
early-onset connections

Oklahoma and Arkansas Chapter
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Early-onset Connections program.

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New Early Stage Advisory members announced

The Early Stage Advisory Group (ESAG) recently held its first call. With the help of Chapters, advisers were recruited who are excited to begin working with the Association. Information about the overall Early Stage Initiative was shared, including the primary activities centered on programming, public awareness, corporate engagement and advocacy in support of early stage issues. The role for the ESAG was also discussed – the most important job for advisers is to share their story and insights about living with dementia to inform) the work of the Association. Advisers will also have opportunities to propose any projects of special interest.

Meeting the New Advisors

Alan Romatowski – Alan is 56 years old, and lives in Butler, Pennsylvania. Alan had a career as a pilot for US Airways for 30 years. He first noticed problems at work, and specifically had problems with simulator testing. His path to diagnosis followed meetings with a work counselor, the family doctor, neurologists, a neuropsychologist, and the local ADRC. Due to his work situation, his timeframe to accomplish a diagnosis and contest the pending job loss and loss of benefits was very short, and made the diagnostic process more stressful. In retrospect he saw some signs 6 months before the events leading up to his diagnosis. Interests include streamlining the diagnostic process, and reducing or eliminating the bureaucracy. Alan has experienced the initial rejection of his SSDI application, but was successful in his 2nd try with the assistance of the ADRC. Alan has spoken before the National Institute of Health, and currently works with a local early onset group.

Steve Hume – Steve is 58 and lives in Wilbraham, Massachusetts. Steve had a career as a clinical psychologist. He was diagnosed in May 2007. Steve did experience some initial missteps in the diagnosis, and was told losing 30 pounds would solve his issue. However, he soon was able to move through the diagnostic process more quickly than most since he was at the university, and was referred quickly and received a comprehensive workup. Before diagnosis problems began to become noticeable in his work, and became obvious to his life partner. Steve would like to develop training for counselors and mental health professionals that would better differentiate depression vs. Alzheimer's. Steve has spoken in Boston about Alzheimer's issues and is deeply interested in advocacy.

Bob Balfour – Bob was diagnosed in February 2007. He is 54 years old, and lives in Alpharetta, Georgia. He has familial early onset Alzheimer's, as did his mother. Bob was working when the disease began to affect his work, ultimately resulting in an early termination. Bob is currently taking Namenda and Aricept and is enrolled in the Élan phase III trial. He would like to increase research to end this

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Encouraging news from ICAD

The Alzheimer's Association 2008 International Conference on Alzheimer's Disease (ICAD 2008) was the largest gathering of Alzheimer's researchers in history. More than 5,000 researchers gathered in Chicago July 26-31, 2008 to share ground breaking information and resources on the cause, diagnosis, detection, treatment and prevention of Alzheimer's and related disorders. ICAD serves as a catalyst for generating knowledge about dementia and a collegial research community working together to find better treatments and a cure for AD. A summary of several reports from the conference is given below. More details are available at <http://www.alz.org/icad/overview.asp>.

Biomarkers Show Promise for Early Detection of AD

Alzheimer's has long been a difficult disease to diagnose and for years we have been told that the only way to obtain an accurate diagnosis was through a post mortem examination of the brain. Scientists have looked for an accurate biomarker for AD for years. A biomarker is a substance or characteristic that can be objectively measured and evaluated as an indicator of the disease process. Recently AD has been a diagnosis by exclusion, ruling out other causes of dementia, but with better laboratory tests and brain imaging techniques the diagnosis is being made earlier and with greater accuracy. Yet scientists continue to search for a definitive marker of this disease prior to the development of cognitive decline in an individual. If these biomarkers are easy to obtain, such as blood or urine samples, or available through technologies such as MRI or PET, this is a plus.

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At the Forefront of a Revolution

Revolution: n.: an activity or movement designed to effect fundamental changes in a situation.

