

early-onset connections

Oklahoma and Arkansas Chapter
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Early-onset Connections program

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Alzheimer's Association cautiously optimistic

The Alzheimer's Association Oklahoma and Arkansas Chapter is cautiously optimistic about the recent results of Etanercept. However, the Chapter points out that as with any new research finding people with Alzheimer's disease should take special care when investigating and discussing drugs already on the market in order that they are not prescribed nor made available inappropriately based on preliminary findings.

"The Alzheimer's Association welcomes new ideas for Alzheimer therapies, such as this.

"But we are concerned that in their strong desire for more effective therapies, people with Alzheimer's and their families may place undue value on this new finding," said Tonda Ames, vice president of Marketing and Programs.

"Although this possible treatment strategy has promising findings, they are preliminary. Therefore, we urge people to be patient and adopt a wait and see attitude," said Alzheimer's Association CEO Judi VerHoef.

Before this drug can become an accepted therapy for Alzheimer's disease, it would need to go through the FDA approval process, including randomized, blinded clinical trials.

In addition, the nature of the drug delivery technique used in this research (injection by needle into the spine at the back of

the neck, followed by a brief period with the head lowered and feet elevated) will make it very unlikely for long term success, though it is an interesting possibility for proof of concept.

"We need better ways to treat, and eventually prevent, Alzheimer's disease. We need to follow through on established therapeutic targets and compounds, and also put more new treatment approaches into the pipeline. For example, a key principle of the Alzheimer's Association's grant funding is to give all good and viable ideas a chance – to fund the basic science that will uncover whether the idea is worth further investigation. If only we had more dollars with which to fund research projects," said Ames.

The Alzheimer's Association is confident that they will defeat Alzheimer's disease. How fast they do it is directly related to the level of investment. In order to follow through on recent advances and get more new ideas into the pipeline, the Association said it needs:

More research dollars for Alzheimer's disease.

More volunteers for clinical studies.

Find out how to get involved at www.alz.org.

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Tulsa Educational Conference set for June 5

"The Emerging Face of Alzheimer's" is the theme set for this year's educational conference scheduled for 8:30 a.m.—4:30 p.m., Thursday, June 5. The Renaissance Hotel in Tulsa will once again be the site of the conference.

The conference is designed for those with a history of Alzheimer's, family members and caregivers, individuals with early-onset Alzheimer's, health care professionals, caregiver agencies and anyone interested in learning more about the disease.

Six different breakout sessions will provide information on the latest research, ethics, activities, and late stage/end of life care issues, as well as a roundtable discussion for individuals with early-onset/early stage and late-onset/early stage Alzheimer's disease. Continuing education units will also be provided for professionals in the healthcare field.

In addition to the conference, the "Celebration of Excellence

Luncheon" will be from 11:30 a.m. –1 p.m. The prestigious Maureen Reagan Memorial Award will also be presented during this time. The Association will also be presenting other awards for commitment and support of the Alzheimer's Association.

Cost is \$75 for professionals and \$35 for family caregivers, students and those with Alzheimer's disease (includes luncheon). Some scholarships are available. The cost to attend the luncheon only is \$35. Registration is available online at www.alz.org/alzokar/in_my_community_events.asp or by calling 800-272-3900.

Sponsors of this year's conference include: The Hille Foundation, Saint Francis Health System, Senior Star Living – Burgundy Place and Woodland Terrace, The Anne and Henry Zarrow Foundation, Grace Hospice Foundation and St. Simeons Episcopal Home.

From JoAnn's Desk



Has Alzheimer's Affected Your Work and Benefits Experience?

The early stage advisory group at the National Alzheimer's Association has requested your input in determining if and how dementia has affected your ability to work and receive health insurance or related benefits.

They have created a survey and asked me to make it available to the "Early-onset connections" mailing list and database. Therefore we are asking your cooperation in gathering this data to advance the cause of persons with Alzheimer's and their families, especially as it relates to their work situation and normally associated benefits.

We would encourage you to please complete this survey online at <http://alz.earlystage.sgizm.com>. If you

do not have computer access, a hard copy of the survey is enclosed as an insert in this issue of the early-onset connections newsletter. Please complete the survey as soon as possible and return it to Jeff Carpenter at the National Alzheimer's Association, 225 N. Michigan Ave, Chicago IL 60601. Data collection will remain open until the end of February.

You should have a diagnosis of dementia to participate in this survey, however if necessary, you may have a care partner assist you. Please answer the questions as they apply to the person with dementia. All questions may not apply to your situation, so please follow the directions within the questionnaire.

As we mentioned in the last issue of "early-onset connections" a bill (S2102) has been introduced into the US Senate to phase out the two year waiting period after beginning SSDI before Medicare benefits start, over a ten year period. Data from this survey will be very beneficial in obtaining support for this bill and is another way we can advocate for changes that will benefit those with Alzheimer's or other dementias, under the age of 65 and their families. Please speak up regarding this important issue, in this election year. (see the article on p.3 regarding the public policy forum)

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 will meet Southern Hills United Methodist Church, 6160 South Lewis, Tulsa, OK, in the evening. This support group is for peo-

ple 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.**

Come to Washington for the Alzheimer's Association Public Policy Forum May 12-14, 2008

Election season creates excitement and a time in which the political landscape is changing. It is also a unique opportunity to increase concern and awareness about Alzheimer's on Capitol Hill. Lawmakers of both parties are developing their policy agendas in light of the 2008 election—and many signs point to efforts to improve the health care system are expected to be a top priority issue in the fall. We need to make sure Alzheimer's issues are part of the debate on health care.

