and to find a cure for the disease
- On behalf of those diagnosed with the disease
- On behalf of caregivers and for future generations to be saved from this disease.

Jill Peters, Admissions Coordinator/Community Liaison at Laureate's Senior Behavioral Health Facility and special advisor for the Memory Walk shared her passion as to why she walks:

“A little over two years ago, I had the great pleasure of meeting a guy named Mark,” said Peters. “Mark was a husband. Mark was a dad. Mark was a coach. Mark was funny. Mark was 46-years-old. Mark was in the end-stages of his battle with Alzheimer's disease. Mark passed away in March of 2009 at age 47. Even though I didn't know Mark very well or for very long, he impacted my life forever. I walk in the Memory Walk every year so Mark's young daughters will not have to experience what he did, and I pray for a cure.”

The Memory Walk is the second largest fundraiser of the year and the signature event of the summer. At the Tulsa Memory Walk last year six younger-onset teams raised over \$17,600 - Let's see if we can top that!

This year we are having an amazing raffle to raise money for the Memory Walk: For a \$100 donation you will receive 1 chance out of 1,000 tickets to win the following package valued at \$40,000:

**2011 Masters Excursion  
Augusta, Georgia  
April, 2011**

The winner will receive: Four Masters Tournament Badges for

two days, accommodations for four in a private home in West Lake, round-trip airfare within the continental U.S., four invitations to a private welcome reception at West Lake Country Club, shuttle service in Augusta, Georgia and four rounds of golf at West Lake Country Club!

To register visit the website [www.tulsamemorywalk.org](http://www.tulsamemorywalk.org). Click on “Masters Raffle tickets” on the left hand side of menu under “Information”.

### **Summer Memory Walk Schedule:**

#### **NORTH CENTRAL ARKANSAS**

- July 31, Cooper Park
- Mountain Home, AR
- 8 a.m.: Memory Walk
- [www.ncawalk.kintera.org](http://www.ncawalk.kintera.org)

#### **TULSA**

- August 28, ORU Campus
- Tulsa, OK
- 8 a.m.: Sanctioned 5k Run
- 9:30 a.m.: Memory Walk
- [www.tulsamemorywalk.org](http://www.tulsamemorywalk.org)

## June Conference Success

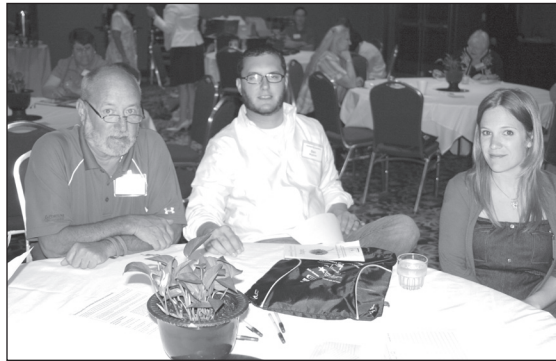
**T**he Education Conference was held June 9 at the Renaissance Hotel in Tulsa. A special thanks to the Hille Foundation who was the Premiere Sponsor for the event.

The Younger-onset/Early Stage track was successful with Dr. Jimmie McAdams with Laureate Senior Behavioral Health, Beverly Castleberry, Peggy Marsh and Ronda Roberts as presenters during a panel discussion. A question and answer time followed the panel discussion. We then had round tables where both caregivers and people diagnosed with the disease could discuss different topics and later report on each group's findings.

The Celebration of Excellence Award Luncheon featured keynote speaker, actress Kate Mulgrew, who shared her personal journey with her mother who had Alzheimer's. Mulgrew gave insight into the love and care her mother received from her caregiver.

Breakout sessions and exhibitors were also a highlight of the day where attendees gathered information about support.

Thank you to LIFE Senior



**Above:** Attendees Steve McGinnis, Ben McGinnis and Ally McGinnis at the Younger-onset/Early Stage Track

**Right:** Mary Ann Hille of Premiere Sponsor, the Hille Foundation.



Services and OASIS for providing respite for caregivers during the conference and off-site, to Peggy Marsh, Ronda Roberts, Carol Monlux, Judi Hurlburt, and Imane Rose for being roundtable facilitators and to Matt and Kristin Reiswig who shared their story of their family's journey with the disease, and to Forest Pharmaceuticals for donating kits which included the "36-Hour Day" and an Alzheimer's Activities Guide.

## Early Stage Alzheimer's Hope and Research Educational Conference

On September 17, 2010 at the OKC Marriott, the Central Oklahoma Alzheimer's Association is hosting a free half-day conference for those in the Early Stages of the disease and their caregivers.

A workshop will be held by Dr. Richard Taylor, author of "Alzheimer's From the Inside Out" who was diagnosed with the disease. He brings a unique and insightful perspective about the challenges that come with Alzheimer's.

A panel will also be available to answer questions from the audience in regards to diagnosis, available treatments, medicines, research, coping with changes in function, care and support services and more.

For more information, please contact the Central OK Alzheimer's Association at 405.319.0780 or go online to register at [www.alz.org/alzokar/in\\_my\\_community\\_events.asp](http://www.alz.org/alzokar/in_my_community_events.asp)

## Launch of Clinical Trial Matching Service

**T**he Alzheimer's Association announced July 12 the launch of Alzheimer's Association TrialMatch™, a confidential and free tool that provides comprehensive clinical trial information and an individualized trial matching service for people with Alzheimer's disease and related dementias.

The Internet ([www.alz.org/TrialMatch](http://www.alz.org/TrialMatch)) and phone-based (800-272-3900) service debuted during the Alzheimer's Association's 2010 International Conference on Alzheimer's Disease (ICAD) in Honolulu, HI.