Dear Friends,

On June 5, at the annual Tulsa Education Conference, three of our Foundation friends were inducted into the National Zenith Society. These friends are The Hille Foundation, The William K. Warren Foundation, and The Anne and Henry Zarrow Foundation. The Alzheimer's Association Zenith Society consists of less than 50 members nationwide, and represents the highest philanthropic leadership of our national efforts. This extraordinary national recognition humbles us beyond words, and also brings our attention to the vital subject of awareness. These friends, through their supreme generosity, help us bring more national awareness to the Alzheimer's cause, including Early-onset Alzheimer's. And it is awareness, perhaps more than any other tool, which will ultimately lead us to a cure.

In his visit to Tulsa on June 5, our National CEO, Harry Johns, once again reminded us, awareness is the key to change.

One of the highlights of the June 5 conference, for those with early memory loss and their care partners was the face-to-face breakout session. This session was facilitated by the early-onset coordinator and several of the care partners and persons with dementia who have participated in our early-onset program and especially the local support group.

The session gave recently diagnosed persons and

their families a chance to talk in small groups with "veteran families" and learn from their experiences. Several families who had participated in the recent EASE (Early Access to Support and Education) program for early stage families, as well as families newly diagnosed, were eager to have an early stage support and education meetings/workshops and social opportunities. We are thrilled that this breakout session resonated with so many of the participants and we are looking for ways to support enhancing opportunities for early stage families to connect.

People with early-onset and early stages are becoming an active voice. Our Chapter prides itself on being nationally recognized in these areas, and we strive to develop innovative programs and services that meet the needs of these groups. We will be adding a third support group for early memory loss persons of any age and their care partners. This fall we are gearing up for another EASE program.

You may ask, "Where do I fit into the revolution? How can I, just one person, make a difference?" One of the chief ways we are having a national impact is through our Advocates. Alzheimer's Advocates help us educate our legislators on the Alzheimer's cause. As an early-onset or early stage advocate, you can take specific action in the form of calling, emailing or writing your legislators, and expressing to them the importance of Alzheimer's research and care.

Recently, Newt Gingrich and Sandra Day O'Connor spoke to Congress about Alzheimer's disease, and the urgency of disease-arresting drugs, and a cure. This monumental occurrence was a direct result of Alzheimer's Advocates nationwide. If you would like to be an Alzheimer's Advocate – we need you. Please call the office nearest you at 800-272-3900 or visit our website at www.alz.org/alzokar, and click on the "Advocate" button in the left column.

Thank you for your role in our efforts, as we all work together in this revolution, toward a world without Alzheimer's.

My warmest regards,

Judi Ver Hoef

President and CEO

Alzheimer's Association Oklahoma and Arkansas Chapter

(*"Early Stage" cont. from pg. 1*)

disease before his children become at risk.

Mimi Steffen – Mimi lives in Honesdale, Pennsylvania and is 80 years old. She was diagnosed 2 years ago. Mimi would like to reduce the amount of denial people have about Alzheimer's, as well as make earlier diagnosis a priority. She says, "The earlier that you can catch it the more hope there is." She would like to increase physician education and awareness and have a more standardized diagnostic process.

Lisa Carbo – Lisa is 54 years old, and lives in Metairie, Louisiana. She was diagnosed last fall, and it took quite a long time to receive a correct diagnosis. She is the caregiver to her mother, who also has Alzheimer's disease. Lisa would like to increase public awareness and also focus on advocacy. She lost her job due to Alzheimer's and wants to increase awareness that this issue could happen to anyone. Additional interests include the planning process for caregivers, reducing costs of care, and improving caregiver education, so others can better understand the person with the disease.

Dick Bernard – Dick is 81 years old, and lives in St. Charles, Missouri. He has a family history of Alzheimer's disease, with his mother, sister, brother, and daughter all currently suffering from the disease. His daughter is in her mid 50's. His symptoms began with mild memory loss and difficulties with short term memory. Dick is interested in anything related to research. He wants to stop this disease and improve diagnostics and treatments.