Although May seems very far away, the 2007 Public Policy Forum is just around the corner. Make your plans now to join us in Washington to learn how the outcome of the elections will impact Alzheimer issues in Congress, meet your lawmakers and enhance your advocacy skills. The Public Policy Forum is also a great time to meet new friends, network with your fellow advocates and honor those who have been touched by Alzheimer's at the candlelight vigil. Registration information can be found at www.alz.org/forum. May 12 will also feature the last in a series of early stage town hall meetings of and for persons with Alzheimer's disease to speak out about their perspectives and concerns. This meeting will be from 9-12 on May 12th at the same hotel as the Public Policy Forum and is free of charge. For more information <http://www.alz.org/townhall/meetings.asp> or contact Jeffrey Carpenter at 312-335-8700.

A Silent Crisis: Working Caregivers are Begging For Help

By *Gema G. Hernandez, D.P.A.* Copyright 2008, Today's Caregiver magazine. Subscriptions are available by calling 800-829-2734 or online at www.caregiver.com

At time when private enterprises are trying to increase productivity, reduce costs and enhance the quality of their products or services there is a growing crisis in corporations today that is preventing them from achieving their corporate goals. Few companies realize the implications working caregivers have on their internal costs and their bottom line. Still fewer companies even know where to look for these hidden costs. Only one in seventy midsize to larger companies knows how to address this issue.

The closest thing a company associates with the cost of caregiving to the company is the absenteeism reports. Even in cases where absenteeism is recorded, the relationship between the numbers of days missed by workers and the reason for the number of days is not clearly established. Absenteeism may be the most obvious cost to the workforce, but it is not the only cost or the most expensive cost. Other factors such as attrition, loss of good workers, increased health insurance coverage, overtime, and constant recruitment of new workers also cost the company and the workers.

The number of caregivers in the workforce has increased threefold in the last five years and will continue to increase in the next ten years. This is no longer a problem that affects only women in the workforce or lower income workers, but is a problem that exists at the CEO level as well as the lower administrative levels of the company echelon. This is a problem that also affects working men, and young and older workers alike.

For years the problem has been handled by

the mid-level managers who have used leniency in granting permission for workers to leave early, come late, refuse to work overtime and while the managers have done their best to help good workers balance jobs and work the poor workers have been left alone to tackle the problem. For years the problem has been handled silently by the working caregiver who has given up promotions, careers, training opportunities to provide care to a family member. But these individual solutions are no longer appropriate or recommended.

The first sign of relief for working caregivers came with the passage of the Family Leave Act which allows workers to take time off to care for a frail family member. This law helps working caregivers by guaranteeing their jobs while they take unpaid leave to care for the family member. But it does nothing to educate, facilitate, support and provide the necessary assistance to working caregivers after the crisis situation ends. It does nothing for the company which loses a valuable worker on a temporary basis and is replaced by a not so experienced worker. Many working caregivers have forfeited this unpaid leave option because of the unbearable financial burden giving up a paycheck represents to them and even though they needed the time off they were not able to afford it. Many working caregivers are not even aware of the law that protect them from losing their jobs,

Many working caregivers have given up a job at a financial cost to be borne by them alone for years to come. Financial costs in the form of a lower pension or no pension at all, lower social security at the time of retirement and the loss of a job at a time in their lives when finding another job becomes almost impossible.

We have reached a point in the road that something should be done. On one hand government can pass a law to financially support the Family Leave Act by mandating that employers

with more than 50 workers offer at least a portion of the time off with pay. California is the first state in the nation that has passed such a law. On the other hand, companies are requesting that the Mandates of the Family Leave Act be weakened in the form of less time off or plain dismissal. This is not going to solve the core problem, on the contrary, it will produce more absenteeism, loss of good workers and increases in health care coverage resulting from higher health claims by working caregivers.

The solution from the point of view of the working caregivers and from the financial perspective of the company is one and the same. That mutually beneficial solution is for companies to include in their benefit package a working caregiver assistance program. Those companies that have done it have achieved a higher degree of worker satisfaction, reduced attrition of good workers, have increased the quality of their products and services and kept the loyalty and goodwill of their workforce. For working caregivers this has been the answer to their prayers. They no longer have to miss work, come late, leave early, be on an infinite number of phone calls or spend their entire working day worried about mother, father, or husband at home.

It is up to us caregivers to make the corporate world aware of our needs and to support efforts that will alleviate our ongoing burden. Contact your human resource department and find out what they offer in terms of working caregivers, and if they don't, let them know that assistance exists to support corporations to deal with this challenging and growing crisis.

For corporations to maintain their competitive advantage in the global market they need dedicated and experience workers willing to give 120% to their jobs this is achievable is they now that corporations are willing to help with their family caregiving responsibilities. The rewards are there for companies that provide assistance to the working caregivers. This is an investment that at the end will save money and generate goodwill for all.

Useful Resources

- National Alzheimer's Association: 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 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.

Email Connections for Kids and Chapter Staff

If you have children ages 11-16 who would like to email their peers, please contact JoAnn Webster. Send her names, ages and email addresses to:
joann.webster@alz.org or call 918-481-7746.

If you would like to have a peer group for Chapter Staff working with early-onset/young-onset families, please also contact JoAnn.