There are as many as 5.3 million Americans living with the disease and every 70 seconds someone in America develops Alzheimer's disease, according to the Alzheimer's Association's 2010 Alzheimer's Disease Facts and Figures.

"Alzheimer's disease is reaching epidemic proportions with devastating impact on families, and the potential to wreck Medicare, Medicaid and the health care system," said William Thies, PhD, Chief Medical and Scientific Officer

at the Alzheimer's Association. "The immediate need for advances in diagnosis, treatment and prevention has led to an unprecedented need for clinical study participants. This, combined with challenges specific to recruitment and retention of participants with Alzheimer's, has created a particularly diffi-

*"By volunteering for clinical studies, people with Alzheimer's and their caregivers can play a more active role in their own treatment while also contributing to scientific discovery and benefiting future generations."*

Dr. William Thies,  
Chief Medical and Scientific Officer,  
Alzheimer's Association

cult situation for the field. That's why the Alzheimer's Association has launched Alzheimer's Association TrialMatch."

Recruiting and retaining participants for clinical studies is one of the greatest obstacles to developing the next generation of Alzheimer's treatments.

"Only one percent of eligible participants are enrolling in trials, and we're looking to

physicians to play a leadership role in referring their patients to clinical trials in Alzheimer's and dementia," said Marilyn Albert, PhD, Professor of Neurology at Johns Hopkins and Director of their Division of Cognitive Neuroscience. "As healthcare professionals, there is more we can do to help our patients

post-diagnosis. By referring our current patients to trials, we offer access to potential cutting-edge treatments while unlocking the door to potentially more widely-available treatments for people with Alzheimer's in the future."

More than 100 clinical studies in Alzheimer's and dementia are currently taking place and dozens more experimental compounds

are moving from the laboratory to clinical testing.

"Families affected by Alzheimer's need better diagnostic and treatment options now, and the lack of participants in clinical studies is a significant public health issue," Dr. Thies said. "Alzheimer's Association TrialMatch is a powerful and user-friendly tool for people with

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## • “CLINICAL TRIALS” CONT.

Alzheimer's, their healthcare professionals, caregivers, and healthy volunteers to learn about and take part in cutting-edge research going on right now. By volunteering for clinical studies, people with Alzheimer's and their caregivers can play a more active role in their own treatment while also contributing to scientific discovery and benefiting future generations. It is public service in the best possible sense.”

Alzheimer's Association TrialMatch is a “dementia friendlier” service than others in this space, with web and phone support, specially trained staff, and tools developed with input from people with Alzheimer's.

The strength of this Web and national 800 line-based service is that Alzheimer's Association TrialMatch contains a comprehensive, constantly updated database of institutional review board-approved Alzheimer's, mild cognitive impairment and other dementia trials taking place across the U.S. Specialists at the Alzheimer's Association's national Contact Center – available 24-hours a day – assist in the process of matching individuals to clinical trials for which they are eligible based on study inclusion/exclusion criteria, diagnosis, treatment history and location. The technology and platform for Alzheimer's Association TrialMatch is provided

by EmergingMed.

Alzheimer's Association Contact Center specialists will not recommend any particular clinical trial, but will describe all studies for which the person is eligible. They will answer questions about the trial process and connect individuals with trial sites based on their unique profile. Patients and caregivers will be encouraged to share their trial matches with their healthcare professionals to help decide whether a clinical trial is appropriate.

Alzheimer's Association TrialMatch can be accessed at [www.alz.org/TrialMatch](http://www.alz.org/TrialMatch) or by calling toll-free, (800) 272-3900.

### ***TrialMatch Quick Facts:***

#### **What is TrialMatch?**

A free, confidential interactive tool that provides comprehensive clinical trial information and an individualized trial matching service for people with Alzheimer's disease and related dementias.

#### **Who can use Alzheimer's Association TrialMatch?**

TrialMatch is for people with Alzheimer's, their caregivers and healthcare professionals to explore and identify clinical trials based on individualized criteria. Healthy volunteers and researchers may also use Alzheimer's Association TrialMatch.

#### **What types of trials are included in Alzheimer's Association TrialMatch?**

Alzheimer's Association TrialMatch contains institutional review board (IRB)-approved Alzheimer's, mild cognitive impairment (MCI) and other dementia trials currently taking place throughout the United States.

#### **How can I get involved with TrialMatch?**

TrialMatch operates through the Internet ([www.alz.org/TrialMatch](http://www.alz.org/TrialMatch)), and through the Alzheimer's Association toll-free phone number (800-272-3900).

**Join The Online Community**

Gain support from professional staff, access exclusive content and stay updated on upcoming events!

**Facebook**

Search for "Younger Onset Alzheimer's Disease" and become a fan and connect with others experiencing Alzheimer's

**Message Boards**

Our message boards provide users with communities of people who understand what you are going through. Visit the message boards at [www.alz.org/login.asp](http://www.alz.org/login.asp).

**Masters Excursion  
Philanthropic Opportunity Drawing**



For a \$100 donation you will receive one chance out of 1,000 tickets to win the following package valued at \$40,000:

- Four Master Tournament Badges for two days
- Accomodations for four in a private home in West Lake Addition
- Round-trip airfare within the continental U.S.
- Four invitations to a private Henderson Golf

- Welcome Reception at West Lake Country Club
- Shuttle service in Augusta, GA
- Four rounds of golf at West Lake Country Club

Buy your ticket TODAY by visiting: <http://www.alz.org/alzokar/>

