

Oklahoma and Arkansas Chapter
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Early-onset Connections program

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Congressional Task Force on Alzheimer's Disease Welcomes Formation of New Expert Study Group

To address the escalating epidemic Alzheimer's disease poses to the nation, co-chairs of the Alzheimer's Disease Congressional Task Force and the Alzheimer's Association welcomed the creation of the Alzheimer's Disease Study Group. Chaired by former House Speaker Newt Gingrich and former Nebraska Sen. Bob Kerrey, this independent, nonpartisan group will evaluate the nation's current effort to combat Alzheimer's disease, which now affects more than 5 million people in the United States, and develop recommendations for the public and private sectors to address the problem in the future.

"This is an opportunity to build on our commitment to finding solutions for all the challenges posed by Alzheimer's Disease," said Senator Hillary Clinton, co-chair of the task force. "From discovering the underlying causes and developing a cure, to improving the long-term care of those suffering from this disease and helping their caregivers cope with the physical, emotional and mental

challenges, we need to keep pressing for progress." Other co-chairs are Senator Susan Collins, and Representatives Ed Markey and Chris Smith.

Today, the cost of Alzheimer's disease and other dementias to Medicare and Medicaid, plus the indirect cost to business – including absenteeism and lost productivity – exceeds \$148 billion annually. Experts predict that by 2030, Medicare spending on those with Alzheimer's alone will cost nearly \$400 billion – roughly equivalent to today's entire Medicare budget.

The Alzheimer's Disease Study Group will play a key role in identifying and assessing the scope and magnitude of the disease and is charged with offering viable solutions and approaches to lessen the human and economic costs of the disease.

"Alzheimer's is a devastating disease that takes a tremendous personal and economic toll on both the individual and the family," commented Senator Collins. "I

(See "Congressional pg. 2)

Clinical Studies Initiative:

Frequently Asked Questions

What is the Clinical Studies Initiative? The Clinical Studies Initiative is a pilot program in five states to raise awareness about local research opportunities and the critical need for more study volunteers. The five participating cities are Indianapolis, Tulsa, San Francisco, Providence, and Atlanta.



How does Alzheimer's disease affect you? There are currently more than 5 million people in the United

States living with Alzheimer's disease, and half a new million case are expected this year alone. Many states were expected to see increases in the number of people with Alzheimer's Disease.

Why is this important?

Recruiting and retaining study volunteers has become one of the greatest obstacles to developing new and better treatments for Alzheimer's disease. There also needs to be greater communication among patients, caregivers, and doctors about the need for participation in research studies and why their involvement

From JoAnn's Desk



How do you know it's time?

The long term care decision

Not long ago this question was asked by a care partner in an early-onset support group. On the surface this question didn't seem to fit the people in the group, both men and women in their early 50's to mid 60's. It was a question that no care partner had voiced in the four year history of this group. It is easy to forget the need for care givers and care partners to be reminded from time to time that Alzheimer's is still an incurable, eventually fatal disease, whether it strikes a person 40 years old or some one near 80.

With Alzheimer's disease our lives settle into a daily routine and after adjustments to the initial diagnosis and its after shocks, we sometimes forget to "keep planning for the future" and looking on down the road to tomorrow. We become accustomed to the "stage" we are in with the person for whom we are caring, and do not notice the subtle disease progression that has occurred.

When tomorrow comes, a care giver cannot continue to keep the individual at home, without a lot of help, which may or may not be readily available. If and

when that happens, caregivers must make the transition to long term care facilities.

So what are the signs that trigger these thoughts that "I cannot do this any longer", "I need help" or "It may be time" to make plans to transition to long term care. Some of the things to consider include **1)** the person requires 24 hour care, 7 days a week; **2)** they can never be left alone, even for a few minutes as the person may fall frequently or have "accidents" more often; **3)** bladder and bowel incontinence occurs; **4)** the person with dementia can no longer perform routine activities of daily living (ADL'S) alone or with cues; **5)** the individual may become aggressive and combative and difficult to manage. They may even physically try to hit or harm the care provider; **6)** a doctor or other health care professional says it is time for long term care; **7)** The care partner is tired, exhausted, frail or ill and their health is being compromised **8)** the care partner is not making good decisions, is forgetting appointments, is angry and overwhelmed. If and when you observe several of these signs, **IT IS TIME.**

Call your local Alzheimer's Association for a care consultation or seek a care manager from your doctor or a local health care agency and begin to transition from being a care giver to a care manager. You do not have to travel this road alone. **We can help;** call us at 1-800-272-3900 or visit Care Finder on the National website, www.alz.org. Ask this question in your support group, and seek the counsel of those in your group who have already made the decision.

(Congressional)

am pleased that this study group is being created with the goal of evaluating the strengths and weaknesses of our nation's current efforts to combat Alzheimer's Disease and identify strategies aimed at preventing, delaying and even curing this terrible disease."

"People with Alzheimer's Disease and their families are heroes, but even heroes need help. And they need all

the help they can get!" Rep. Markey said, "As the Co-Chairs of the Bipartisan Congressional Task Force on Alzheimer's Disease, we welcome this new Study Group and thank the co-chairs for their work in addressing one of the most pressing health care issues of our time. We are pleased to be joined by partners from all backgrounds, all industries and all across the political spectrum who are serious about putting an end to this terrible disease."

(Trials)

is important.

What is the OK/AR chapter doing for the initiative, and who's involved?