(*"ICAD" cont. from pg. 1*)

Results from two such studies were announced at ICAD 2008

Blood Test on White Blood Cells

Healthy brain cells do not go through the process of division and replication (called the "cell cycle") as do other cells in the body. In Alzheimer's, brain cells "try" to enter the cell cycle and replicate and this may increase their likelihood of dying or cause their cell death. A similar process occurs in lymphocytes, a type of white blood cell (WBC). These cells can be easily collected by a simple blood draw. CD-9, a protein involved in WBC growth and production can be measured, and in preliminary tests in 88 individuals, differentiated people with Alzheimer's, from people with Parkinson's dementia and from cognitively normal individuals, and did not vary with the dementia severity. Professor Thomas Arendt at the University of Leipzig in Germany says a much larger trial is underway. If results are confirmed, this test could provide primary care physicians a non-invasive, more accurate test for AD.

Spinal Fluid Markers Track Brain Amyloid before Symptoms Appear

Anne M. Fagan, PhD of Washington University School of Medicine in Saint Louis previously demonstrated that AB42 (a particular "sticky" variety of an amyloid protein fragment) is likely to aggregate and cluster into plaques, a hallmark of Alzheimer's. PET scans using the Pittsburg compound (PIB) can detect these plaques in the brain. Fagan reported on a larger study which found an inverse relationship between the PIB compound in the brain and the cerebrospinal fluid (CSF) AB42 protein, with excellent sensitivity.

Phase II Trial Reports of a Potential New Treatment

In a small study of 321 patients, three doses of Rember were given 3 times a day. After 19 months using the middle dose, patients had not cognitively declined and it appeared that the tau tangles were being dissolved by the treatment according to Claude Wischik, a biologist at University of Aberdeen in Scotland. The low dose was too weak and the highest dose had a flaw in formulation. The data is only suggestive, Wischik warned, but the company is raising funds to start another test of the drug next year.

Mary Jane Sorensen – Mary Jane is 81, and has just recently received her diagnosis. She lives in Prescott Valley, Arizona. Her grandson noticed problems and suggested she see a doctor. She has participated in an 8 week early memory loss class with her chapter, and has spoken at a caregiver conference. She would like to improve the materials that are available to someone newly diagnosed, that would include items like "What to do", "What to expect", etc.

Karen Zimmerman – Karen was diagnosed in March of 2008. She is 52 and resides in Alexandria, Virginia. Karen's interests include advocacy and raising funds for research and care. She'd like to help raise awareness and help people get a better understanding of what Alzheimer's is all about. She spent 21 years in the meeting/planning industry for Hyatt Hotels. Problems with multitasking led to her meeting with her doctor and a neurologist. She was able to receive SSDI and disability through her labor union as well. She is currently building her retirement/dream house in Asheville, North Carolina.

Paul Tompkins – Paul lives in Avon, Ohio and is 69 years old. Paul has vascular dementia. He has given some presentations for his chapter, and wants to participate as fully as possible.

Donna Beveridge – Donna is 65 years old and lives in Saco, Maine. She was diagnosed in August 2007. She is interested in educating physicians and the general public. She lists her greatest strengths as "my positive attitude and my intention to live my life well each day". Her interests include early detection and helping physicians to understand more about early stage Alzheimer's disease.

Oklahoma Candlelight Vigil

Mark your calendar to join Alzheimer's advocates from across the state for the 2008 Alzheimer's

Candlelight Vigil.

If you're concerned about Alzheimer's, we hope

you'll join your fellow Oklahomans for a first-ever Candlelight Vigil on the south steps of the Capitol

on November 13 to let our voices be heard that it's time to take action for Alzheimer's.

We ask that each person attending wear a VOICE, MOVE, OPEN or ACT purple t-shirt that can be

purchased at www.alz.org/shop. If you are unable to purchase a t-shirt, please consider wearing something purple.

For more information go to www.alz.org/alzokar

and click on the capitol dome picture on the home page where you will be directed to more information and details about the event. Please call 800-272-3900

◆ National Alzheimer's Association: www.alz.org;

Find your local chapter, the early-onset Message

Board and Clinical Trials. Check out the new de-

sign and information on this site.

◆ If you have moved and have a new mailing ad-

dress, 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 or 918-481-7746.

◆ CareFinder: 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. A useful

website for finding financial assistance for getting

prescription medications.

DASN International www.dasninternational.org.

Dementia Advocacy and Support Network for

persons with dementia.