The chapter has convened a taskforce of local physicians to raise awareness of Alzheimer's studies and to advocate for participation. Members of the taskforce are featured in brochures, posters, and radio and television public service announcements that will be distributed throughout our community. Other aspects of the campaign include educational events for medical professionals and consumers,

advertising, and extensive community outreach.

Where can I get more information?

To find out if there's a research study going on in your area, or to get more information, you can visit the association's web site at www.alz.org. The web site will allow you to search for research studies by city and state. You can also call the association's 24-hour hotline at 1-800-272-3900. A new toll-free number 1-800-892-8299 has been secured to handle

inquires specifically about clinical studies and the Clinical Studies Initiative. The Call Center will be staffed by trained Information Specialists to provide information about clinical studies specific to each city. All callers seeking clinical studies information will also be asked if they would like to learn more about Alzheimer's Association services and support. Callers responding affirmatively will then have the option of being transferred to the local chapter or offered a follow-up call at a later time.

Voices that are Heard

“I will never forget that face and that story.” This is a quote from a United States Senator who heard testimony from a man in his 50s with early-onset, early stage Alzheimer’s. This Senator didn’t remember much about the facts and figures presented by the Alzheimer’s Association at the Senate hearing on the need for more funding for Alzheimer’s research, but he vividly remembered the face, voice and story of the person with Alzheimer’s. That face, voice and story motivated him to vote for an increase in research funding.

Volunteer advocates who have early stage, early-onset Alzheimer’s disease have been making a greater and greater impact on policy-makers in recent years. The annual Public Policy Forum held each year in Washington, D.C. has asked these advocates to come and speak to the

“EMAIL CONNECTIONS” Expanding to include Children Ages 12—16

Plans are being made to expand *email connections* to include children still at home, especially those who are computer savvy and can use the internet. We are very sensitive to keeping our children and young teens safe when they are on the web, so we will plan to make the initial connections via parents or a parent, who is currently involved in our *email connections* program as a spouse/ care partner.

There were three families who spoke at our June 12 conference here in the Tulsa area and have children in this

attendees and to Congress, with impressive results. It seems that the voices of people who have the disease make a greater impression than anything else. The reality of the disease cannot be ignored when someone who has it speaks.

Please consider becoming a volunteer advocate. All you need is your story. Contact your local chapter and send them a copy of this article! Also, please consider attending the Public Policy Forum in Washington, D.C., May 12 – 14, 2008. For more information about the Forum, call 202-393-7737 or email forum@alz.org.

If you live in Oklahoma or Arkansas and would like to attend the Forum or would like to be involved as an Alzheimer’s Advocate, you may contact Mary Ann Duncan, Director of Public Policy and Diversity at 800-272-3900 or 918-481-7741 or email her at mary.duncan@alz.org. **Let your voice be heard!**

age group, who are interested in such a program. If you have children in this age group and think they would benefit from speaking via the internet or even by phone with their peers, who have a similar experience, please email joann.webster@alz.org. Please give me your name, address, email address and names, ages, and gender of the children and their relationship to the person with dementia. Provide me permission to list your name (parents) and email on a list of parents who have kids in this age group. I will connect the parents and then let you contact each other, and then connect your kids.

After several months of trying this within our *email connections* list, we’ll post a notice for others on the National EO message board about the children’s email connections and open it up to other parents.

Chapter Website has New Look and Address

In an effort to create a branded look throughout the entire Association, the Alzheimer’s Association’s national office embarked on a huge project to have all websites be consistent in design and overall general content. We are proud to say that the Oklahoma and Arkansas Chapter was one of the first to “go live” with the new website in late July.

There are a couple of things you will need to know to find our new website: 1) the new address is www.alz.org, 2) then click on the “Find Us Anywhere in the U.S.” link and type in Oklahoma or Arkansas.

<p>August 26—29: 15th Annual Dementia Care Conference Chicago Illinois. www.alz.org/careconference. Topics: Early stage and early-onset issues, Community based care, Residential care, Alzheimer's Association Chapter Showcase. (Look for a presentation from the OK/AR chapter in this section)</p> <p>September 22: Oklahoma City Memory Walk. www.okcmemorywalk.com</p> <p>September 29: Tulsa Area Memory Walk www.tulsamemorywalk.com. Join the Tulsa early-onset team, or form a team in your area! Check out the national website for the chapter close to you.</p> <p>October 27: Early-Memory Loss Forum 9:30-3:45 Los Angeles, CA 90049. An unprecedented one day event created by and for people with early stage memory loss. This forum has been designed by former journalist Richard Bozanic, and former architect Jay Smith. These men met in an early-onset support group, in California. They had read in the Newsletter "Perspectives" about a conference in NY for people with early memory loss, and said "Lets do it here!" For more information or to register call 323-900-3180 or email earlystageforum@alzarsb.org. Cost is \$25.00 for persons with dementia and a care partner and \$75.00 for professionals.</p> <p>May 12—14: Public Policy Forum, Washington, DC</p>	<p>Useful Resources</p> <ul style="list-style-type: none"> • National Alzheimer's Association: www.alz.org; Find your local chapter and read the Early Dementia Report. Check out the new design and information on this site. • Oklahoma and Arkansas Chapter: www.alz.org. 24-hour Helpline: 1-800-272-3900 or 918-481-7741 • CareFinder: www.alz.org/carefinder/index.asp. A new website to assist in finding good care, coordinating care, planning, and resources in the community. • Neady Meds: www.nceedymeds.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.
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MetLife Foundation

Working toward an Alzheimer's cure

early-onset connections available
online at www.alz.org